

A toolkit on the Right to Health

Health is a Human Right, take action!



LEARNING NETWORK

First Edition



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Credits

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Siniko: Toward a Human Rights Culture in Africa. 1999: Amnesty International.

Hassim, A., Heywood, M. & Berger, J. 2007. *Health and Democracy: a guide to human rights, health law and policy in post-apartheid South Africa*. Cape Town: Siber Ink.

Farell, E., Goodnow, M. & Lohman, M. (2009). *Human Rights Toolkit*. Minneapolis: Advocates for Human Rights

Train-the-Trainer Manual: participation, civic education and community mobilisation. Netherlands Institute for Southern Africa

Padarath, A & Friedman, I. 2008. *The status of clinic committees in primary level public health sector facilities in South Africa*. Durban: Health Systems Trust.

The work of many NGOs struggling to advance human rights has inspired this toolkit, particularly the People's Health Movement, whose People's Health Charter recognises health firmly as a right, and whose work aims to build global community action to realise the Right to Health.

About the Learning Network

The Learning Network, established in 2008, draws together six civil society organisations and four Universities around a programme in which research, training and advocacy are linked to empower organisations and their members to assert rights for health.

The Network is made up of the following members:



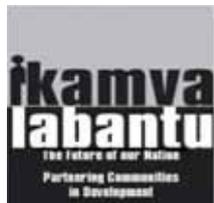
Cape Metropolitan Health Forum

The Cape Metropolitan Health Forum is the current structure for community participation in health, with eight sub-district Health Forums and 76 clinic (health) committees. Health committees act as the interface between communities and health care services.



Epilepsy South Africa

Epilepsy South Africa is a non-profit organisation that renders developmental services to people with epilepsy and other disabilities. It uses an integrated approach to development and aims to empower its constituents through social development, individual and family counselling, disability sensitisation, public education and awareness raising and training on disability and human rights, as well as empowerment that provides employment opportunities for people with epilepsy and other disabilities. For more information visit <http://www.epilepsy.org.za/wcape/index.php>



Ikamva Labantu

Ikamva Labantu provides services to the residents of South Africa's township communities through all the stages of life. Its mission is to build community capacity that is self reliant and sustainable through programmes driven by community needs. The main focus areas are: education and skills development, food security, health & nutrition at primary level and building community infrastructure through securing land and buildings. The primary means of delivering services is through strategically located community-based multi-purpose centres which serve as hubs where community members can access a vast array of support services. For further information see <http://www.ikamva.org>

Ikhaya Labantu

A shelter for the homeless in Langa, Cape Town, facilitating rehabilitation and skills acquisition.



Maastricht Centre for Human Rights - Faculty of Law, Maastricht University, the Netherlands

The Centre hosts research activities in the field of human rights of the members of the staff of Maastricht University Faculty of Law, reflecting an integrated view of economic, social and cultural rights. Research conducted by members of the Centre has contributed to clarifying the normative content of social and economic rights, such as the right to food, health, housing and education. For more information visit <http://www.maastrichtuniversity.nl/humanrights>



The Women's Circle

An organisation of grassroots women working together to promote a culture of equity and women's rights around a programme of action that aims to encourage respect for women's rights and for women amongst all members of society; expose women of all ages to a wide range of opportunities; showcase innovative women-led projects and programmes; and celebrate women's achievements through ongoing collaboration.



University of Cape Town

The School of Public Health and Family Medicine has a diverse involvement in human rights teaching, research and advocacy. Currently the Health and Human Rights Programme is involved in collaboration with NGOs and other research and training institutions to explore how collective action and reflection can identify best practice with regard to using human rights to advance health. In addition, it runs an annual Train the Trainer programme for staff who teach health professional students and produces materials on health rights. For more information visit <http://www.hhr.uct.ac.za/about/about.php>



University of the Western Cape

The School of Nursing at the University of the Western Cape aims to contribute to health care delivery and research nationally and internationally. It trains nurses and midwives to work on sexual and reproductive health rights. For more information visit <http://www.uwc.ac.za> and navigate to the School of Nursing page.



Women on Farms Project

A rural feminist NGO working to strengthen the capacity of women who live and work on farms to claim their human rights by taking both individual and collective action. We do this through socio-economic rights-based and gender education, advocacy and lobbying, case work and support for the building of social movements of farm women. For more information visit <http://www.wfp.org.za>

Warwick University

The Health and Human Rights Research Group, within the Institute of Health, supports the development of multi-disciplinary research in the field of health and human rights.

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Introduction

In South Africa, we have a Constitution that guarantees us the right to health, but we know how difficult it is to implement in practice. The South African Human Rights Commission has identified in various hearings ongoing violations of the right to access to health care, and of rights to enjoy healthy living conditions. Their reports also highlight the fact that many patients are not even aware of their health rights.

In some cases, people in communities are aware of their health rights and realise that they are experiencing serious violations of their rights, but they don't know who to hold responsible or even how to hold people responsible for these violations.

This toolkit was designed in response to the need for a practical tool to empower communities on what the right to health means, how to identify violations of health rights and how to respond to these violations. The toolkit can be used as a stand-alone source of information or as training tool for workshops on the right to health. Each section uses practical examples to illustrate ideas, and has a number of exercises and case studies that could be used for training purposes. At the end of each chapter is a set of workshop handouts that can be photocopied for participants. Many of these examples are actual cases that emerged from the work of the Learning Network for Health and Human Rights over the past few years.

The toolkit is designed for use by Civil Society Organisations (CSOs) such as health committees, NGOs working with health issues, educational institutions, community members or anyone with an interest in health rights.

The toolkit is divided into four main sections:

The first section aims to improve a general **understanding of human rights**, focusing on the different rights set out in the South African Constitution, limitations on rights and the role of community members in claiming rights.

The second section on health and human rights discusses why the **relationship between health and human rights** is important. It covers rights in the Bill of Rights related to health; international and national laws on the right to health; criteria for deciding whether the right to health is being met; and the duties of government in realising the right to health.

The third section focuses on **violations of the right to health**. It looks in detail at health rights guaranteed in the Constitution, the National Health Act and the Patients Rights Charter. The toolkit gives an approach to identifying violations of the right to health, and suggestions on whom to hold accountable when rights are violated and also how to complain about violations of health rights.

The last section is about citizen or **community participation in health** as a way of realising the right to health. It covers the role that citizens could play in a democracy; participation as a right; and why participation is essential for the realisation of the right to health. Finally, this section focuses on governance in health and the role that health committees could play as formal structures set up for community participation in health.

By providing practical tips, this toolkit is intended to help organisations and individuals in civil society to be able to take action to realise the right to health.

Symbols



The **Goal** icon can be found at the beginning of each section of the toolkit and sets out the overall learning aim of the section.



This icon refers to **Activities** that are designed for participants to do practical tasks or to answer a series of questions.



This is where practical **Examples** are given to help participants to better understand ideas.



Case studies are practical examples of people's real experiences. They are used to illustrate ideas or to explore participants' ability to apply ideas.



Handouts can be found at the end of each chapter. They summarise key points made in the workshops and can be photocopied for participants to take home.

Section 1

Key Words

Accountable	Being responsible for your actions
Adequate	Enough for what is required/what is necessary
Anti-retroviral drugs (ARV's)	The medicine that is used to treat HIV & AIDS
Campaign	A group of connected activities working to achieve a certain common goal (e.g. a campaign against violence)
Civil rights	Rights related to people's personal freedom and equality
Claiming rights	To ask for or take rights as something due to you
Consent	To agree or give your permission
Constitution	The highest law of the country that all other laws and policies must follow
Cultural rights	The rights of everyone alone or in a community to choose and express their cultural identity
Dignity	Everyone's right to be treated as someone of importance who is worthy of respect
Discrimination	Being treated unfairly or differently because of your race, gender, sexual orientation, physical or mental disabilities or health status
Duty Bearers	People who are responsible for making rights real
Economic rights	Rights related to money and earning a living
Exploitative labour	Taking unfair advantage of or abusing employees e.g. not paying them enough or using illegal child labour

Fulfil rights	To act in order to make rights real
Limiting rights	When rights are controlled or restricted (normally to protect the rights of others)
Minorities	A smaller racial, religious, political or other type of grouping that differs from the larger group
Moral principles	Ideas about what is right or wrong that are generally accepted by a person or a group of people
Non-State Actors	People, groups or companies that are not part of government
Non-derogable rights	Human rights that cannot be taken away or limited by the government under any circumstances
Obligation	A duty or a binding promise to do something
Policy	A plan of action or guideline agreed to by a government or an organisation
Political rights	The right of people to participate in the political life of their community (e.g. by voting)
Public hearings	A meeting between government officials and community members where people in the community can share their views on an issue with officials
Realisation	To make something real and effective (e.g. realise your right to health care)
Reasonable	To be fair and logical in making decisions
Redress	Making right something that is wrong, or to try and repair the damage that has been done
Responsibility	The duty to carry out a task or accept being responsible for an action
Rights holders	Those who can claim rights

SA Bill of Rights	The list of human rights in our Constitution
Social Assistance	Money provided by government to take care of people who are not able to take care of themselves
Social Rights	Rights that relate to our lives at home and in the community (e.g. right to education, food, health care, social assistance)
Standards	The ideal in terms of which something is judged. Standards relate to how we would like things to be
State	A country or government
Universal Declaration of Human Rights	A statement agreed on by the United Nations as the first worldwide expression of the rights of all human beings
Vulnerable groups	People that need special protection (e.g. children, the elderly)

What are Human Rights?

“
All human beings are born free and equal in dignity and rights
(**Universal Declaration of Human Rights**)”



The goal of the first section is to gain a basic understanding of human rights and the concepts related to human rights.

Human Rights and Basic Needs



Activity 1

Purpose

To make the link between basic needs and human rights clear.¹

Process

(Time 20 minutes)

1. Ask members of the audience what every person needs to survive. Write down what they say on a piece of flipchart paper with the heading 'What you need to survive'.
2. Stick this flipchart up where it can be seen clearly.
3. Sort through the answers to decide which are wants and which are actually needs. Explain that 'wants' are things that would be nice to have, but 'needs' are things that are essential and which people cannot survive without.
4. Talk about how for every basic need there is a matching human right – using the examples below.

1. This exercise has been adapted from Claude, Richard P. 2000. *Popular Education for human rights: 24 participatory exercises for facilitators and teachers*. Cambridge: Human Rights Education Associates.

Human rights address basic needs (like the need for food, water, housing, freedom of religion, freedom from torture, to be able to speak out, social support from the state). For every basic need there is a matching human right.

For example:

- need for shelter → right of access to housing
- need to be treated fairly → right to equality
- need for freedom → right to freedom and security
right to freedom of expression
- need to survive → right to social assistance from the state if you are disabled or have children and don't have enough resources



What are Human Rights?

Activity 2

Purpose

To check out participants' basic understanding of human rights.

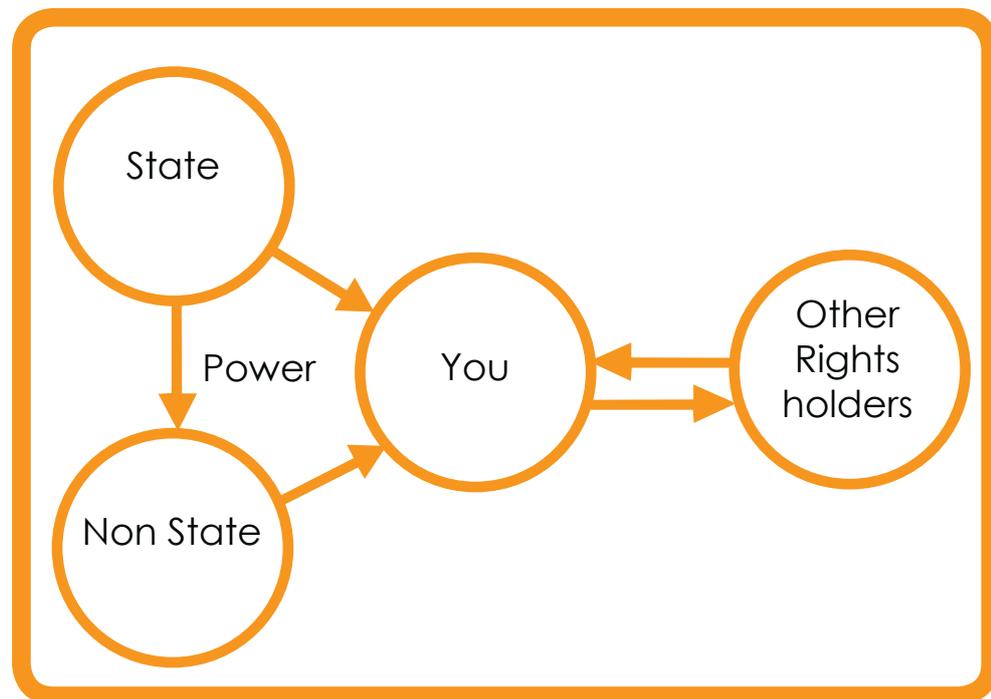
Process

(Time 40 minutes)

1. Divide the larger group into small groups where each group discusses what human rights are (give every group a chance to report back).
2. Stick each group's flipcharts up where they can be seen clearly.
3. Talk about human rights regulating your relationship with state and non-state actors (see meanings below). Then present a number of meanings of human rights and point out where the participants' definitions of human rights are the same as yours.



Rights – regulating your relationship with the State



What is the State?

We usually say “country” instead of “state” but they are both the same thing. Countries or states have recognition from other countries (were voted into the club by other countries) and have internationally recognised boundaries or borders. The state has an organised economy and is normally controlled by government. Government provides public services (like education, health, transport) and police or military power.

In the language of human rights, ‘state actors’ are government officials and the officials of any bodies owned and operated by the state.

What are Non-State Actors?

Non-state actors are normally companies, transnational corporations, private citizens, NGO’s or institutions (eg. Universities or the World Bank or even armed groups that are rebelling against governments). Non-state actors are therefore basically any individuals or organisations that are not controlled by the state or the country.

Rights set minimum standards for how individuals and institutions should treat people. Human rights tell both state (national and local government and government officials) and non-state actors (individuals, companies, institutions) what they can do, what they can't do and what they should do for you.²

The Treatment Action Campaign took government to court over provision of antiretroviral medicine (ARVs) to all pregnant women with HIV. At the time ARVs were only provided at some clinics (18 pilot sites). The Constitutional Court ruled that the state had to provide ARVs to pregnant mothers at all sites and had to come up with a plan for how they would start doing this.



In this way the state was told what it could not do and what it should do as a result of human rights agreements.

Non-state actors can also be forced to respect your rights through laws made by the state.

In the past medical aids (a non-state actor) excluded those who are HIV-positive from joining medical aids and having access to medical cover. This medical aid rule discriminated unfairly against those who are HIV-positive. The government then made a law to protect those with HIV from being excluded from medical aids.



In this way the government protected citizens from abuse by non-state actors. In this case the non-state actor was the medical aid. People who are HIV-positive are covered by medical aids today.

Basically, human rights protect you from abuse by those who have more power than you, whether it is the state or private individuals or organisations.

Some Possible Definitions of Human Rights:

Basic standards that you need to live in dignity

A set of moral principles that apply to everyone equally

A claim that we are justified in making

Something that we are entitled to and can expect to be met (promise or guarantee)

2. *Haki Zetu (Our Rights)*. Amnesty International

Human Rights are:

Universal: Belong to everyone

Inherent: We are born with rights just because we are human

Inalienable: They exist no matter what happens (we cannot give up, we still have rights - even if they are being violated).



Poor people who don't have houses still have the right to adequate housing, even if the right is not currently being provided. The state should, over time, put in place measures so that everyone has access to housing.

Interdependent: All are linked and depend on each other. The realisation of one right often depends on acknowledging and realising other rights. For example, when you have been educated (the right to education) it is easier to find a job (the right to work).

Indivisible: All rights form a whole and cannot be divided; no right is more important than any other right.



In the Grootboom Constitutional Court case which looked at the right to housing, the court said that all the rights in the South African Bill of Rights depend on each other and form one whole (they can't be separated). When people live without shelter, food or water, this also interferes with their right to live with dignity, equality and freedom.³



3. Grant, K., Lewis, M. & Strode, A. 2006. *HIV/AIDS and Human Rights in Southern Africa*. AIDS and Rights Alliance for Southern Africa.

Tree of Rights



4

In South Africa we have a Bill of Rights, which is part of our country's law. The Bill of Rights (the trunk of the tree) is what forms the basis of our rights. Things like the right to health, the right to water, the right to freedom or the right to vote and all the other kinds of rights are the fruits of the Bill of Rights, and can be claimed by rights holders. These fruits (rights) are produced and upheld by the Bill of Rights (and other laws and policies) which stand at the centre. Sometimes there are vulnerable groups or people who find it difficult to access their rights (like disabled people, children or immigrants). In cases like this it is the duty of NGOs or other individuals to put up a ladder and help those who can't reach their rights. This assistance then makes it possible for vulnerable groups to reach the fruits (rights).

Vulnerable groups like children, disabled people or those who are in prison (who may have less power than others) often have some extra or special rights to make sure that they are protected.

4. This illustration and the explanation is sourced from a workshop on discrimination by the Early Learning Resources Unit (www.elru.co.za)

Important Human Rights Ideas

Rights Holders: Those who can claim rights or are entitled to rights.

Duty Bearers: Those who have obligations to fulfil rights, making sure that people's rights are made real. Duty bearers include local, provincial and national governmental authorities.



Activity 3

Purpose

To show clearly how every right we have also has a responsibility attached to it.⁵

Process

(Time 30 minutes)

1. Ask participants to turn to the person next to them, so that they can work together.
2. Each person must list three rights they feel they should have at home. Then the two people working together should swap their lists of rights with each other.
3. Once they have swapped lists, each person should write down three responsibilities related to the rights listed by their partner.
4. The partners will share one or two rights and their matching responsibilities with the rest of the larger group.
5. The facilitator writes down the rights and responsibilities on a flipchart and displays it where it can be clearly seen.
6. Talk about how we don't just have rights, but that there are also responsibilities related to those rights – using the material below.

5. This exercise has been adapted from *Siniko: Toward a Human Rights Culture in Africa*. 1999. Amnesty International.

Responsibility: Every right has a matching responsibility. If you want to have your rights met, you need to behave in a way that allows the state to meet your rights and to allow others to have their rights met. We are also all responsible to continue the struggle for human rights.

If you go to the clinic for treatment, the health worker will ask for information about your medical history. If you want the health care worker to treat your problem properly, you need to give the correct information. To have your right to access to health care met, you have a responsibility to share medical information that is needed for your treatment.



Another example is the right to freedom of expression. You have the right to express yourself, but you also have a responsibility to tell the truth and not abuse the dignity of others in what you say.⁶



Participation: All people have a right to participate in public affairs and to be consulted in public decision-making.

Non-discrimination: All human beings are entitled to their human rights without discrimination on the basis of gender, race, sexual orientation, religion, political opinion, national or social origin or disability⁷

Progressive realisation: Steps to improve access to rights over a period of time (a plan for improvement).

Equity: Fair and reasonable distribution of resources - allocating the most resources to those with the greatest need.

Dignity: The idea that every human being has worth and should be treated with respect and without discrimination.



6. Siniko: *Toward a Human Rights Culture in Africa*. 1999. Amnesty International.
7. *Toolkit: A human rights based approach*. 2009. Vietnam: United Nations.

The Constitution

The South African Constitution is the highest law in South Africa. This means that all other laws and policies must fall in line with what the Constitution says. Human rights are set out in the Bill of Rights in Chapter 2 of the Constitution. Therefore in South Africa human rights are also legal rights. The South African Human Rights Commission is the body set up to monitor whether government takes up its human rights commitments and is the body that investigates human rights complaints.

Different Kinds of Rights



Activity 4

Purpose

To find out what rights participants already know about, and to improve their knowledge of different kinds of rights.⁸

Process

(Time 50 minutes)

1. Divide the larger group into smaller discussion groups.
2. Ask people in each small group to imagine that they are responsible for writing the Bill of Rights document for a new country. Each individual must list three human rights that they feel the country should have.
3. After this ask them to discuss their lists and to decide together on ten rights for the country, agreed on by everyone in the group.
4. Each group should give their country a name and write down the ten rights they have decided on flipchart paper.
5. The groups then report back one by one to the large group.
6. The workshop facilitator uses the feedback to create a Master List of rights by writing down each different or new one presented.
7. Put the Master List up where everyone can see it.
8. Compare the Master List to the list from South Africa's Bill of Rights below.

8. This exercise has been adapted from *Siniko: Toward a Human Rights Culture in Africa*. 1999. Amnesty International.

When one looks at the following list of different rights it is clear that some rights fall into more than one of the groups (see *italics*). It shows that rights are not easily separated into these different groups and they might belong in two or more of the groups at the same time. People sometimes cluster these rights together and talk about economic, social and cultural rights as one group and civil and political rights as another group.

Civil Rights are about an individual's place in a country and maintaining a free, orderly and secure society. These rights allow people to some extent to be free from fear.

- Right to be a citizen of SA
- Children have the right to an identity
- Right to life
- Right to equality
- Right to privacy*
- Right to non-discrimination
- Right to own land*
- Right to dignity
- Right to freedom from slavery
- Right to just administrative action
- Right to equality before the law
- Right to access to courts
- Right to a fair trial
- Rights of arrested persons
- Right to fair labour practices; children have a right not to be subjected to labour that affects their health or schooling.*
- Right to access to information
- Right to freedom of movement and residence
- Right to freedom of religion



Political rights focus on an individual's right to participate in public affairs and political processes (through standing for election, voting or even being part of peaceful demonstrations). These rights allow people to some extent to be free from threats or discrimination.

- Right to freedom and security of the person
- Right to freedom of expression
- Right to assembly, picket and demonstration
- Right to stand for election
- Right to vote
- Right to free and fair elections
- Right to make political choices
- Right to freedom from torture
- Right to strike
- Right to form a trade union



Social rights are about our lives at home and in our community. Their focus is on things we need to survive and relate to 'freedom from want'.

- Right to sufficient food and water
- Right to adequate housing
- Right to adequate sanitation
- Right to social assistance
- Right to basic education
- Right to access to health care
- Right to fair labour practices; children have a right not to be subjected to work that affects their health or schooling.
- Right to privacy
- Right to dignity
- Right to freedom of movement and residence
- Right to a healthy environment
- Children's special rights (food, education, shelter and protection from abuse)

Cultural rights have to do with the language, beliefs and religion of groups of people and the protection of their cultural identity.

- Right to freedom of religion and belief*
- Right to your own language and culture – eg. for members of minority groups



Economic rights are rights to do with money and earning a living. They also relate to the necessities we need to survive and are an aspect of 'freedom from want'.

- Right to freedom of trade, occupation and profession
- Right to an adequate standard of living
- Right to fair working conditions
- Right to social assistance (social security, grants)
- Right to freedom from slavery
- Right to strike
- Right to join a trade union
- Right to own land (not have your property taken away)

It is important to note that economic, social and cultural rights can't be seen separately from civil and political rights, and also that one group of rights is not more important than the other.



All economic, social and cultural rights are part of the right to life. Without food, water and decent living conditions the right to life and health becomes threatened. When people are tortured (violating civil and political rights) it impacts on their right to the highest attainable standard of health (an economic, social and cultural right). The right to speak freely and form a group with others (civil and political rights) are what makes it possible for people to campaign for economic, social and cultural rights.⁹

⁹. *Haki Zetu (Our Rights)*. Amnesty International

Limiting and Balancing Rights



Activity 5

Purpose

A role play to stimulate discussion and to get people involved in understanding and balancing rights

Process

(Time 25 minutes)

1. Get three volunteers to act out the following scenario. One is the husband, the other a wife and the third is a policeman called to the scene. The husband is abusing the wife; but when she calls the police the policeman refuses to come and help, saying it is a private matter between husband and wife happening in their home.
2. Ask the group to discuss the rights that are being balanced against each other here (right to privacy vs. right to be free from public and private violence)
3. Give input on the limitations to rights and balancing rights.

Rights are often subject to restraints (mostly to respect the rights of others). The rights of two people or organisations may clash and one person's rights may need to be balanced against another person's rights and interests.





Case study



The policy at schools in South Africa is that parents have to provide clinic cards to prove that their children have been vaccinated, before children may start school. In 2006 a newspaper reported on a Rastafarian family who wanted their children to start school. Because of Rastafarian cultural beliefs which reject Western medicine, the children had not been vaccinated. As a result these children were not able to start school. The rights that have to be balanced in this case are the children's right to education and the other children at the school's right to be protected from disease (through being vaccinated) as well as the right of Rastafarian people to practise their cultural beliefs. In this case the South African Human Rights Commission ruled in favour of the family and asked that the children be admitted to school. They argued that the school's admission policy requiring vaccination wasn't a good enough reason to deny children their right to education.

Sometimes rights can be suspended (taken away) or restricted by the state. However, for the state to be able to limit or restrict rights:

- The restriction of rights must be set out in a law or regulation
- The restriction is for the purpose of respecting the rights of others
- The restriction is reasonable or justifiable
- The restriction meets the requirements of morality, public order and general welfare in a democratic society

Courts will look at whether a restriction or limitation is justified as follows:

- By examining whether the limitation is likely to result in the intended outcome
- By asking if the reason for limitation is important
- Looking at the degree of limitation (how much is the right being limited)
- By checking if there are perhaps other better (less restrictive) ways to achieve the same purpose without limiting the right?



What if the South African government says that despite the right to housing, they will only plan to provide houses to South African citizens? They could defend this decision in terms of not having enough resources to provide housing to non-citizens as well.¹⁰ Another example of limiting rights would be when people's right to freedom of movement is suspended or taken away as a result of having committed a crime.

10. Liebenberg, S. & Pillay, K. (eds). 2000. *Socio-Economic Rights in South Africa: A resource book*. Cape Town: Community Law Centre (UWC) and Foundation for Human Rights in South Africa.

There are certain rights that can never be limited. They are non-derogable rights, in other words rights that must be guaranteed under all circumstances. These include the following:

- Right to life
- Right to be free from discrimination
- Right to freedom from torture
- Right to human dignity
- Right not to be punished in a cruel, inhuman or degrading way
- Right not to be subjected to medical or scientific experiments without consent or permission
- Right to be free from slavery and servitude
- Children's special rights to be protected from abuse or neglect, exploitative labour and not to be imprisoned except as a last resort
- Various rights of those who have been arrested to be provided with a lawyer, access to courts, etc.

What is My Role?

“

Every individual and every organ of society...shall strive by teaching and education to promote respect for these rights and freedoms...”
(Universal Declaration of Human Rights)

Human rights will only be met if individuals demand their rights. As individuals we are both rights holders and duty bearers. We have the responsibility to claim our rights, to make others aware of their rights and to avoid violating the rights of other people.

Actions you could take:

Know your rights





Case study

"There was this day when I felt ill. When I went to the clinic I asked the sister if she could check my blood pressure, because I think there is something wrong with my blood pressure because I get terrible headaches. Then she said to me I can't decide here what I want to have done. I felt I had the right to ask her and I wasn't being rude. I told her I know my rights and if she wants to violate my rights then we can discuss it, because I feel it is ok to ask what I want done... So she tested my blood pressure."

Teach others about their rights

Hold duty bearers (such as government) accountable, by complaining about violations of rights to the South African Human Rights Commission



After receiving many complaints about violations or abuse of people's health rights, the South African Human Rights Commission called for public hearings on access to health care. As a result of these hearings, the Commission produced a report highlighting violations of health rights and drawing government's attention to these problems.

Use the law or a complaints mechanism



Case study

The Aids Law Project in South Africa made a complaint to South Africa's Competition Commission about pharmaceutical companies Glaxco Smith Kline and Brehinger Ingelheim. They said that private drug companies were abusing the right to health care by charging prices that were too high for ARVs. This case examined the duties of drug companies to charge affordable rates for life-saving medicines. As a result other companies were given the option (licenses) to produce or import affordable generic ARVs thus bringing down the costs of these essential medicines.¹¹

Work with NGOs (advocacy and lobbying)

Get compensation (redress) for violations of rights

11. Grant, K., Lewis, M. & Strode, A. 2006. *HIV/AIDS and Human Rights in Southern Africa*. AIDS and Rights Alliance for Southern Africa.



Activity 6 (optional)

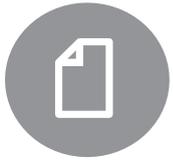
Purpose

To be able to identify issues related to human rights and apply knowledge of human rights to real life situations. This activity may only be possible if you are working with the same participants over a number of weeks.¹²

Process

1. Ask participants to look at newspapers and magazines for pictures and text that relate to human rights and to cut out these news items or pictures. Pictures could be related to stigma or discrimination against women or a news report on war or torture in another country.
2. Have a special notice board / poster board where these pictures or newspaper reports can be displayed.
3. The notice board could have the following headings: rights denied, rights protected, rights in action - for people to put up the different items they have collected.

12. This exercise has been adapted from *Siniko: Toward a Human Rights Culture in Africa*. 1999. Amnesty International.



Workshop Handouts

The pages that follow can be photocopied to give to workshop participants as handouts during the workshop.



What are Human Rights?

Basic standards needed to live in dignity

A set of moral principles that apply to everyone

A claim that we are justified in making; something that we are entitled to and expect (promise or guarantee)

“
All human beings are born free and equal
in dignity and rights.”
(From the Universal Declaration of Human Rights)



Properties of Human Rights

Universal: Belong to everyone

Inherent: Born with rights because we are human

Inalienable: Exist no matter what happens (cannot give up)

Interdependent: All linked and depend on each other

Important Human Rights ideas

Rights Holders

Those who can claim rights

Duty Bearers

Those who have responsibility to fulfil others' rights (make sure they are real)

Responsibility

Treating other rights holders equally in dignity and justice. Take forward the struggle for human rights.



Different Kinds of Rights

Civil and Political rights (freedom, my right to be me)

- right to vote
- right to participate in government
- right to freedom of expression
- right to equality

Social, Cultural and Economic rights (need for work, health, food, social assistance)

- right to basic education
- right to access to health care
- right to fair working conditions
- right to social assistance from the state



Limiting and balancing rights

Rights of one person may conflict with another person

This could result in restriction of rights

State may limit or restrict rights if:

The restriction of rights is set out in law

The restriction is for the purpose of respecting the rights of others

The restriction is reasonable or justifiable

The restriction meets the requirements of morality, public order and general welfare in a democratic society

Section 2

Key words

Acceptable	Enough to satisfy needs or standards and respectful of the culture of individuals
Accessible	To be able to reach, understand or make use of
Adequate	Enough in quality or quantity to meet a need
Asylum seekers	People who leave their own country to seek safety or protection in another country
Availability	Easily accessible/obtainable and suitable for use
Bodily integrity	Having a say in what happens to your body and the right not to have your body interfered with or hurt
Charter	A formal agreement between two or more countries that can be enforced by law
Code	A set of standards or collection of rules and regulations
Coercion	When government or another person uses force to make something happen. To make someone do something against their will
Confidentiality	The rule that information will be kept secret, unless a person gives their permission for the information to be shared
Constitution	The highest law of the country that all other laws and policies must follow
Convention	A formal agreement between two or more countries that can be enforced by law
Covenant	A formal agreement between two or more countries that can be enforced by law

Declaration	A document stating a set of values or how we would like things to be
Deprive	To prevent someone from having, keeping or getting something, or taking it away from them
Dignity	Everyone's right to be treated as someone of importance who is worthy of respect
Emergency	A sudden disastrous event, which calls for immediate action to prevent the situation from becoming worse (e.g. poses an immediate risk to health)
Equitable	Fair to everyone concerned
Exclusion	Being deliberately left out or not accepted
Female genital mutilation	The cultural practice of partially or totally removing a woman's sex organs (vulva, clitoris)
Fulfil	When government takes action to make it possible for people to have the benefit of human rights; satisfying, supplying or completing something
General Comment	A General Comment on a specific right is usually issued by a United Nations treaty body to advise governments on the meaning of a right or to provide advice on how to implement the right in question.
Human rights instruments	Includes any regional or international human rights agreements (treaty, charter, covenant) or human rights standards
Implementation	Putting a plan or design into action; to provide somebody with the tools to do or achieve something
Informed consent	Giving your permission after getting all the information needed to decide (what are the choices, how will it be of benefit, what are the possible harms)
International Covenant of Civil and Political Rights (ICCPR)	An International legal agreement between countries relating to the civil and political rights of people

International Covenant of Economic Social and Cultural Rights (ICESCR)	An International legal agreement between countries relating to the economic, social and cultural rights of people
Legislation	Laws that are made by Parliament or Municipalities
Obligation	A duty or a binding promise to do something
Palliative care	Medical treatment that aims to ease suffering and promote the quality of life of those facing serious illness
Progressive realisation	Steps taken to improve access to rights over a period of time (continuous improvement)
Promote	To push for rights to become known and meaningful
Protect	When government prevents others from violating your human rights
Quality	The general standard or grade of something; the extent to which something conforms to standards of excellence
Ratification	Government confirmation that it will commit to the terms of an international agreement and make it part of its laws
Rehabilitation	Restoring someone to their former state of health and participation in normal life (through medical treatment or physical therapy)
Respect	When government does not interfere with people exercising their rights or restrict the extent of a right
Retrogressive	To move backwards from progress made; to return to an earlier and usually worse situation
Sanitation	Maintenance of public health especially through the water supply – toilets & sewage systems; and the removal of rubbish
Social determinants of health	Conditions that are necessary for health and influence people's health (e.g. access to safe drinking water, sufficient food, shelter, freedom from violence)

Standard of living	The level of wealth, comfort, possessions and necessities available to a community or society
Treaties	An agreement between two or more countries that can be enforced by law
Violation	Abusing or not respecting a right
Vulnerable groups	People that need special protection (e.g. children, the elderly)
World Health Organisation	The organisation in the United Nations system that is responsible for health (providing leadership on global health and promoting co-operation between countries in improving health)

Health and Human Rights

“

The right to health does not mean the right to be healthy, nor does it mean that poor governments must put in place expensive health services for which they have no resources. But it does require governments and public health authorities to put in place policies and action plans which will lead to available and accessible health care for all in the shortest possible time...”

(Mary Robinson, United Nations High Commissioner for Human Rights)



The goal of the first section is to understand the connection between health and human rights. To do so, we aim to get deeper insight into what health is, and how the right to health can best be understood.

Defining Health

According to the World Health Organisation health is a “state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity.” When talking about the right to health, we take a similar broad view of health. This means thinking about your health as more than just going to a clinic or a hospital for treatment. We must also think about how to prevent illness and promote healthy living. But there are many social conditions and factors related to your standard of living that influence health. For example, living in a healthy environment, having access to shelter, food, water and adequate sanitation are all important in maintaining good health.¹ So, in defining health, it is important to talk not only about access to health care but also about these social conditions that affect your health – we call these factors the conditions necessary for health.²

1. Asher, Judith. 2004. *The Right to Health: A Resource Manual for NGO's*. London: The Commonwealth Medical Trust.

2. See also “*The Commission for Social Determinants of Health report*” summary at <http://www.csr360gpn.org/library/file/who-commission-on-social-determinants-of-health-executive-summary/>

Rights related to Health



Activity 1

Purpose

To brainstorm what general rights are related to the right to health.

Process

(Time 20 minutes)

1. Ask members of the audience what human rights affect health. Write down their responses on a page of flipchart paper with the heading 'Rights Affecting Health'.
2. Stick this page up where it can be seen clearly.
3. Go through the list, pointing out the rights they have named and confirm these as correct. Then add any other rights that they may not have mentioned. Remind the group how all rights are connected and that we cannot really enjoy one without having the other.

In the first section of this toolkit, we refer to the fact that all human rights depend on each other to be realised and that all rights form a whole and no rights are more important than other rights. In the case of health there are a number of human rights in our Constitution that are closely connected to the right to health. These rights are listed below.

Key Health-related Human Rights:

The Right to life

When your health is threatened, it can also lead to your right to life being violated.

The Right to dignity

The way you are treated by health services may violate your right to dignity; having to live a life deprived of health rights may also result in your living without dignity.



For example, if you have a chronic ulcer or a leaking bladder that you cannot get treatment for, your disability may result in your dignity being affected.

“

The Constitution requires all of us to respect the dignity of South Africans and one can't speak of a person's dignity when the person is living in squalor and that person can't have access to facilities, medical facilities and it is for that reason I presume that we have in our Constitution ... socio-economic rights.”
(Justice T.L Skweyiya, Constitutional Court, October, 2003)

The Right to bodily and psychological integrity

This means people have the right to have control of their body and mind. They should be free of violence and assault, even in their homes. They should also make their own decisions about their reproductive choices (e.g. to have or not to have a baby). Another aspect of this right is that people should not be part of medical treatment or experiments without their permission.

The Right to education

The way that the right to education affects health is that people with better education are able to lead healthier lives and can ensure that their children are healthier.

The Right to a healthy environment

When you live in an environment that contains many harmful factors (e.g. pollution, infections, physical dangers), this can increase your risk of becoming ill.

The Right to food and water

We need enough food and water to grow up and to stay healthy. Children and adults that don't have enough to eat are more likely to get infections and die. Clean water is also very important, because when water is contaminated (with germs that cause infections) people can get diseases (like cholera or diarrhoea).



The Right to housing

Living in a house that has been built properly and that has good sanitation will help to keep you healthy. If your house is overcrowded or leaking, you are more likely to get an infectious disease.

The Right to equality

The right to be treated equally is essential for protecting the health status of vulnerable and disadvantaged groups. Unfair discrimination and exclusion are both seen to be causes of poverty and poverty is a major risk for poor health. Poor people are also often excluded from having access to good health care.³

The Right to access to information

It is important to be able to access information to protect the right to health. You can use information to monitor government health policy and implementation and get access to important health information (e.g. your own records, general information on the causes of illnesses).⁴

The Right to participation

The right to participate is important for the realisation of all human rights and people have a right to participate in any decision making processes that might affect their health.

“

The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.”
(Alma Ata Declaration on Primary Health Care.)⁵



3. *Haki Zetu (Our Rights)*. Amnesty International and Asher, Judith. 2004. *The Right to Health: A Resource Manual for NGOs*. London: The Commonwealth Medical Trust.

4. *Haki Zetu (Our Rights)*. Amnesty International

5. From http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf

Link between Health and Human Rights



A lack of human rights / abuse of rights can affect health

When people are denied the right to access to clean water, it could result in illnesses like diarrhoea or cholera.

People who have been tortured can suffer terrible health problems, both immediately and long after the torture.

Violence against women can negatively affect their health (for example the health effects of rape or domestic violence).

Harmful traditional practices, like female genital mutilation, can cause health problems (for example when a woman gives birth, the procedure she had done to her as a child can hinder her baby from being born, causing childbirth complications which can result in her death or long-term disability).



Health problems can cause discrimination and violation of rights

Someone with a mental illness may be discriminated against in the workplace (for example by being denied the opportunity to work as a result of the employer knowing about their mental illness)

People who are HIV-positive may be denied the opportunity to join medical aids (they are thus denied the right to be treated equally and will have to carry the full financial burden of being ill)

People who are deaf are discriminated against when health services do not provide adequate translation for them. This interferes with their access to appropriate health care.



Health problems make it difficult to claim other rights

A child who is very sick, and has to stay in bed, can't go to school and therefore is unable to access the right to education. Similarly, children denied access to sufficient food will be starving while at school, unable to concentrate and learn.

People with epilepsy may be denied the right to work, because employers are afraid to employ someone with this condition.

A child whose parent is HIV-positive and can't work may be denied his/her right not to be subjected to labour/work that interferes with his/her schooling.

Health policies and programmes can deny rights to certain people



The government's previous policy wanted to provide pregnant women with access to antiretroviral medicines (ARVs) only in certain places, therefore denying access to ARVs to people who didn't live in those areas.

Certain kinds of treatment may be provided in private hospitals and clinics, but not in public facilities. That means that people using public health care may be denied treatment that is essential for their health, which is a violation of their rights.

One health policy is to encourage routine HIV testing in health facilities. If the health personnel are over-enthusiastic in testing people for HIV without their consent, then patients' rights to bodily integrity and privacy are violated.⁶

Rights are given Power through Law

How do rights become law?

In South Africa our human rights are also legal rights because they have become part of our National Law, through the Bill of Rights in the South African Constitution.

To try and avoid the human rights abuses of the past, in 1948 after World War II, fourteen countries put together the Universal Declaration of Human Rights (UDHR). The purpose of this declaration was to protect the human rights of all people across the world. Although it isn't legally binding, the UDHR is a standard for all nations to achieve a 'hoped for world', where there is a common understanding and realisation of the rights and freedoms of all people.



6. Grant, K., Lewis, M. & Strode, A. 2006. *HIV/AIDS and Human Rights in Southern Africa*. AIDS and Rights Alliance for Southern Africa.

Legally binding treaties like the International Covenant of Civil and Political Rights (ICCPR) and the International Covenant of Economic Social and Cultural Rights (ICESCR) are documents that were developed to put into practice what is contained in the Universal Declaration of Human Rights. It is important to know and understand international human rights instruments because:

Many national Bills of Rights have been modelled on international human rights instruments.
International conventions are part of international law.
Courts in South Africa have to keep in mind international human rights law when interpreting our national laws on human rights⁷.

Important concepts when working with international human rights instruments:

Declaration

A document stating agreed standards or principles. It is not legally binding but has strong moral force e.g. the Universal Declaration of Human Rights.

Code

A document setting out principles to guide states. Some countries can use the code as a basis for their laws, or refer to the code in their laws. e.g. SADC Code on HIV and employment

Conventions, Treaties or Charters

Written, legally binding agreements between states or organisations (ruled by international law)

e.g. The Convention on the Rights of the Child
International Convention on Civil and Political Rights
African Charter on Human and People's Rights⁸

If a government **signs**, they indicate that they support the agreement in principle and make a commitment not to act against the agreement. After signing, governments are expected to ratify a treaty or covenant. When a government **ratifies** a treaty or covenant it means they officially agree to abide by the treaty. They must amend their own laws or pass new laws in line with the treaty.⁹

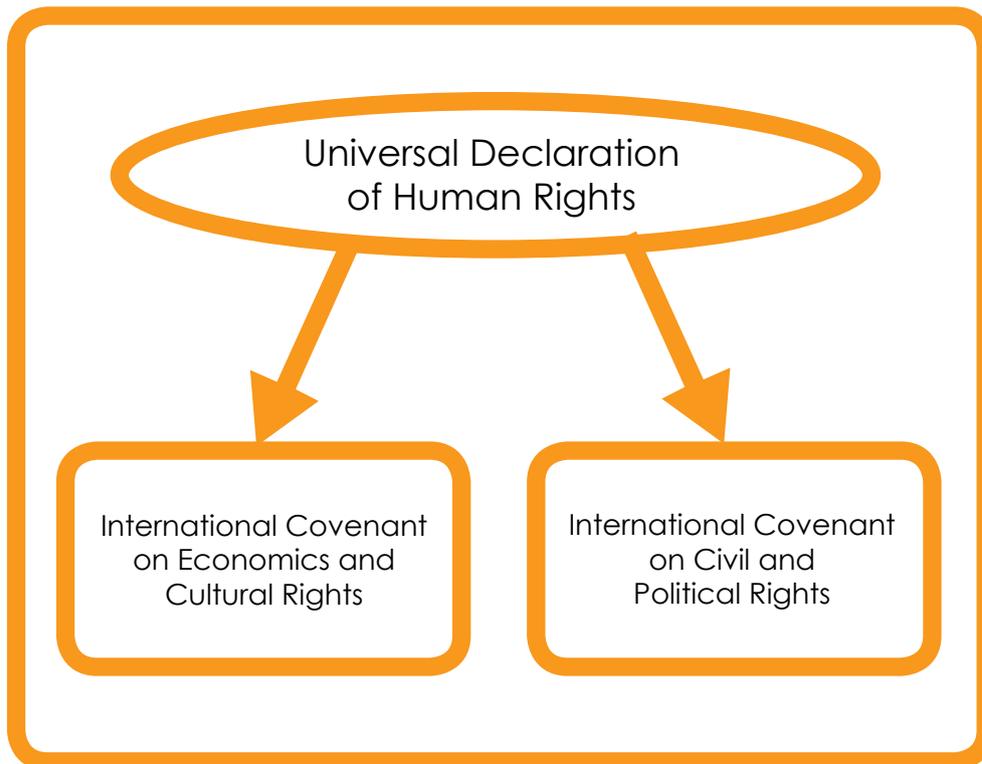


7. Grant, K., Lewis, M. & Strode, A. 2006. *HIV/AIDS and Human Rights in Southern Africa*. AIDS and Rights Alliance for Southern Africa.

8. Grant, K., Lewis, M. & Strode, A. 2006. *HIV/AIDS and Human Rights in Southern Africa*. AIDS and Rights Alliance for Southern Africa.

9. Grant, K., Lewis, M., Nongogo, N. & Strode, A. 2005. *HIV/AIDS and the Law: A trainers manual*. Joint OXFAM HIV/AIDS Programme.

International Bill of Human Rights



10

The Universal Declaration of Human Rights together with the International Covenant of Civil and Political Rights (ICCPR) and the International Covenant of Economic Social and Cultural Rights (ICESCR) are collectively known as the International Bill of Human Rights.

What is the Right to health?

The right to health does not mean we have a right to be healthy. However, the state does have a duty to promote health services, provide access to health care and to provide access to the conditions needed to be healthy (like a healthy environment, access to enough food, water and proper sanitation).

10. Diagram sourced from Farrell, E., Goodnow, M. & Lohman, M. (2009). *Human Rights Toolkit*. Minneapolis: Advocates for Human Rights

Key treaty provisions on the right to health

Universal Declaration of Human Rights

Article 25

Everyone has the right to a standard of living adequate for the health and well being of himself and of his family, including food, clothing, housing and medical care and necessary social services and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

International Covenant on Economic, Social and Cultural Rights

Article 12

The right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

African Charter on Human and People's Rights

Article 16

1. Every individual shall have the right to enjoy the best attainable state of physical and mental health.
2. States parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.

The right to health in the South African Constitution



Section 27

1. Everyone has the right to have access to -
 - a) health care services, including reproductive health care;
 - b) sufficient food and water; and
 - c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.
2. The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.
3. No one may be refused emergency medical treatment.
4. Everyone has the right to an environment that is not harmful to their health or well-being.

International Covenant on Economic, Social and Cultural Rights - General comment 14

General Comments are normally put in place to advise and guide states/governments on how fulfil their rights obligations, deal with violations of rights and specify how International rights agreements should be implemented. They also have explanations of the content or meaning of a right and can be used as tools when claiming rights from the government.

In the case of the right to health General Comment 14 of the Covenant on Economic, Social and Cultural Rights provides guidelines on the implementation and obligations of governments related to the right to health.¹¹

Dimensions of the Right to health

General Comment 14 provides the following guidelines to understand how to assess if the right to health has been met. The Comment suggests you should ask the following questions about health:

Is there Availability of the basics needed for health?

Functioning health-care facilities (hospitals, clinics, enough staff) goods (drugs, equipment) and services (mental health care, family planning, immunisation), as well as programmes available in sufficient quantity to all communities

Access to the underlying conditions upon which health depends, such as safe and potable drinking water and adequate sanitation facilities

Availability of urgent medical care for accidents and disasters

Trained medical and professional personnel

Access to essential drugs, as defined by the WHO Action Programme on Essential Drugs

Are the basics needed for health Accessible?

(physically accessible, economically accessible, accessible in a non-discriminatory way, accessibility of information)

Existence of services at community level



11. *Haki Zetu (Our Rights)*. Amnesty International



Health facilities, goods and services have to be accessible to everyone without discrimination (especially the vulnerable)

Health care is distributed equitably (resources allocated according to need)

This includes physical accessibility (access for disabled, distance to facility, opening hours)

Facilities should be affordable for everyone

Information should be accessible (simple explanations, health information, access to health records, people being spoken to in the language they understand)

Are services Acceptable?

Responsive and sensitive to patient needs, fostering a culture of dignity

All health facilities, goods and services must be respectful of medical ethics (informed consent)

Must be culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities

Translation/interpretation should be available as a standard service

Sensitive to gender and age

Designed to respect confidentiality/privacy and improve the health status of those concerned

Are goods and services of good Quality?

Goods and services must also be scientifically and medically appropriate and of good quality (safe, timely, patient-oriented)

Standards for treatment are enforced and there is quality control

Measured by how well programme meets health needs

Skilled and trained medical personnel

Scientifically approved and unexpired drugs and hospital equipment

Quality of buildings

Safe and potable water, and adequate sanitation

Work through the case study below with the larger group, before asking people to tackle the related activity on their own.

Case study



"My daughter is 24 years old; she was pregnant and had a baby in March last year. The baby was very small, but when I asked them about it at the hospital they said that the baby was normal and that there was nothing wrong. Later my daughter had to take the baby to the clinic. When she came back from the clinic she was crying and crying. When I asked her what was wrong she told me that the nurse at the clinic had spoken to her in front of all the other ladies and asked her why this baby is so small, she asked her in front of everyone if the baby is HIV-positive." – **(Experience as related by the mother of the young woman).**



Case questions

1. Is this an example of services not being accessible, available, acceptable or of good quality?

Answer

This young woman is dealing with a violation of her right to privacy and confidentiality. She isn't being treated with respect or dignity.

Clearly the health service provided is not **acceptable** because:

The mother of the baby is not treated in a way that fosters a culture of dignity

The person's confidentiality and privacy is not respected, and in this way the service is not responsive to patient needs.

In addition one can ask questions about the **quality** of the health service provided:

It is not medically appropriate to disrespect the privacy and confidentiality of the patient.

One would need to look at whether staff are appropriately trained to deal with issues related to HIV and how clear the complaints procedure is at this facility (quality control).

If the baby was born with HIV infection, then the programme to detect pregnant mothers who have HIV infection must have failed to screen the mother of the baby or treat her effectively.

If the mother of the baby is too embarrassed to go back to the clinic, then she will not have proper **access** to health services.



Activity 2

Purpose

To apply knowledge gained on how to understand the different areas of the right to health.

Process

(Time 50 minutes)

1. Divide the participants into four smaller groups. Hand out one case study to each of the four groups (see handouts at the end of the chapter for case studies 1-4).
2. Participants should read through the case study individually or one person could read it aloud to the rest of the group.
3. Each group should work together to answer the questions related to their particular case study and capture it on a flipchart. Each group will have an opportunity to report back on their answers to the larger group.

Governments have four types of obligations related to the Right to health.

Respect

According to General Comment 14 government has an obligation to respect the right to health. What this means is that they must not directly or indirectly prevent the enjoyment of the right to health or interfere with persons exercising their rights.¹²



Some examples of the obligation to **respect** the right to health would be that government:

Must not withhold accurate health information (e.g. the negative health impacts of smoking)

Must not make health care services (hospitals or clinics) too expensive for the poor to afford

Must not deny or limit access to health care for all persons, including prisoners and asylum seekers or illegal immigrants

Must not refuse to provide a service that only a particular group of people might need (e.g. sign language interpretation at clinics for people who are deaf)

12. Farrell, E., Goodnow, M. & Lohman, M. (2009). *Human Rights Toolkit*. Minneapolis: Advocates for Human Rights.

Should keep in place existing services (clinics or hospitals) or programmes (immunisation programmes) and realise that shutting down existing programmes counts as moving backwards and not towards improvement¹³

Protect

Government must prevent others from interfering with rights or committing human rights abuses. They should make and enforce laws that protect the right to health.

Some examples of the obligation to **protect** the right to health would be that government:

- Puts in place laws that prevent organisations from polluting the environment and causing harm to the health of communities
- Has laws to regulate the creation and marketing of medicines
- Ensures that medical practitioners are properly trained and comply with medical ethics (do not harm others)
- Protects members of the community from harmful traditional practices (e.g. virginity testing for young girls)



Fulfil

The obligation to fulfil the right to health means that government must take positive action to ensure that rights are enjoyed. In other words government should adopt laws, budgets and measures in court that work to ensure the realisation of the right to health. In addition they should allocate resources to programmes for human rights.

Some examples of the obligation to fulfil the right to health would be that government:

- Supports civil society and public participation in decisions and policy making regarding health
- Providing health care and increasingly giving more resources to deprived regions (e.g. prioritising the provision of health care in rural areas)
- Giving access to water for all (OR having a plan to work towards this)
- Recognising the right to health in law and in the national health policy
- Budgeting enough money for expenditure on health (to provide access to affordable medicines and to set up local health centres) and having a plan to realise the right to health¹⁴



13. Asher, Judith. 2004. *The Right to Health: A Resource Manual for NGO's*. London: The Commonwealth Medical Trust.

14. Asher, Judith. 2004. *The Right to Health: A Resource Manual for NGO's*. London: The Commonwealth Medical Trust.

Promote

The obligation to **promote** the right to health means that government should take steps to ensure that people are aware of their health rights and that they understand how to use them. In order for communities to enjoy the right to health, government must promote health through providing health information.



Some examples of the obligation to **promote** the right to health would be that government:

- Ensures that people are aware of their health rights (through awareness campaigns on TV, radio and in newspapers)
- Does research on health
- Promotes health by making sure people have accurate information on health and health risks (e.g. what causes illness)





"I went to the clinic on the 20th of May 2010, for family planning, but at reception I was asked to sit in another room. I was approached by a young man, who indicated to me that I can't get contraceptives unless I first do an HIV test. When I asked him why I had to do an HIV test, he told me that 'they know that people who use contraceptives usually have unprotected sex'. He said that anyone who comes for prevention (contraceptives) must do an HIV test. I did not want to do an HIV test, but I was told that if I didn't do the test they would not give me contraceptives. I was taken to a room at the clinic to have blood drawn. No one counselled me before or after the test. They just suddenly told me I could go home because my HIV test was negative".

Case questions

Is this an example of the government not respecting, protecting, fulfilling or promoting the right to health?

Answer

This young woman is dealing with a violation of her right to bodily integrity. She was forced to do the HIV test and therefore did not give proper consent for the test. The test was also not explained to her and therefore she didn't really have enough information to make a decision. If she had refused to do the test she would have been denied the right to have access to reproductive health care (access to contraceptives).

In this case the government did not comply with its obligation to **respect** the right to health:

The young woman is in a situation where her access to reproductive health care services has been limited (she can't access contraceptives if she does not do a test)

It is also a failure to respect, because the department of health's policy to date has been that HIV testing is voluntary. Moving to a system of routine or forced testing would be a step backwards (retrogressive)

Patients' Rights Charter (SA Department of Health)

In 1997 the South African Department of Health launched the Patients' Rights Charter, which aims to make sure that the right of access to health services is realised. They see the Patients' Rights Charter as a way to empower patients in their relationships with health care service providers.

The Patients' Rights Charter lists both the rights and the responsibilities of people using health services. According to the Charter patients have the right to:

A healthy and safe environment

Participation in decisions about their health

Access to health care which includes:

- i. receiving timely emergency care at any health care facility that is open, regardless of one's ability to pay;
- ii. treatment and rehabilitation that must be made known to the patient to enable the patient to understand such treatment or rehabilitation and the consequences thereof;
- iii. provision for special needs in the case of newborn infants, children, pregnant women, the aged, disabled persons, patients in pain, persons living with HIV or AIDS;
- iv. counselling without discrimination, coercion or violence on matters such as reproductive health, cancer or HIV & AIDS;
- v. palliative care that is affordable and effective in cases of incurable or terminal illness;
- vi. a positive disposition displayed by health care providers that demonstrates courtesy, human dignity, patience, empathy and tolerance;
- vii. and health information that includes the availability of health services and how best to use such services and such information shall be in the language understood by the patient.

Patients have the right to:

- Knowledge of one's health insurance/medical aid scheme
- A choice of health services
- Be treated by a named health care provider
- Confidentiality and privacy
- Informed consent (information about condition, procedure explained, risks explained)
- Refuse treatment
- Be referred for a second opinion
- Continuity of care (co-operation between health care facilities)
- Complain about health services (poor quality of care)

Patients have the responsibility to:

- Advise the health care providers on his or her wishes with regard to his or her death
- Comply with the prescribed treatment or rehabilitation procedures
- Enquire about the related costs of treatment and/or rehabilitation and to arrange for payment
- Take care of health records in his or her possession
- Take care of his or her health
- Care for and protect the environment
- Respect the rights of other patients and health providers
- Utilise the health care system properly and not abuse it
- Know his or her local health services and what they offer
- Provide health care providers with the relevant and accurate information for diagnostic, treatment, rehabilitation or counselling purposes¹⁵

15. From <http://www.doh.gov.za/docs/legislation/patientsright/chartere.html>



Activity 3

Purpose

To apply knowledge gained on the South African Patients' Rights Charter and on government obligations related to the right to health.

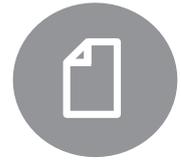
Process

(Time 50 minutes)

1. Divide the participants into four smaller groups. Hand out one of the four different case studies related to patient rights (see handouts at the end of the chapter for case studies 5-8).
2. Participants should read through the case study individually or one person could read it aloud to the rest of the group.
3. Each group should work together to answer the questions related to their particular case study and capture it on a flipchart
4. Each group will have an opportunity to report back on their answers to the larger group

Workshop Handouts

The pages that follow can be photocopied to give to workshop participants as handouts during the workshop.





Rights related to Health

The Right to life

The Right to dignity

The Right to bodily and psychological integrity
(make decisions, control over body, informed consent)

The Right to education

The Right to a healthy environment

The Right to food and water

The Right to housing

The Right to equality

The Right to access to information

The Right to participation

The Right to privacy



Link between Health and Human Rights

A lack of human rights or the abuse of rights can affect health

When people are denied the right to access to clean water it could result in illnesses like diarrhoea or cholera.

People who have been tortured can suffer terrible health problems both immediately and long after the torture.

Health problems can cause discrimination and violation of rights

Someone with a mental illness may be discriminated against in the workplace (for example by being denied the opportunity to work as a result of the employer knowing about their mental illness)

People who are HIV positive being unable to join medical aids (they are denied of the right to be treated equally and will have to carry the full financial burden of being ill)

Health problems make it difficult to claim other rights

A child who is very sick and has to stay in bed, can't go to school and therefore is unable to access the right to education. Similarly, children denied access to sufficient food will be starving while at school, and unable to concentrate and learn.

People with epilepsy may be denied the right to work, because employers are afraid to employ someone with this condition

Health policies and programmes can deny rights to certain people

The government's previous policy wanted to provide pregnant women with access to antiretroviral medicines (ARVs) only in certain places, and denied access to ARV medicine for people who didn't live in those areas.

One health policy is to encourage routine HIV testing in health facilities. If the health personnel are over-enthusiastic in testing people for HIV without their consent, then patients' rights to bodily integrity and privacy are violated.



Rights are given Power through Law

How do Rights become law?

Through:

National law - Constitution

International law (our courts must
consider this) -

Conventions, Treaties, Charters

Written legally binding agreements between
states or organisations (ruled by International
law)

e.g. The Convention on the Rights of the Child
International Convention on Civil and
Political rights
African Charter on Human and People's
Rights

Declaration

A document stating agreed standards or principles. Not a legally binding document but has strong moral force
e.g. Universal Declaration of Human Rights

Code

A document setting out principles to guide states e.g. SADC Code on HIV and employment

Signing a treaty

Government says they support the agreement in principle and make a commitment not to act against the agreement. After signing, governments are expected to ratify a treaty or covenant.

Ratification

Government officially agrees to abide by the treaty. They must amend their own laws or pass new laws in line with the treaty.



What is the Right to Health?

- Right to health – not necessarily the right to be healthy
- Right to access to health care
 - Right to conditions needed for health (water, sanitation, food, housing, environment)

Universal Declaration of Human Rights

Article 25

Everyone has the right to a standard of living sufficient to provide for the health and well being of himself and of his family, including food, clothing, housing and medical care and necessary social services; and also the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

International Covenant on Economic, Social and Cultural Rights

Article 12

The right of everyone to enjoy the highest attainable standard of physical and mental health.



Dimensions of the Right to Health

Availability

Functioning **health-care facilities** (hospitals, clinics, enough staff) **goods** (drugs, equipment) and **services** (mental health care, family planning, immunisation), as well as programmes available in **sufficient quantity to all communities**

Access to **conditions upon which health depends**, such as safe and potable drinking water and adequate sanitation facilities

Availability of **urgent medical care** for accidents and disasters

Trained **medical and professional personnel**

Access to **essential drugs**, as defined by the WHO Action Programme on Essential Drugs

Accessibility

(physical, economic, non-discrimination, information)

Existence of **services** at community level

Health facilities, goods and services must be accessible to everyone **without discrimination** (especially the vulnerable)

Health care is distributed **equitably** (resources allocated according to need)

This includes **physical accessibility** (access for disabled, distance to facility, opening hours)

Facilities should be **affordable** for everyone

Information should be readily accessible (simple explanations, health information, access to health records, language spoken)

Acceptability

Responsive and sensitive to patient needs, fostering a culture of **dignity**

All health facilities, goods and services must be **respectful** of medical ethics (informed consent)

Must be **culturally appropriate**, i.e. respectful of the culture of individuals, minorities, peoples and communities

Translation/interpretation should be available as a standard service

Sensitive to **gender** and **age**

Designed to respect **confidentiality/privacy** and improve the health status of those concerned.

Quality

Goods and services must also be scientifically and medically **appropriate** and of good **quality** (safe, timely, patient-oriented)

Standards for treatment are enforced and there is **quality control**

Measured by how well programme **meets health needs**

Skilled and trained medical **personnel**

Scientifically **approved and unexpired drugs** and hospital **equipment**

Quality of **buildings**

Safe and potable **water**, and adequate **sanitation**



LEARNING NETWORK

Case Study 1

One of the women went to the local clinic to obtain contraceptive pills. The sister at the clinic blurted out what type of medication she wanted in front of everyone in the waiting room and asked her why she wanted to take the pills. What was implied was that she wanted to have sex without having children... so she never went back to the clinic for contraceptives.

Question

Is this a problem of availability, acceptability, quality or access? Explain why you say this.



Case Study 2

Mr P goes to the clinic because he has a bad cough. The nurse tells him they don't have cough mixture and advises him to make his own home remedy. A month later he comes back to the clinic, complains of sweating a lot at night and he is still coughing, has lost weight and has no appetite. The nurse sends him home with cough medicine. Later he goes to a different clinic, where they diagnose him with TB that is very serious and ask him why he took so long to come for treatment.

Question

Is this a problem of availability, acceptability, quality or access? Explain why you say this.



LEARNING NETWORK

Case Study 3

My mother is very old and she has to go to hospital X for her treatment. Because of the rules at the hospital she has to go in there alone - I can't go in with her to help her - and she is so sick that she can't speak, so no one will know what is wrong with her.

If you want to complain about something they always say you must speak to the head sister, but the head sister is never available, so you can't speak to her. You can also put a complaint in the complaints box, but nothing ever happens.

Question

Is this a problem of availability, acceptability, quality or access? Explain why you say this.



Case Study 4

I work at an Early Childhood Development (ECD) centre or crèche in the community. The nurses are supposed to go to all the ECDs in the area to do vaccinations with the children. They are supposed to come and give them those drops for polio, but on the date that they were supposed to come they didn't arrive.

I was worried and so I asked the parents to rather take their children to the clinic for the vaccinations. They had to take time off work to take their children to the clinic. The people there at the clinic they don't care about us. When these parents took their children to the clinic, they said they couldn't vaccinate the children because the date for it is over. They said to those parents "maybe you can come again next year". So some of the children haven't till now been vaccinated for polio.

Question

Is this a problem of availability, acceptability, quality or access? Explain why you say this.



Obligations (What government has to do about Health Rights)

Respect (no interference in exercise of rights)

Government must not prevent either directly or indirectly the enjoyment of the right to health.

e.g. interfere with people's right to health
prevent access to health care facilities
and services
state must not allow rights to be taken
away

Protect (prevent violations from third parties)

Government must prevent others from interfering with rights or committing human rights abuses
Make and enforce laws that protect human rights

Fulfil (positive action in providing resources and policies to ensure rights are enjoyed)

Government must adopt laws, budgets and measures in court that work to ensure the realisation of the right to health
Allocate resources to programmes for human rights

Promote

Take steps to ensure that rights become known and meaningful

Government must take actions that create, maintain and restore the health of the population



LEARNING NETWORK

Case Study 5

I went to the day hospital, for treatment for myself. The nurses there don't care about people. They don't explain things to people. There was this patient, he was very ill. I think he was HIV-positive. He was vomiting. The nurse wanted to make him clean the floor. I told the nurse it was her job to clean the floor as she was working at the clinic. She refused. Eventually I went and fetched a mop to clean up the vomit. I tried to complain about this incident to the head nurse at the facility, but I could not find her. I am sorry that I forgot to take that nurse's name.

Questions

1. Which rights from the Patients' Rights Charter are not being met here?
2. Is this case an example of government's failure to respect, protect, fulfil or promote the right to health?



LEARNING NETWORK

Case Study 6

I accompanied a patient who was very sick and weak to the day hospital. As the man was practically unconscious, I had someone with me to help me to carry this man. When we got to the gates of the clinic they refused to let the helpers in to help to get this man into the building. As there was no one to help me with him, I left him outside and went in to see if I could get a wheelchair. The only wheelchair I could find was full of blood and I couldn't use it. I was worried about the patient outside as I knew he needed help immediately. I asked one of the nurses to help me to find a wheelchair. When we got outside the man was on the point of dying. They eventually took him into the health care facility on a stretcher. I went in with him. The doctors asked me if I was his wife. I said that I wasn't and they asked me to go and wait outside.

Later they came outside and said I should call his wife on the phone, because she needed to be with her husband. I called her, but when she got to the clinic they would not let her in at the front gate. Finally they made an announcement on the intercom asking them to let her in at the front gate.

When she came in they told her to sit down and wait. She was hysterical screaming and asking what was wrong with her husband. The doctor came and told her that her husband had passed away. People are dying in these day hospitals.

1. Which rights from the Patients' Rights Charter are not being met here?
2. Is this case an example of government's failure to respect, protect, fulfil or promote the right to health?



Case 7

If the doctor can't understand what you are telling them, there are nurses who can interpret for you. But these nurses don't tell the doctor exactly what you have said. Because the nurses tell the doctor the wrong thing, then the doctor gives you the wrong medicine.

Questions

1. Which rights from the Patients' Rights Charter are not being met here?
2. Is this case an example of government's failure to respect, protect, fulfil or promote the right to health?



LEARNING NETWORK

Case Study 8

The doctors at the clinics don't examine people anymore. I don't know what has made the doctors at the clinic stop examining people. They just listen to what you say and then write a prescription. Before they used to let you sit on the bed and listen to your heart and check you out.

I went to the doctor at Clinic X. The doctor was an old man. I had something like the flu. I was feeling very hot and weak. The doctor just wrote down the medicine that I must get. When I asked him if he wasn't going to examine me, he told me to take off my panty. There was no problem with my womb, but he gave me a vaginal examination. He pricked me so badly that it made me get more sick. I felt so weak that I didn't do anything about what he had done. But now I don't ever ask the doctors to examine me anymore, I am too afraid.

Questions

1. Which rights from the Patients' Rights Charter are not being met here?
2. Is this case an example of government's failure to respect, protect, fulfil or promote the right to health?

Section 3

Key words

Accountable	Being responsible for your actions
Addressed	Being dealt with or to attended to
Administration	Handling and being in charge of the supply of resources or services
Advice Office	An organisation that offers free advice to anyone in need of help and information. For example pensions advice, advice on legal problems, rights issues
Allocate	To distribute according to a plan
Antiretroviral drugs (ARVs)	The medicine that is used to treat HIV& AIDS
Asylum seeker	People who leave their own country to seek safety or protection in another country
Awareness	To have knowledge of/ to be informed
Campaign	A group of planned connected activities working to achieve a certain goal (e.g. a campaign against violence)
Civil society	Organisations and individuals that are independent of government (e.g. non-profit organisations, trade unions, faith-based organisations)
Coherent	Making sense (being logical and giving valid reasons)
Comprehensive	Complete, including everything and having all necessary parts
Co-ordinated	To work together in an organised way, to bring into proper order
Corruption	Giving or getting an advantage in ways that are dishonest or that interfere with the rights of others

Detained	To hold someone in prison for a short time (e.g. prisoners that are awaiting trial, suspects held for questioning)
Disability	A physical or mental impairment that limits one or more major life activities to a large extent
Discrimination	Being treated unfairly or differently because you are female, black, living with a disability, HIV-positive, lesbian
Duty-bearer	Someone who is responsible for making rights real
Emergency	A sudden disastrous event, which calls for immediate action to prevent the situation from becoming worse (e.g. poses an immediate risk to health)
Ethics	The system or code of morals of a particular person, religion, group, profession
Food security	The ability of individuals to obtain enough good quality food on a day-to-day basis.
Fulfil	When government takes action to make it possible for people to have the benefit of human rights
Governance	The process whereby an organisation or society manages itself
Grassroots	The ordinary people in a community or ordinary members of an organisation (not the leaders)
Harassment	To torment or bother someone continuously
Hate speech	Speaking in a way that causes hatred and discrimination against specific groups of people
Health insurance	Financial protection against loss as a result of being ill or injured
Health status	A person's current level of health (including their level of wellbeing, illnesses or injuries)

Illegal immigrants	People that enter or stay in a country without the formal permission of the government
Implement	To carry out by means of a definite plan or procedure; to put a plan into action
Infrastructure	The basic physical resources needed to for an organisation to operate (staff, buildings, equipment)
Interpret	To explain or make understandable
Judgement	The decision of a court of law on matters brought before it
Justice	The quality of being fair or defending rights
Mobilise	To make ready for action or to organise for a purpose
Negligence	Failing to take care of someone who has a right to our attention or avoiding responsibilities
Operating schedules	How a clinic or health centre is managed (e.g. times of opening, services offered)
Paralegal	Someone who is trained to perform certain legal tasks, but is not a lawyer
Policy	A plan of action or guideline agreed to by a government or an organisation
Primary health care	The first level of contact with health care. It includes promoting health, preventing illness, the early identification of illness and providing care for common illnesses
Principles	Accepted rules of action and behaviour
Procedure	A surgical operation or technique; an established or correct method of doing something
Progressive realisation	Steps taken to improve access to rights over a period of time (continuous improvement)

Promote	To push for rights to become known and meaningful
Protect	When government prevents others from violating your human rights
Public hearings	A meeting between government officials and community members where people in the community can share their views on an issue with officials
Ratified	To confirm that a government commits to the terms of an international agreement and will make it part of their laws
Reasonable	In agreement with sound thinking/ logical reasoning; acceptable and according to common sense; not expecting more than is possible or achievable
Registered	Medical doctors are registered when their name is on an official list, which means they are qualified and can legally practice medicine
Regulate	To bring under the control of laws or rules
Remedy	Putting something right or getting rid of something undesirable; correcting a fault or improving conditions
Respect	When government does not interfere with people exercising their rights or restrict the extent of a right
Sexual orientation	A person's natural choice of sexual partners (e.g. men, women or both men and women)
Social assistance	Money provided by government to take care of people who are not able to take care of themselves

Social insurance	Money provided by government to protect people from unexpected events like unemployment or being injured while working (unemployment fund, compensation for occupational injury)
Sterilisation	The use of surgery to ensure that someone will never be able to have children
Termination of pregnancy	Medically ending a pregnancy so that the woman will not continue carrying a child and will not deliver a baby
Virginity testing	Examination of a woman's vagina to see if she has had sexual intercourse (by checking if the hymen is intact). The hymen is a thin flap of skin located ½ inch inside most women's vaginas upon birth.

Dealing with Violations of Health Rights

“

Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm, or office where he works...Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world. ”

(Eleanor Roosevelt)

The goal of the third section is to gain a deeper understanding of what it means when health rights are violated, and what an individual or group of people could do about such violations .



Health Rights in the South African Constitution

The South African Constitution refers to health rights in a number of different ways, firstly through the Bill of Rights that supports the values of human dignity, equality and freedom.



Section 7

Section 7 of the Constitution calls on government to respect, protect, fulfil and promote all the human rights in the Bill of Rights. To **respect** the right to health they must not directly or indirectly prevent the enjoyment of health rights.



Some examples of how the government would **respect** the right to health are:

- by providing equal access to health care for everyone (prisoners, asylum seekers, illegal immigrants and people in rural areas)
- by ensuring that only safe medicines or drugs are marketed or sold
- by encouraging effective participation of communities in health-related matters

For government to **protect** the right to health they must prevent others from interfering with health rights or committing health rights abuses. To do this they should make laws that protect the right to health.



Some examples of how the government would **protect** the right to health are:

- putting in place laws that require medical aids to provide cover for certain common conditions or illnesses
- making sure that all health care providers have been properly trained and that they comply with medical ethics
- ensuring that people are not forced to undergo harmful traditional practices (e.g. virginity testing)

To **fulfil** the right to health means that government must take positive action to ensure that health rights are enjoyed (by allocating resources to health and making laws or policies that protect the right to health).



Some examples of how government would **fulfil** the right to health are:

- by putting in place policy or laws that guarantee health rights
- by planning to ensure that everyone has equal access to the conditions needed for health (nutritious safe food, clean water, proper housing and decent living conditions)
- by providing health facilities and services to ensure safe motherhood (particularly in rural areas)
- by providing a health insurance system that everyone can afford

In order to **promote** the right to health, government should take steps to make sure that people are aware of their health rights and that they understand how to use them.

Some examples of how government would **promote** the right to health are:

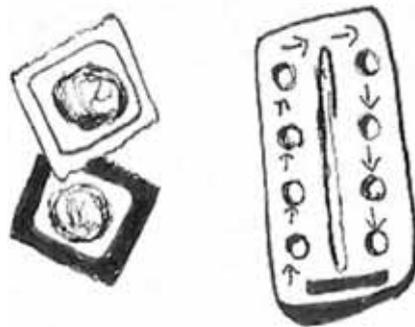


- by making sure communities are given basic education about health matters
- through information campaigns about important health issues like (HIV, domestic violence, abuse of alcohol or drugs)
- by making use of the media to inform people about their health rights and where they could go if they feel these rights have been violated¹

Section 27

Section 27 of the Constitution focuses specifically on health rights and rights related to the conditions needed for health, stating that:

“
Everyone has the right to have access to health
care services, including reproductive health care.”



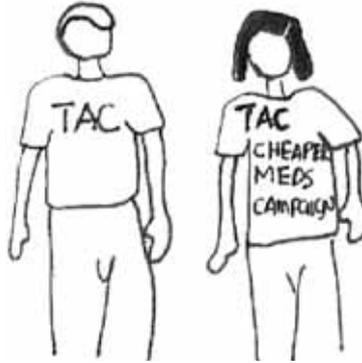
Health care services are only accessible to people if there are enough facilities available and people can get to them (in other words if they are not too far away so that it is expensive to get to them). Access is only possible if people can afford the costs of health care. People need to know which services exist and feel that they will get good quality medical care there. Language and communication are also issues that may prevent access to services – e.g. if patients can't communicate in their first language or if health care providers are dismissive or disrespectful in their communication with patients.

1. General Comment 14 on the right to health – see <http://www.unhchr.ch>



Case Study

Organisations like the Treatment Action Campaign (TAC) say that government can improve access to health care services if it finds ways to bring down the cost of medicine, so that it will be cheaper for the state and for people to buy medicines.²



The minimum required reproductive health care provided by government should include:

- Family planning
- Sexually transmitted disease prevention and treatment
- Interventions for safe motherhood³

In addition, Section 27 says that everyone has the right to have access to:



“
sufficient food and water; and social security,
*including, if they are unable to support themselves
and their dependants, appropriate social
assistance.*”

The right to sufficient food is closely connected to being healthy. When people are malnourished it can affect how they grow (their physical development) and they can become sick more easily. When people have food security they have enough of the right kind of food (healthy and nutritious) and quality of food (safe and containing no harmful substances) to lead a healthy life.

In order to have enough food or pay for the costs of health care people need money. The guarantee of social security involves two things, social assistance and social insurance from government.

2. Grant, K., Lewis, M., Nongogo, N. & Strode, A. 2005. *HIV/AIDS and the Law: A trainers manual*. Joint OXFAM HIV/AIDS Programme.

3. Khoza, Sibonile. (ed). 2007. *Socio-Economic Rights in South Africa: A resource book*. Cape Town: Community Law Centre (UWC).

Social assistance includes grants (money) provided to people if they are unable to support themselves or their children (e.g. disability, child support and old age grants). Social insurance is protection for unexpected events like becoming unemployed (unemployment insurance fund) or injured at work (compensation for occupational injuries and diseases).⁴

However, **all of the rights discussed above are limited by this clause:**

“
The state must take reasonable legislative and other measures, within its available **resources**, to achieve the **progressive realisation** of each of these rights.”

This means that the rights discussed in the first part of Section 27 are rights that government does not have to provide immediately. As long as they can show they have a plan to fulfil the rights over time (progressive realisation) and prove that they are limited in realising rights by the amount money and other resources (buildings, equipment, health services staff) that they have, they are fulfilling their duty as set out in the Constitution. It is important to note that this is not an excuse for the state to do nothing to improve health rights. They must do as much as they possibly can with the available money and resources. They can also appeal to other countries to provide them with financial or other assistance in order to fulfil their obligations or duties related to the right to health, or any other rights.



Case Study



In a ruling in Minister of Health vs. TAC the court said that government has to be able to prove how it is taking steps to improve health care services for everyone. They indicated that by not providing ARVs to all pregnant women government was not fulfilling its duty. The court ordered the government to make ARVs (nevirapine) available to pregnant moms living with HIV.^{5, 6}

A health right in Section 27 that is **not limited** and that has to be realised immediately is the right that:

“
No-one may be refused emergency medical treatment.”



Emergency medical treatment can be defined as sudden disastrous event which calls for immediate medical attention. If this attention is

4. Khoza, Sibonile. (ed). 2007. *Socio-Economic Rights in South Africa: A resource book*. Cape Town: Community Law Centre (UWC).

5. Grant, K., Lewis, M., Nongogo, N. & Strode, A. 2005. *HIV/AIDS and the Law: A trainers manual*. Joint OXFAM HIV/AIDS Programme.

6. Hassim, A., Heywood, M. & Berger, J. 2007. *Health and Democracy: a guide to human rights, health law and policy in post-apartheid South Africa*. Cape Town: Siber Ink.

not received the person may suffer permanent damage or their life could be threatened. Anyone who is experiencing such an emergency should be given treatment at the closest (public or private) health care facility, whether they can afford the fees for treatment or not.



Case Study

In September 2004, a 57 year old man, Simon Radebe, died on the street in Johannesburg. The two paramedics called out to assist Mr Radebe before he died, refused to take him to hospital, claiming that he was too dirty to transport in the ambulance. This was a clear violation of Mr Radebe's right to emergency medical treatment. As a result the two paramedics were dismissed from their position in emergency medical services and two years later the Health Professions Council took away their license to work as paramedics permanently.⁷

Section 24

A further section of the Constitution relating to health rights is dealt with in Section 24 which states that:

“
Everyone has the right to an environment that is not harmful to their health or wellbeing.”

The guarantee of an environment that is not harmful to your health means that government should ensure that the environment is not polluted or that health services are not dumping harmful medical waste in areas where people live. This section also means that people have the right to protection if they are living or working in an area that is regularly sprayed with pesticides.



7. Hassim, A., Heywood, M. & Berger, J. 2007. *Health and Democracy: a guide to human rights, health law and policy in post-apartheid South Africa*. Cape Town: Siber Ink.

Section 28

There are also sections of the Constitution protecting the health rights of groups of people who are more likely to be at risk of violations of their rights. Children are such a vulnerable group, and therefore in Section 28 of the Constitution are guaranteed the right to:

“
basic nutrition, shelter, basic health care services and social services.”

These are rights that have to be realised immediately and in terms of South African law children under the age of six have to be provided with free health care.

Section 35

Another group that is at risk of being victims of the abuse of power is people who are detained or imprisoned.

Case Study



Death in detention

In September 1977 Stephen Bantu Biko died 6 days after being detained and questioned by police. The first doctor who was called in to examine Biko was told that he was acting strangely and did not respond to questions. The doctor found that he was unable to co-ordinate his movements and found bruising and swelling on various parts of his body. The doctor did not ask Biko how he was injured and he reported that he found no evidence of abnormality or illness.

As his condition got worse Biko was examined by other doctors who found various signs of evidence of brain damage (slurred speech, left sided weakness and blood in his spinal fluid) but who did not provide treatment. An inquest found that Biko's death was caused by complications following a head injury, most likely sustained during his questioning. Seven years after his death the doctors who treated Biko were found guilty of improper behaviour and one doctor was stripped of his medical qualifications.^{8,9}

To prevent this kind of treatment of prisoners today everyone who is detained, including every sentenced prisoner, has the right:

8. Hassim, A., Heywood, M. & Berger, J. 2007. *Health and Democracy: a guide to human rights, health law and policy in post-apartheid South Africa*. Cape Town: Siber Ink.

9. Apartheid Museum. 2007. *Biko: The Quest for a true humanity*. Apartheid Museum, SteveBiko Foundation

“
...to conditions of detention that are consistent
with human dignity, including at least exercise and the
provision at state expense of adequate accommodation,
nutrition, reading material and medical treatment.”



In a recent High Court ruling related to the provision of medical treatment for prisoners, government was ordered to provide ARV treatment to HIV-positive prisoners.

In South Africa Courts are directly able to enforce the rights set out in the Bill of Rights. The health rights in our Constitution are also important because they must inform the kinds of laws that the government makes.

National Health Act

The National Health Act 61 of 2003 (NHA) is a law passed by Parliament to ensure the right of everyone to have access to health care services.

The purpose of the NHA is to:

Regulate national health, with a national health system that includes public and private health care providers

Provide the people of South Africa with the best possible health services that available resources can afford (in a way that is fair)

Set out the rights and duties of health care providers, health workers, health services and users

Protect, respect, promote and fulfil the rights of people in South Africa by progressively realising the right of access to health care services, including reproductive health care

To provide the people of South Africa with an environment that is not harmful to their health or well-being

To provide vulnerable groups such as women, children, older persons and persons with disabilities with access to health care services

To provide children with basic nutrition and health care services¹⁰

In addition the NHA requires:

1. All users to have **full knowledge**

of their health status

the different tests and treatment options

the benefits, risks and costs associated with each treatment option

their right to refuse health services and to have the implications and risks of refusal explained to them

10. Hassim, A., Heywood, M & Honermann, B. (eds). *The National Health Act 61 of 2003: a guide*. Cape Town: Siber Ink.

all the information above should be provided in a language the user understands

2. All users to have access to **emergency medical treatment**

3. **Free health care** services for

Pregnant and breast feeding women who are not members of medical aids

Children below the age of six who are not members of medical aids

All persons who are not members of medical schemes (this refers to primary health care only)

Pregnant women who require termination of pregnancy services¹¹

4. All users to **provide informed consent** for treatment after being informed

What the treatment or the test is

Why the treatment or test is being done

What the result of the treatment or test could mean for him or her

That they have a right to agree to the treatment or test or to refuse treatment¹²

5. All users to **participate in any decision** affecting his or her health and treatment

6. The Department of Health to **disseminate information** about

the types and availability of health services

the organisation of health services

operating schedules and timetables of visits

procedures for access to health services

other aspects of health services which may be of use to the public

procedures for laying complaints

the rights and duties of users and health care providers

7. All users to have the **confidentiality** of their information respected (this means that the person has to give their permission for information about their illness or treatment to be given to any other person).¹³

8. Any person to be able to **lay a complaint** about the manner in which he or she was treated at a health establishment and have the complaint investigated.¹⁴



11. Hassim, A., Heywood, M & Honermann, B. (eds). *The National Health Act 61 of 2003: a guide*. Cape Town: Siber Ink.

12. Hassim, A., Heywood, M & Honermann, B. (eds). *The National Health Act 61 of 2003: a guide*. Cape Town: Siber Ink.

13. Grant, K., Lewis, M., Nongogo, N. & Strode, A. 2005. *HIV/AIDS and the Law: A trainers manual*. Joint OXFAM HIV/AIDS Programme.

14. Hassim, A., Heywood, M & Honermann, B. (eds). *The National Health Act 61 of 2003: a guide*. Cape Town: Siber Ink.



The Right to confidentiality

“Mr McGeary wanted to apply for a life assurance policy. The insurance company told him he had to have an HIV test. He went to his doctor and asked him to do the HIV test. When the doctor got the results of the test back, he told McGeary that he was HIV positive. The next day his doctor played golf with another doctor and a dentist. During the game they discussed AIDS, and McGeary's doctor told the other two that McGeary had tested positive for HIV. He later claimed he had told the other doctors because they may treat Mr McGeary in the future. Within days, news of McGeary's condition had spread through the small community. McGeary began a civil claim to get compensation from his doctor for breaching his right to confidentiality. During the trial, he died of an AIDS-related illness, but lawyers continued with the case on his behalf. The court decided that Dr Kruger had not respected McGeary's rights and therefore he should pay McGeary's estate R5000 in compensation for breaching his right to confidentiality.”¹⁵

The Patients' Rights Charter

The Patients' Rights Charter is an example of a policy that provides guidelines about health rights. It is not legally binding like the National Health Act, but a means to put into practice the principles related to access to health care in the Constitution and in the National Health Act and to provide a way for users of services to realise their rights to health. It is also a way for users to be able to lodge complaints against health care providers and facilities if they feel their rights were violated by them.

The adoption of the Patients' Rights Charter by the National Department of Health was a result of widespread civil society mobilisation. A campaign to raise awareness and understanding of patient rights was led by the National Progressive Primary Health Care Network (NPPHCN) which comprised a number of health organisations and non-governmental organisations (NGOs).¹⁶

15. Grant, K., Lewis, M., Nongogo, N. & Strode, A. 2005. *HIV/AIDS and the Law: A trainers manual*. Joint OXFAM HIV/AIDS Programme. Direct quote from page 67

16. London, L., Holtman, Z. et al. 2006. *Operationalising Health as a Human Right: Monitoring tools to support the Implementation of the Patient Rights Charter in the Health Sector*. Health Systems Trust

International Law related to the Right to health

International law states that there are certain minimum obligations and conditions of equal importance that all states are expected to provide immediately regardless of their economic resources (how much money they have). This makes sure that all people are given at least the minimum conditions needed to ensure their health. South Africa has not ratified the International Covenant on Economic Social and Cultural Rights, which means they cannot be held legally accountable for not meeting minimum core obligations related to the right to health. However, the courts in South Africa are advised to take international law into account when interpreting the Constitution.

In some cases states hold other states accountable when they infringe on International law. Countries may express concern about human rights abuses for which a state is responsible. In cases like this states are often "named and shamed" in the hopes that drawing attention to these human rights abuses will cause the state to stop such abuses.



Explaining Violations of Health Rights



Activity 1

Purpose

To examine participants' ideas and views about what it means to have health rights violated.

Process (Time 30 minutes)

1. Ask the volunteers from the larger group to tell you about a situation when they felt their health rights were violated or saw someone else's health rights being violated.
2. Summarise the main points in the stories told on a flipchart.
3. Compare the information participants have given to the input on violations (pointing out which of the situations were actually violations) and distinguishing violations from wrongdoing or failures by health care workers.

Human rights violations take place when government fails to respect, protect, fulfil or promote rights because of:

Direct actions of the government (e.g. adopting a law that is incompatible with the right to health, like a law that results in medicines being unaffordably expensive)

Negligence (deliberate failure to take the necessary steps to fulfil or protect the right to health, e.g. by not providing enough budget or staff for health services to function properly)

Discriminatory policies or practices related to people's rights (like not having sign language interpretation for deaf patients who use health care facilities)¹⁷

Not every situation of wrongdoing, failure or bad service by a government authority or health care worker is a violation of health rights. There is a difference between complaints about health care services (e.g. about nurses not allowing patients access to toilets in the facility) and violations of health rights (not having any clinic or health service in a rural town, which is a violation of the right to have access to health care).

17. *Haki Zetu (Our Rights)*. Amnesty International

It is also important to note that there may be good reasons why a government authority or a health care worker is unable to meet their duties related to health rights. Here it is important to note the difference between the government being **unwilling** to meet its obligations and being **unable** to meet its obligations. Sometimes governments don't have the resources (money, buildings, knowledge) to meet their obligations, but one should check if the government then at least has a plan to move forward towards meeting its obligations over a period of time and whether government is using the most of their available resources to meet their obligations. Governments can also call on other countries for financial assistance to meet their minimum obligations related to the right to health.¹⁸

When has the Right to Health been violated?

According to the SA Constitution the right to health has been violated when government:

1. Fails to **respect** health care rights

Government fails to respect rights when it interferes with a person's access to health care services or takes away health rights, by moving away from progress that has been made. Examples of failures to respect health rights include:

- Denying access to health care to non-citizens
- Only providing sexual and reproductive health care treatment if you consent to an HIV test
- Closing existing health care facilities or shortening the hours that clinics stay open
- Deliberately withholding health information that is vital for prevention or treatment¹⁹

2. Fails to **protect** the right to health

Government fails to protect the right to health when it doesn't prevent powerful people or organisations from violating your health rights or doesn't remove obstacles to the immediate fulfilment of a right. Examples include:

- Failing to put in place laws that stop factories from polluting drinking water
- Failing to ensure that hospitals take measures to make sure the medical treatment of patients is of a high quality and that the staff they employ are registered to practice medicine



18. Asher, Judith. 2004. *The Right to Health: A Resource Manual for NGO's*. London: The Commonwealth Medical Trust.

19. *Haki Zetu (Our Rights)*. Amnesty International

Failing to protect people from discriminatory practices of medical aids

3. Fails to **fulfil** the right to health by not taking reasonable steps towards the progressive realisation the right to health. Examples include:

Not allocating enough budget nor having a plan to improve health care services
Failing to plan to ensure that essential medicines are available at health care facilities

The courts in South Africa have interpreted the government's obligation to take **reasonable steps** in the following way. Government's programmes to fulfil the right to health must:

Be comprehensive, coherent and co-ordinated
Measures taken must be able to facilitate the right to health
Provide for short, medium and long term needs
Allocate responsibilities and tasks to different parts of government
Ensure that financial and human resources are available
Be reasonably formulated and implemented
Must provide for the needs of those most desperate²⁰

4. Fails to **promote** the right to health. Examples include:

Not using the media to inform people about the right to health and where people can complain
Failure to display the Patients' Rights Charter or complaints procedures at clinics



20. Khoza, Sibonile. (ed). 2007. *Socio-Economic Rights in South Africa: A resource book*. Cape Town: Community Law Centre (UWC).

Work through the case below with the larger group, before asking people to tackle the additional activity on their own:

Case Study



Involuntary sterilisation

A young woman went for a termination of pregnancy (abortion) at a hospital. They did the termination, but two days later she had severe pain and she was admitted to hospital again.

They then did emergency surgery at the hospital. After the surgery she found out that she had been sterilised. She had not been informed that this was possible nor had she given her permission for this procedure to be performed and she had still wanted to have children later in life.

The organisation she went to for advice had experienced a number of cases where women had gone for a termination of pregnancy and ended up being unable to have children afterwards. This all happened at the same hospital and the organisation suspects that the hospital is routinely sterilising women who come for terminations without their permission.

Case questions

Has the right to health been violated in this case? Explain why you say this.

Answer

Yes. The right to health has been violated in this case. The government failed to protect the right to health. The health care providers had not sought informed consent before the procedure and had therefore not acted ethically. It is the duty of the government to protect people's right to health by ensuring that medical practitioners comply with ethics and to take action against practitioners who have not acted ethically.

In another similar case (Stoffberg vs. Elliott) a patient took a surgeon to court for performing surgery on him without his specific consent. Even though the surgeon did the surgery to prolong the patient's life, the court pointed out that any medical operation that the patient does not consent to is a violation of the patient's rights. This right is not given up simply by the person going to hospital for treatment or as a result of them consenting to another type of surgery.²¹



21. Hassim, A., Heywood, M. & Berger, J. 2007. *Health and Democracy: a guide to human rights, health law and policy in post-apartheid South Africa*. Cape Town: Siber Ink.



Activity 2

Purpose

To apply knowledge gained about violations of the right to health.

Process

(Time 50 minutes)

1. Divide the group into four smaller groups. Distribute one of the four different case studies (see handouts at the end of the chapter for case studies 1-4).
2. Participants should read through the case study individually or one person could read it aloud to the rest of the group.
3. Each group should work together to answer the questions related to their particular case study and capture it on a flipchart. Each group will have an opportunity to report back on their answers to the larger group.



Accountability

It is not enough to know when our health rights have been violated. We also have to be able to do something about these violations by holding government or others accountable. When we hold an institution **accountable** we make them aware of their responsibility and we ask them to give us answers about decisions they have made or to justify their actions.

As a duty-bearer the government is accountable (responsible) for ensuring that people's rights are realised. It can be held accountable on the realisation of the right to health in a number of different ways. A few examples are:



checking that enough budget is put aside for providing health care and the services needed for health

making sure that the government is appointing sufficient staff to provide health care and provides the infrastructure needed for health

approaching bodies set up in law to which one can complain about rights violations

using the law or the courts to enforce our rights

demonstrations or marches, protesting against government not realising rights

approaching civil society organisations that deal with violations of rights²²

22. UNCT. 2009. *Toolkit: a human rights based approach, a user friendly guide from UN staff in Viet Nam.*

Organisations in South Africa that can deal with violations of Rights

In South Africa we have a number of formal organisations whose main purpose is to deal with violations of rights or hold government accountable in different ways. These organisations include:

South African Human Rights Commission

The South African Human Rights Commission (SAHRC) is an independent body that keeps an eye on government actions that affect human rights and that is also tasked with monitoring how private institutions respect human rights. The aim of the SAHRC is to create a culture of rights and to promote respect for human rights. The SAHRC can:

- Receive complaints regarding the violation of human rights
- Investigate and report on human right violations
- Give people assistance when their rights have been violated or find solutions to remedy violations of rights
- Conduct research on human rights issues
- Have public hearings (where people can talk about violations of their rights) to gather information on specific rights issues
- Report to Parliament on matters relating to human rights
- Regularly publish reports on government departments' performance on realising socio-economic rights
- Make recommendations to government to improve the carrying out of human rights
- Create awareness of human rights²³

Any individual or group can make a complaint to the SAHRC if they think their rights have been violated. Even if it takes a while for them to respond to your complaint, it is still important to complain, because they keep a record of the types of rights complaints they get. These records of complaints can then be used to track the patterns and kinds of human rights violations occurring most often in South Africa. The SAHRC will use this in their reports to government and to decide which rights issues should be investigated in more depth. There is no cost involved in complaining to the SAHRC. Their website has a complaints form that can be completed online. For more information on how you could complain see the SAHRC website.

23. Khoza, Sibonile. (ed). 2007. *Socio-Economic Rights in South Africa: A resource book*. Cape Town: Community Law Centre (UWC).

The SAHRC will ask for the following basic information if you are complaining about a rights violation:

- Your name, ID number and contact details
- A brief description of what happened
- The date, time and the place where the incident happened
- Which of your rights you feel were violated
- The name and contact details of the person who violated your rights
- The names and contact details of any people who saw what happened to you (when your rights were violated)

Equality Court

The Right to equality is one of the most basic rights in our new Constitution.

To ensure this right the Constitution calls for a specific law to be put in place to prevent unfair discrimination. In September 2000 the Promotion of Equality and the Prevention of Unfair Discrimination Act, 2000 (Act No. 4 of 2000) came into operation. In order to deal with unfair discrimination specific Equality Courts were established to enforce this law. You can approach the Equality Court with any complaint about:

- Unfair discrimination
- Publication of information that unfairly discriminates
- Harassment
- Hate speech²⁴

The Constitution says that the state or any other person may not discriminate against anyone on the basis of; race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language or birth. If the Equality Court finds that you have been discriminated against on the basis of any of the grounds given in the Constitution, there are a number of things the Court can do:

- They can order the guilty party to make an unconditional apology
- They could instruct the respondent to do or not do something, or stop an unfair discriminatory practice
- They may ask for payment of damages to you for actual financial loss, loss of dignity, or pain and suffering (including emotional and psychological suffering)
- They may order the payment of a fine to an appropriate organisation
- They may declare a law or policy to be unconstitutional (and therefore against the law)²⁵

24. From <http://www.capegateway.gov.za/eng/directories/services/11458/94929> and http://www.justice.gov.za/EQCact/eqc_main.html

25. From <http://capegateway.gov.za/eng/directories/services/11458/94929> and http://www.justice.gov.za/EQCact/eqc_main.html

Going to the Equality Court is free and the Court must help you to find legal assistance. This legal assistance does not need to be from a qualified advocate - it can be from a paralegal, a law student or someone from an Advice Office.



Public Protector

“

The Public Protector South Africa strives to make constitutional democracy and the fulfilment of human rights a reality to South Africans through the improvement of national governance.”

(Chief Executive Officer)

The Public Protector receives and looks into complaints from the public against government agencies or officials who deliver a service to the public or who are responsible to the public in some way. This includes provincial government, state departments, local authorities or someone employed by the government e.g. policeman, nurse or doctor, electoral officer and people elected to parliament or local councils. The Public Protector's services are free and available to everyone and, if you lay a complaint, your name will be kept confidential as far as possible.



The Public Protector will investigate:

- Abuse of power and corruption
- Unfair or rude behaviour
- When government decisions take too long for no valid reason
- The violation of a human right
- Any other decision taken, or situation brought about, by the authorities that results in unfair discrimination
- Bad administration of government resources

If the Public Protector finds that there are good reasons for your complaint, they have to do something that will correct the problem. This can be recommending changes to government, reporting on the issue to Parliament or referring you to a court of law that will investigate the charges against the members of state involved.²⁶

Health Professions Council

The Health Professions Council of South Africa (HPCSA) was established by the Health Professions Act 56 of 1974. Its purpose is to control the behaviour of health care providers in order to protect the rights of users of health care services.²⁷ The council does this by:



- Setting standards for training health care providers
- Making sure that health care providers have continuous training and keep their knowledge up to date
- Upholding the professional and ethical standards of health care providers
- Hearing complaints from the public about health care providers²⁸

“

...to ensure that persons registered in terms of this Act behave towards users of health services in a manner that respects their constitutional rights to human dignity, bodily and psychological integrity and equality

”

(Health Professions Act 56 of 1974)

It is important to note that the HPCSA accepts only written complaints from members of the public. There are many processes that have to be followed and it may take quite a long time before getting a response to your complaint or for an investigation of your complaint to start. They give the health care provider a chance to respond to the complaint you have made and, if they decide the matter is serious, they will investigate. The Council has a duty to take action against health care providers that do not comply with professional and ethical standards.

26. For more information see <http://www.pprotect.org/>

27. Hassim, A., Heywood, M. & Berger, J. 2007. *Health and Democracy: a guide to human rights, health law and policy in post-apartheid South Africa*. Cape Town: Siber Ink.

28. Information sourced from www.hpcs.co.za

Nursing Council

The Nursing Council²⁹ was established by the Nursing Act 50 of 1978 for the purpose of controlling the nursing and midwifery professions to ensure safe and quality practice. This council has the power to ensure that nurses comply with their ethical and legal duties and it investigates complaints regarding the behaviour of nurses or midwives. They can act against nurses by:



- Cautioning or reprimanding them
- Giving fines
- Withdrawal of their registration to practice as a nurse.

Pharmacy Council

The Pharmacy Council³⁰ aims to make sure that quality pharmaceutical services (provision of medicines) are available for all the people of South Africa. It assists in the promotion of health and advises on any matter relating to pharmacy (medicines). One of its objectives is to protect the rights of the general public to acceptable standards of pharmacy practice. It also makes sure that pharmacists work and behave ethically and are competent to practice.

The Council will investigate complaints against registered pharmacists and may order further investigation or a formal inquiry. If the pharmacist is found to have acted unprofessionally or unethically, the committee that deals with the inquiry may:

- Reprimand or caution the pharmacist
- Suspend them from practicing for a specific period
- Fine them
- Remove their name from the register, which means they can no longer practice as a pharmacist

Civil Society

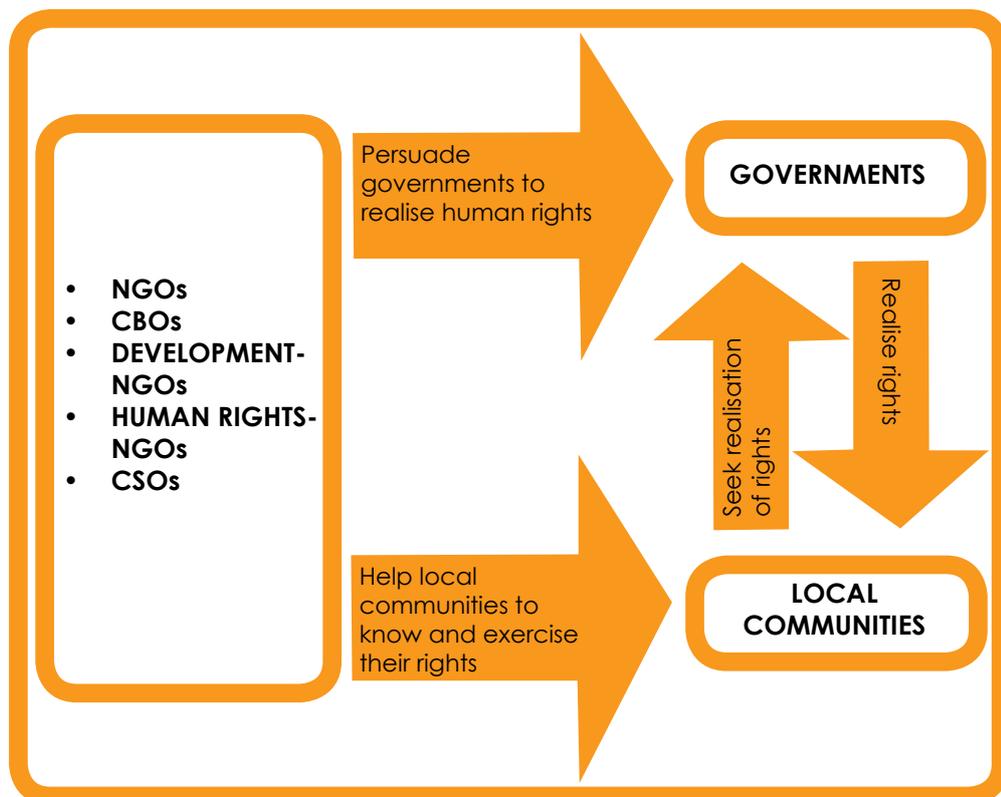
Members of civil society are any groups that are not affiliated with government or with business for example non-profit organisations, unions, educational institutions, community based organisations, advocacy or religious groups. Civil society organisations can play a critical role in dealing with rights violations, through making members of communities aware of their rights, assisting vulnerable groups to join forces in protesting against violations of rights and holding the state responsible to its human rights obligations.

29. Information sourced from www.sanc.co.za/

30. Information sourced from www.pharmcouncil.co.za/

Organisations like the People's Health Movement (PHM) play an important role in campaigning for the right to health. PHM is an international movement committed to the realisation of health as a right. PHM South Africa organises campaigns, media and materials around health rights.

Other non-governmental organisations (NGOs) like the Black Sash, the Treatment Action Campaign, the Community Law Centre, the Legal Resources Centre, the Women's Legal Centre, Equal Education, Section 27 and the Social Justice Coalition have a history of assisting community members when their rights have been violated.



South African Medical Association

The South African Medical Association (SAMA) is a non-profit organisation that aims to empower doctors to bring health to the nation. It is a trade union and "a champion for doctors and patients". SAMA provides guidelines on fees charged for medical services and deals with any complaints or questions about the fees that doctors charge.

Democratic Nursing Organisation of South Africa

The focus of the Democratic Nursing Organisation of South Africa (DENOSA) is on the needs of their members (nurses) and the health needs of grassroots communities. It aims to promote equal access to health care for everyone and the health of all citizens. DENOSA has an email facility where the general public and members of DENOSA can ask questions or complain.

Complaining effectively about rights violations

“
Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.
”
(Margret Mead)

Activity 3

Purpose

For the group to think about their own experiences of complaining or standing up for their own rights or for the rights of other people.

Process

(Time 50 minutes)

1. Ask each person in the group to think about a time when they stood up for their own rights or for the rights of other people.
2. Create a flipchart with the following questions:
 - When was a time that I stood up for rights?
 - What happened when I did this?
 - Where did this happen?
 - Why did I stand up for rights?
 - Who or what helped or supported me with this?
 - Was there a time that I stood up for rights in a group with other people?





3. After 10 minutes each person should have their answers to these questions ready.

4. In the 10 minutes when everyone is thinking, the facilitator makes five headings on a flipchart, what, where, when, why and sources of support and individual or group complaints. As each person tells their story, the facilitator writes down the main points under the appropriate headings.

5. Draw attention to the fact that all the participants have already been human rights defenders and also to the things that are similar or very different in their stories. Also make a connection between what they have said and any of the input on how to complain below.³¹

Why Complain?

If you feel that the state or someone employed by the state (nurses, doctors) or anyone else has failed to respect, protect or fulfil your right to health or has discriminated against you when you have accessed health services, you have the right to complain. It is important to complain:

So that something can be done to deal with the violation or to make up for what has happened

To prevent the violation from happening to others in the future

So that government can't deny that there are problems with health rights violations

To keep an eye on patterns or trends (to see if rights violations are getting better or worse or if the kinds of rights violations people are complaining about are changing)

Approach to Complaining

There are a couple of things that are important to remember when you are complaining. Firstly, you should keep copies of all the letters you have sent or forms you completed in order to complain. If you complain in writing and make copies of your complaint letter, then you have proof of your complaint. Normally government institutions have a procedure (a formal series of steps that need to be followed)

31. This exercise has been adapted from *Siniko: Toward a Human Rights Culture in Africa*. 1999. Amnesty International.

when you complain. It is easiest to work through these steps and you are more likely to eventually get a response to your complaint. In most cases, when you complain effectively, you are always moving one step up (complaining to someone who has more authority or control) until you are satisfied with the response you get.



It is important to start off by complaining to the person directly involved (in other words the person who you feel has violated your rights e.g. nurse, doctor, pharmacist or security guard)

If you don't feel satisfied with how the problem was resolved you can then complain to that person's boss or manager (e.g. Sister in Charge, Facility manager)

You could try to approach the clinic health committee if neither the sister in charge nor the Facility manager can resolve your complaint or if they don't respond to you

You could also try the sub-district manager (health department) if neither the sister in charge nor the facility manager can resolve your complaint or if they don't respond to you

If your complaint still has not been resolved you can contact the Provincial Department of Health (write to or call the complaints manager)

If you don't have a satisfactory response from the provincial department of health you can contact the National Department of health (contact the national complaints centre)

If your complaint has still not been resolved you can complain to the South African Human Rights Commission

Information needed for Complaints

When you complain about a rights violation, always remember to make sure you have the following information:

The name of the facility or organisation where the violation occurred

The names of anyone who was involved in the complaint (if people do not have a name tag, you can ask them what their name is)

Also remember to have names of any witnesses (other nurses, doctors, patients who saw what happened to you when your rights were violated)

The time and date of incident

Which of your rights you feel were violated

Your name and contact details (so that they know who they should respond to)

Keep a record of any reference numbers you are given in the process of complaining or copies of any letters or complaints forms

Complaints to the Department of Health

If you feel your rights were violated and you want to complain directly to the health care service, because you are not happy with the response you got from the person directly involved, you can contact your clinic health committee. Each clinic or community health centre should have a health committee. Health committees represent the community's interests in the facility and they can assist you with complaints. You should be able to get the contact details of the health committee members from facility staff or you can call the Cape Metro Health Care Forum (umbrella body for all health committees) to get contact details for the health committee at your clinic.

If you want to complain directly to the health care facility or clinic, the name and contact details of the facility manager at a clinic or a community health centre should always be clearly displayed. If it is not displayed a member of staff at the facility should be able to give you the contact details of the facility manager.

Also remember that every clinic or community health centre should have:

- A formal, clear, structured complaints procedure

- The complaints procedure should be clearly displayed at the clinic

- If there is a problem you should be informed of your right to complain and the complaints procedure should be explained to you

- The clinic should provide assistance for those who don't understand the procedure as well as providing help for those who need assistance with complying with the complaints procedure (e.g. someone who is blind or deaf)

- Each clinic should have a register of complaints and keep a record of how these complaints were addressed

If you are not satisfied with the response you get from the clinic or community health centre when you complain, you may contact the Provincial Department of Health. When you complain to the Provincial Department, they should give you a reference number for the complaint and they will probably respond to you in writing.

Developing effective strategies for dealing with violations of rights

Besides **complaining** as an individual to an organisation or a government department there are a number of other things you could do to deal with violations of your rights. As an individual you could also get the support of a NGO or a human rights organisation to advise or assist you with rights violations. Sometimes people will go to court or take **legal action** as a way to deal with violations of their rights.

It is often easier if groups of people are able to get together and support each other (**mobilise or campaign**) to achieve their goals. If you find other organisations or people who are also concerned about health rights violations you could work together. Groups of people have more power to influence decision makers or government to make changes. In a joint campaign people may organise protest marches to government, create awareness of the problem in the media or even do a presentation in Parliament to try and bring about change. Groups of people can also take legal action together and this may be a more effective strategy than an individual going to court alone.

Examples of **complaints** you could make as an individual or as a group:

You could complain to the South African Human Rights Commission about a violation of health rights

You could complain to the Public Protector about the actions of a nurse, doctor, facility manager or other public official that you believe has violated your rights

You could inform government officials or the Department of Health about health rights violations and ask them to take action

You could arrange a meeting to speak to your ward councillor or local councillor about health rights violations

You could write to an official or councillor to make a complaint about health rights violations or to give suggestions on how to deal with violations

If it is difficult to approach officials directly you could ask a large NGO to visit an official's office and represent your complaint

Examples of **legal action** you could take as an individual or as a group:

You could approach organisations like Black Sash, the Legal Resources Centre or the Women's Legal Centre for free legal advice to decide if you have a strong case to take to court



You could file a complaint at the Equality Court (if you feel it is an issue of unfair discrimination) by contacting the Equality Clerk at your local magistrate's office

You could request a lawyer to take the case to court (some lawyers will work for free on human rights cases)

You could get a Legal Aid lawyer or an NGO to assist you to go to court (organisations like the Women's Legal Centre, Black Sash, Legal Resources Centre sometimes assist with court actions)

After a court has upheld a right, you could get a lawyer to take action to persuade the authorities to implement the judgement

You could go to court to bring an individual or group who has violated your rights to justice

Examples of **mobilising or campaigning** about a rights issue as a group:

You could inform others about health rights issues (distribute pamphlets or write an article for your community newspaper)

You could make a public statement informing NGOs and others involved in the issue about health rights violations

As a group you could gather signatures from people affected by violations of health rights and send a petition to your local political representative or member of parliament

You could record violations that you have experienced or seen and when you have enough evidence (data gathered) you could write a report on the patterns and kinds of violations experienced

As a group you could do a presentation to the South African Human Rights Commission on health rights violations

Some NGOs or organisations have regular meetings with government officials or councillors. Such meetings may be an opportunity to raise health rights concerns

As a group you could try to persuade important members of the community to put pressure on the authorities responsible for the rights violations

You could do a presentation on health rights violations to the Standing Committee or Parliamentary Portfolio Committee on Health

You could hold a press conference about government health related obligations and compare these obligations to what actually happens at health care facility level

You could speak to the media (newspapers, television, radio) about health rights violations

You could run workshops or training on health rights violations and their effects with health care workers or policy makers

You could organise a protest march/demonstration/mass action about health rights violations

You could invite an official to participate in an event, such as to open a workshop or visit a community where there is a problem with rights violations

You could hold a seminar on specific health rights topics (especially those that happen to be in focus for some reason) and invite a guest speaker with enough status to attract health officials

You could ask officials to open or close community workshops or other events on health rights

You could join in campaigns at local, national or regional levels (for example by supporting Black Sash's campaign to get the government to ratify the International Covenant on Social, Economic and Cultural Rights)





Activity 4

Purpose

To apply knowledge gained on strategies for dealing with violations of rights.

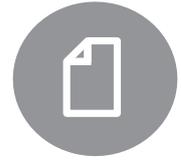
Process

(Time 50 minutes)

1. Ask the larger group which are the three main health rights violations that they face in their communities and to give a real life example of each of these violations.
2. Divide them into three small groups and allocate one of the three rights violations to each group to work on.
3. Each group has to develop some possible strategies to deal with the health rights violation that has been given to their group.
4. The three groups are all given an opportunity to report back to the larger group. Have some discussion in the big group about the strategies people came up with to deal with rights violations.³²

32. This exercise has been adapted from Claude, Richard P. 2000. *Popular Education for human rights: 24 participatory exercises for facilitators and teachers*. Cambridge: Human Rights Education Associates.

Workshop Handouts



The pages that follow can be photocopied to give to workshop participants as handouts during the workshop.

Organisations you can contact about rights complaints

Organisation	Postal Address	Phone Number	Email	Website
South African Human Rights Commission	7th Floor ABSA building 132 Adderley Street Cape Town	021 426 2277 (Cape Town) 011 484 8300 (Head Office) 0860 120 120 (Advice Line)	info@sahrc.org.za	www.sahrc.org.za
Equality Court		Phone your nearest Magistrates Court (ask for the Equality Court Clerk)		http://www.capegateway.gov.za/eng/directories/services/1458/94929#1
Public Protector	P.O. Box 712 Cape Town 8000	0800 11 20 40 (toll free) 021 423 8644 Western Cape	kgalalelom@pprotect.org	http://www.pprotect.org
Health Professions Council	P O Box 205 Pretoria 0001	012 338 9378	cliffn@hpcsa.co.za	http://www.hpcsa.co.za

Organisations you can contact about rights complaints

Organisation	Postal Address	Phone Number	Email	Website
Nursing Council	P O Box 1123, Pretoria 0001	012 420 1000	registrar@sanc.co.za	http://www.sanc.co.za/
Pharmacy Council	PO Box 40040 Arcadia, 0007	012 319 8500 or 012 319 8562 0861 7272 00	Customercare@sapc.za.org	http://www.pharmcouncil.co.za/
Cape Metro Health Care Forum	D. Kiewiets Private Bag X7 Woodstock, 7915	021 460 9267	dfritz@pgwc.gov.za	
Western Cape Department of Health	The Complaints Manager Dept. of Health P. O Box 2060 Cape Town, 8000	021 483 5624	Gaaliver@pgwc.gov.za	http://www.capegateway.gov.za/eng/your_gov/305/contacts

Organisations you can contact about rights complaints

Organisation	Postal Address	Phone Number	Email	Website
Department of Health – National Complaints	The National Department of Health Directorate Quality Assurance Private Bag X828 Pretoria 0001	012 312 0709	sekgoj@health.gov.za COPY mthemr@health.gov.za	http://www.doh.gov.za/department/dir-qassurance.html
South African Medical Association	P O Box 74789 Lynwood Ridge Pretoria 0040	012 481 2000	online@samedical.org	http://www.samedical.org/
Democratic Nursing Organisation (SA) South Africa	P O Box 1280 Pretoria 0001	012 343 2315	info@denosa.org.za	http://www.denosa.org.za/

Organisations you can contact about rights complaints

Organisation	Postal Address	Phone Number	Email	Website
The People's Health Movement			phmsc@lists.sangonet.org.za	http://www.phmovement.org/en/southafrica
Black Sash	PO Box 1282 Cape Town 8000	072 66 33 739 (Advice Line)	help@blacksash.org.za	http://blacksash.org.za/
Treatment Action Campaign	PO Box 2069 Cape Town 8001	021 422 1700		http://www.tac.org.za/community/
The Community Law Centre (UWC)	Private Bag X17 Bellville 7535	021 959 2950	tfortuin@uwc.ac.za	http://www.ommunitylawcentre.org.za/
The Legal Resources Centre	P O Box 9495, Johannesburg 2000	011 836 9831 021 481 3000		http://www.lrc.org.za/

Organisations you can contact about rights complaints

Organisation	Postal Address	Phone Number	Email	Website
The Women's Legal Centre	7th Floor Constitution House, 124 Adderley Str. Cape Town	021 424 5660	jody@wlce.co.za	http://www.wlce.co.za/
Equal Education	PO Box 40114 Elonwabeni 7791	021 387 0022	info@equaleducation.org.za	http://www.equaleducation.org.za/
Section 27	PO Box 32361 Braamfontein 2017	011 356 4100	info@section27.org.za	http://www.alp.org.za/
The Social Justice Coalition		078 371 4147		http://sjc.org.za/
AIDS Legal Network	PO BOX 13834 Mowbray Cape Town 7705	021 447 8435	alncpt@aln.org.za	http://www.aln.org.za/



Health Rights in the South African Constitution

1. To **respect** the right to health government must not directly or indirectly prevent the enjoyment of health rights
2. For the government to **protect** the right to health they must prevent others from interfering with health rights or committing health rights abuses
3. To **fulfil** the right to health means that government must take positive action to ensure that health rights are enjoyed (by allocating resources to health or making laws or policies that protect the right to health)
4. In order to **promote** the right to health government should take steps to make sure that people are aware of their health rights and that they understand how to use them.



Health Rights in the South African Constitution

Everyone has the right to have access to health care services, including reproductive health care.

The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights

No one may be refused emergency medical treatment

Everyone has the right to an environment that is not harmful to their health or wellbeing

Children have a right to basic nutrition, shelter, basic health care services and social services

Prisoners have a right to conditions of detention that are consistent with human dignity, including the provision at state expense of adequate medical treatment



National Health Act

1. All users to have **full knowledge** of their health status, treatment options and the risks and costs of treatment
2. All users to have **access to emergency medical treatment**
3. **Free health care** services for pregnant and lactating women, children under the age of six
4. All users to provide **informed consent** for treatment after being informed why treatment is needed, what the treatment will be and what the risks of the treatment are
5. All users to **participate** in any decision affecting his or her health and treatment
6. The Department of Health to **disseminate information** about the types of services offered, timetables or schedules of services, patient rights and complaints procedures
7. All users to have the **confidentiality** of their information respected



Violations of Rights

- 1. State deliberately prevents realisation of a right (failure to RESPECT the right to health)**
Denying access to health care facilities, goods, services
- 2. State allows others to prevent realisation of a right (failure to PROTECT the right to health)**
State allows private medical aids that don't cover those who are HIV positive
- 3. State does not act when able to deliver a right (failure to FULFIL the right to health)**
Not enough budget for health
- 4. Retrogression (taking steps backwards, moving away from progress that has been made)**
Closing of existing health care facilities
Stopping treatment of HIV positive people with ARVs



Case 1

There isn't good medication for our children, for our people. Sometimes the Sister says; no we only got so many pills, we can't give all of you pills. You must come tomorrow to get more pills. Many people take the day off to come and get their pills. Now the person must stay at home tomorrow again to get those pills. There is never enough medication... The treatment is not good. There are never pills, there is never medication. People come here for a certain illness. Then there is never this or that...there is never enough of anything.

Questions

Has the right to health been violated in this case? Explain why you say this.



LEARNING NETWORK

Case 2

When you go to the doctor, you know what you feel in your body. But these doctors, they don't listen to you. He doesn't listen when you tell him that the medicine (for high blood) is making you feel bad, making you feel very hot and making your tears come down and making you not able to sleep. He doesn't believe you and he argues saying he knows best because he studied medicine. If you argue too much about the medicines then they will refuse to even give you a prescription.

Questions

Has the right to health been violated in this case? Explain why you say this.



Case 3

A young woman who was pregnant went to the clinic because she had stomach pains. They told her it was not her time yet... not time yet to deliver. And she was given some tablets, and she wasn't sure if it was the right tablets, and they sent her home with all the tablets and told her to drink all those tablets. I think it was 6,7, or 9 tablets... And just after she took the tablets, she got severe cramps and stuff and she called the ambulance and the ambulance came and she delivered triplets, but two of them died immediately.

On the way to the hospital the third one also died. She wasn't aware of the fact that she was having triplets, she was told it was twins. She went to the clinic... the sister said she wasn't sure what's wrong with her. And they didn't deal with her in the way she wanted to be dealt. The sister just examined her stomach...gave the tablets, and sent her home. She had to call the ambulance by herself at home, and that's where according to her, her problems started...



Questions

Has the right to health been violated in this case? Explain why you say this.



Case 4

I went to the clinic in February 2010 for treatment for a sexually transmitted infection (STI). I was embarrassed in the reception area when I was asked very private questions about the treatment I needed in front of a number of people.

I spoke to the nurse about the STI and she told me that I had to have an HIV test. I said that I didn't want an HIV test and that I had only come for treatment for an STI. The nurse (who wore no name tag) then said we will not treat your STI unless have a HIV test. I then did an HIV test so that I could get treatment for the STI. I felt that I had no choice about having the HIV test.

Questions

Has the right to health been violated in this case? Explain why you say this.



Complaints at the Clinic / Community Health Centre

According to the Department of Health each clinic should have:

1. A formal, clear, structured method for complaining
2. The method to complain should be displayed at the clinic
3. If you have a problem at the clinic, the method for complaining should be explained to you. Those who need help should be assisted to complain according to the correct method.
4. Each clinic should have a register of complaints and a record of how they have dealt with all complaints



Examples of Strategies for Dealing with Violations

Examples of **complaints** you could make as an individual or as a group:

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You could organise a protest march/ demonstration/mass action about health rights violations

You could invite an official to participate in an event, such as to open a workshop or visit a community where there is a problem with rights violations

You could hold a seminar on specific health rights topics (especially those that happen to be in focus for some reason) and invite a guest speaker with enough status to attract health officials

You could ask officials to open or close community workshops or other events on health rights

You could join in campaigns at local, national or regional levels (for example by supporting Black Sash's campaign to get the government to ratify the International Covenant on Social, Economic and Cultural Rights)

Section 4

Key words

Acceptable	Enough to satisfy needs or standards and respectful of the culture of individuals
Accessible	To be able to reach or make use of
Accountable	Being responsible for your actions
Advocacy	Active verbal support for a cause or position; expression of support for disregarded people; organised efforts by citizens to influence both government policy and practice
Annual general meeting	A yearly meeting of all people involved in a particular organisation or group to review the work of the last year and to choose new members
Available	Obtainable and suitable for use
Bodily integrity	Having a say in what happens to your body and the right not to have your body interfered with or hurt
Campaigning	A group of connected activities working to achieve a certain goal (e.g. a campaigning against violence)
Chairperson	The person in charge of a meeting or committee
Citizen	Legal resident of a country; someone who owes loyalty to that country and is entitled to the protection of that country
Committed	To have promised support or to become part of a particular cause, action or attitude
Community	A group of people living in a particular local area, or the public in general

Comprehensive	Complete; including everything and having all necessary parts
Constituency	The whole body of people who elect one representative
Consultation	A meeting between two or more people where advice is given or views are exchanged in order to make a decision
Dehydration	A condition caused by the excessive loss of water from the body through illness or other causes
Democracy	A system of government in which power is vested in the people, who rule either directly or through freely elected representatives
Elected	To choose someone to be a representative or a public official by voting
Emergency services	An organisation or group that responds to and deals with emergencies (e.g. fire brigade, police and ambulance services)
Empowerment	To invest with power or control
Essential medicines	Necessary or fundamental medicines that address the most important health care needs of the population
Feedback	Response in the form of comments or opinions; reaction to something; the return of useful information for future decisions and development
Governance	The process whereby an organisation or society manages itself
Hygiene	Clean or healthy practices that serve to support or maintain health
Individual	A single human being (a specific person different from a group)
International covenant on civil and political rights	An International legal agreement between countries relating to the civil and political rights of people

Legislation	A fully enforceable law or group of laws
Liaising	Communicating and maintaining contact to make it possible for groups to work together
Mandate	Authority or permission given to representative(s) to act on behalf of a group
Manipulation	Controlling or influencing someone in order to get what you want
Monitor	To watch over, observe, or check closely or continuously with a view to collecting information; checking for incorrect or unfair conduct
Negotiate	To bargain with others to achieve mutual agreement through discussion and compromise
Norms	A standard pattern of behaviour that is considered normal or required
Official	A person who holds a position in a government department or organisation
Participate	To take part or become actively involved in
Partnership	A mutual relationship between people or groups who agree to share responsibility for achieving some specific goal
Performance standards	The criteria against which actual performance is measured or judged
Placation	Actions taken to calm someone and make a group less hostile or angry
Pneumonia	Inflammation or infection of the lungs in which air sacs fill with pus, causing coughing and chest pain
Policy making	The creation of a plan of action or guideline agreed to by a government or an organisation

Population	All the people inhabiting a country, city, or other specified place
Power	The ability or capacity to perform or act effectively to control the environment or the behaviour of others
Pressurise	To make somebody do something or make insistent demands of someone
Principles	Accepted rules of action and behaviour
Priority	The main concern, of the highest importance or urgency
Procedure	A step-by-step order of activities
Public affairs	Issues that affect people generally, or issues arising from the relationship of the public to a government body
Public services	The business of supplying essential goods, such as water or electricity, or a service, such as communications or transportation, to the public
Quality	The extent to which something holds to standards of excellence
Rates	A tax imposed by local municipalities on those who own their own homes
Redistribution	To share out again, to make sure that benefits are shared more equally
Refuse	Anything thrown away; waste; rubbish
Representations	The presentation of facts and reasons made in appealing or protesting
Representative	Someone who speaks, stands or acts in the place of others and is given their authority
Responsibility	Being accountable, the duty to carry out a task

Right of residence	The right to live in a country
Role	The proper or expected tasks and responsibilities of a person or group
Sanitation	Toilets, sewage systems, rubbish and the removal of rubbish and sewage
Societal problem	A social condition that a segment of society views as harmful to members of society and in need of remedy (e.g. crime, unemployment, poverty)
Solidarity	A feeling of unity between people (a sense of standing together)
Standards	The ideal in terms of which something is judged. Standards relate to how we would like things to be
Strategy	Refers to a plan of action designed to achieve a particular goal or things that could be done
Therapy	A treatment method where a mental health professional (psychiatrist, psychologist, counsellor) and a patient discuss problems and feelings to find solutions
Tokenism	The practice of doing something only to meet minimum requirements, prevent criticism and give the appearance that people are being treated fairly
Transparency	Lack of hidden agendas and conditions, accompanied by the availability of full information required for collaboration, cooperation, and collective decision making
Trust fund	An amount of money which a person places in the care of someone (to be managed for the benefit of another person or a group)

Universal Declaration of Human Rights	A statement agreed on by the United Nations as the first world-wide expression of the rights of all human beings
Volunteer	A person who does a job willingly and without pay (normally to benefit the broader community or a specific group of people)
Vulnerable groups	People that need special protection (e.g. children, the elderly)
Wellbeing	The state of being healthy, having a good quality of life and being satisfied with one's life

Citizen Participation in Health

“
The price of freedom is never-ending watchfulness... we should never take our freedom for granted...and we should never be afraid to ask [government] the awkward questions...”
(Archbishop Desmond Tutu)

The goal of the fourth section of the toolkit is to understand how members of the community can be part of making sure that the right to health is realised through their participation.



Activity 1

Purpose

To understand the potential role participants play in how the country is governed.

Process

(Time 20 minutes)

1. Ask participants if they think they are part of running government. If they respond that they are part of running government ask them for examples of how they do this. If they say they are not part of running government ask them why they aren't.
2. Give some examples of how people do have a role in running government in a democracy (see information below).¹



1. This activity has been sourced from *Train-the-trainer manual: participation. Civic education and community mobilisation*. Netherlands Institute for Southern Africa.



What is a democracy?

A democracy is a type of government in which citizens rule, either directly or through representatives that they have chosen. This way of governing is meant to prevent a situation where power is held in the hands of only a few select people. In a democracy communities should partner with government in making the decisions that affect their lives.²

Who are citizens?

“

Citizens are the owners of society. The government is made by the people. People are you and me simply.³”

Zimbabwean

A citizen is someone who has full rights and duties in a country either by being born in that country or by applying to adopt the country as their own. It involves a relationship between an individual and the state that is recognised by law.

There are a number of different qualities of citizenship. Citizenship can relate to:

A legal relationship between a person and the state (through rights of residence, obeying the law and having the protection of the law)

The political power of individuals (to vote, write petitions and participate in political parties)

A social responsibility to respect other citizens and support or serve one's community or country

Psychological identity, a subjective sense of membership of or belonging to a country and of having an identity of which one is proud.⁴



2. McQuoid-Mason, David. (ed). 1994. *Democracy for all: education towards a democratic culture*. Kenwyn: Juta and Co Ltd.

3. VeneKlasen, L. & Miller, V. 2002. *A New Weave of power, people and politics: The Action Guide for Advocacy and Citizen Participation*. United States: Stylus Publishing

4. Sourced from <http://plato.stanford.edu/entries/citizenship/>

Citizens have a variety of rights and privileges as set out in the Constitution of our country, but they also have a set of duties or responsibilities. In previous sections of this toolkit we have spoken quite a lot about the rights of citizens of South Africa. As citizens people also have duties to:

- obey the law
- vote
- pay rates
- pay taxes to government
- to be productive members of society
- to be involved in how government runs the country (participate)
- be part of the military (if necessary to defend the country)⁵

Active citizenship can involve the following:

- Exercising rights
- Treating others equally and respecting the rights of others
- Objecting when rights are violated
- Being concerned about the rights of vulnerable groups
- Teaching others about their rights
- Being informed about issues
- Attending community meetings
- Debating issues
- Protesting government actions
- Contributing in the community to support a cause (volunteer at a soup kitchen, join a NGO)
- Starting community or grass roots organisations
- Working with government to solve problems⁶



What does it mean to be a representative?

In a democracy it is not always possible for all citizens to be directly involved in governing the country. So what happens is that people in the country are represented by the political parties that they have chosen, or on a local level through local government representatives (e.g. ward councillors), or even represented through NGOs or members of the community who speak out about problems on their behalf.

5. VeneKlasen, L. & Miller, V. 2002. *A New Weave of power, people and politics: The Action Guide for Advocacy and Citizen Participation*. United States: Stylus Publishing

6. McQuoid-Mason, David. (ed). 1994. *Democracy for all: education towards a democratic culture*. Kenwyn: Juta and Co Ltd.



A **representative** is someone who has been chosen to speak, act and make decisions on behalf of a large number of people. Normally the group of people that the representative speaks for is called a **constituency**. Representatives should give feedback to the group (giving them the different options available) and asking them which decision or action they support. Once the whole group has agreed to support a specific decision or has chosen a course of action, then the representative has a **mandate** from that group.



For example, ward councillors are chosen to represent the people who live in a ward or a specific area. They represent the interests of communities at municipal meetings. A ward councillor should be in touch with the issues and key problems in the area, know the environment of the ward (housing, schools, hospitals, clinics, shops) and understand and monitor development and service delivery. The ward councillor should meet regularly with community members to ensure that he/she knows their opinions and views on municipal proposals and plans. All this information about the ward coming from community members should be fed into the municipality's planning process.

Participation



Political representatives, community leaders or local government members should be representing the needs of the community. Even if this is the case it is still vitally important for citizens or community members to be informed, consulted and to have the power to influence decisions that affect their lives.

Participation is a process in which individuals and groups in communities discuss and reach agreement with government and other interested parties on:

- how information is shared
- requests for changes in laws
- how policies are set and implemented
- how tax resources are allocated
- how benefits are parcelled out
- how government programmes are operated
- how government programmes are evaluated⁷

Another more organised way in which citizens can participate and work together is through **advocacy**. Advocacy consists of:

"...organised efforts and actions based on the reality of **'what is'**... to influence public attitudes and to enact and implement laws and public policies so that visions of **'what should be'** in a just, decent society become a reality."⁸

7. Arnstein, Sherry. 1969. A Ladder of Citizen Participation. *Journal of the American Institute of Planners*, 35(4) 216-224

8. VeneKlasen, L. & Miller, V. 2002. *A New Weave of power, people and politics: The Action Guide for Advocacy and Citizen Participation*. United States: Stylus Publishing

Advocacy is very much a part of challenging power relationships through people's participation that:

“ supports and enables people to better negotiate on their own behalf, for basic needs and basic rights ”
(ActionAid (UK))



Why is it important to participate?

Activity 2

Purpose

To discuss and uncover some of the reasons why people decide to participate and how participants in the group are already participating through the work of the NGO they are involved with.

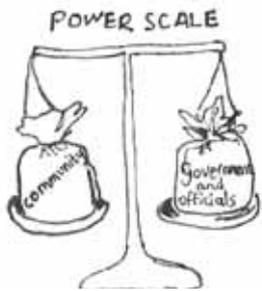
Process

(Time 20 minutes)

1. Ask members of the audience why they think people are part of NGOs or why they are part of a specific NGO.
2. Note down their responses on a flipchart.
3. Make a connection between their responses on why participation is important to them and some of the reasons why participation is listed as being important (see list that follows).



9. VeneKlasen, L. & Miller, V. 2002. *A New Weave of power, people and politics: The Action Guide for Advocacy and Citizen Participation*. United States: Stylus Publishing



When citizens participate it leads to:

- Communities that are able to challenge the current situation/status
- People having the opportunity to create and to see positive change
- People having access to information about government decisions and strategies
- People having equal opportunities to influence decision making
- People being more likely to be committed to government programmes or policies
- Government working with and building on the strengths and knowledge of communities
- The redistribution of power (meaning that power is more equally shared between government and its officials on one hand and communities on the other)¹⁰

Active participation means that communities are able to:

- Provide government with the information it needs to make better decisions by bringing different needs, concerns and perspectives into the decision-making process

When citizens participate they can:

- Make sure that government is held accountable (held responsible for its decisions)
- Pressurise government to provide improved delivery of public services
- Try to make sure that leaders do not abuse their powers
- Try to make sure that the interests of their communities are advanced¹¹



Participation can build stronger communities by:

- Educating and empowering communities by making them more aware of problems and involving them in finding the solutions to these problems
- Encouraging communities to promote their vision for themselves and/or society
- Promoting community solidarity (communities standing and working together)¹²

10. *Train the trainer manual: participation. Civic education and community mobilization.* Netherlands Institute for Southern Africa

11. Information sourced from www.idasa.org.za

12. *Train the trainer manual: participation. Civic education and community mobilization.* Netherlands Institute for Southern Africa

The right to participation

The right to participate is a basic human right, which is set out in the Universal Declaration of Human Rights (UDHR) as well as in the International Covenant on Civil and Political Rights (ICCPR). Both these human rights instruments guarantee people the right to participate in government as well as the right to participate in free and fair elections. Article 25 of the International Covenant on Civil and Political Rights (ICCPR) includes:

the right to participate in public affairs (directly or through chosen representatives)
voting rights
the right of equal access to public services¹³

The right to participate is also set out in the South African Constitution which stipulates that:

“
People's needs must be responded to, and the public must be encouraged to participate in policy-making. ”

“
Transparency must be fostered by providing the public with timely, accessible and accurate information. ”

The right to participation can only be exercised if citizens have access to other important rights like:

the right to have access to information
the right to vote
the right to stand for election
the right to make free political decisions
the right to freedom of expression
the right of freedom of association
the right to freedom of assembly, demonstration, petition and picket¹⁴

In South Africa, government has to provide the financial, administrative and practical assistance to help communities participate effectively. The government also has to provide information to citizens about how they make decisions and what they are doing. This system is one where government can be held **accountable** (asked to explain their decisions or failures).

13. Sourced from http://www.osce.org/documents/odihr/1996/07/1707_en.html

14. Potts, Helen. 2009. *Participation and the right to the highest attainable standard of health*. University of Essex: Human Rights Centre

Participation and the Right to health

“

Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people.”

(World Health Organisation Constitution)

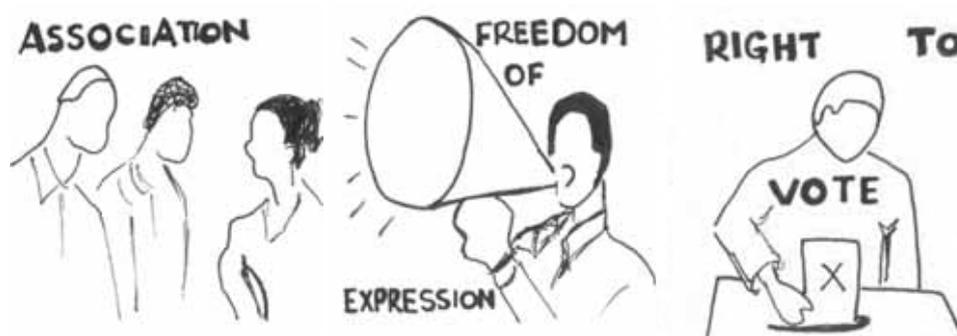
Participation is both a right itself and also involved in the fulfilment of other rights, including the right to health.



For example, in order for people to exercise their right to vote, they would need to participate in elections. In order to realise their right to fair working conditions, people may participate in the activities of a trade union. At the heart of the right to bodily and psychological integrity is the principle that people should always be able to participate in any decisions related to their body or their wellbeing.

One of the key principles of the right to health is the right of communities to participate in decision-making (including the design and implementation of policies) that affect their health.¹⁵ Participation is essential to ensure that there are accessible, available, quality and acceptable health care services and that the conditions that support health are in place.

In order to make sure that health care services are **available**, people need to participate to inform government that they don't have health care facilities in the area where they live, that there are an insufficient number of health care workers or that they don't have access to essential drugs. People should also be involved in questioning health budgets to make sure that resources are shared fairly (prioritising those who need services the most).¹⁶



15. Asher, Judith. 2004. *The Right to Health: A Resource Manual for NGO's*. London. The Commonwealth Medical Trust.

16. Potts, Helen. 2009. *Participation and the right to the highest attainable standard of health*. University of Essex: Human Rights Centre

Case study



Health committees are the formal organisations set up for community participation in health. Most clinics or health centres have a health committee to represent the interests of community members at the clinic or more broadly. A health committee in the Eastern Cape said that they had negotiated and managed to get more ambulances made available in their area. They also found ways to make sure that medicines were regularly available at the clinic at all times. This is a clear example of how community members have participated to realise the right to health by making sure that goods and services were available.¹⁷

In order to make health services accessible people need to participate in planning for health services. Citizens should be involved in making suggestions on how to make health services more physically accessible, affordable or how to ensure that services don't discriminate unfairly against certain groups. Access to information is a key element that makes participation possible because people can only participate effectively if they have information on government policies on health, budgets for health or on how health decisions are being made.

Case Study



A health committee in the Western Cape assisted in making the clinic in their area, which used to only be open during working hours, into a 24-hour facility. This made emergency services accessible for many more people, including vulnerable groups.¹⁸

Quality (meeting required standards) and **acceptable** (culturally appropriate) health facilities and services can only exist in a context where government and health care workers can be held accountable. Participation by communities and the feedback that they provide about services is essential in assessing the quality or acceptability of services.¹⁹

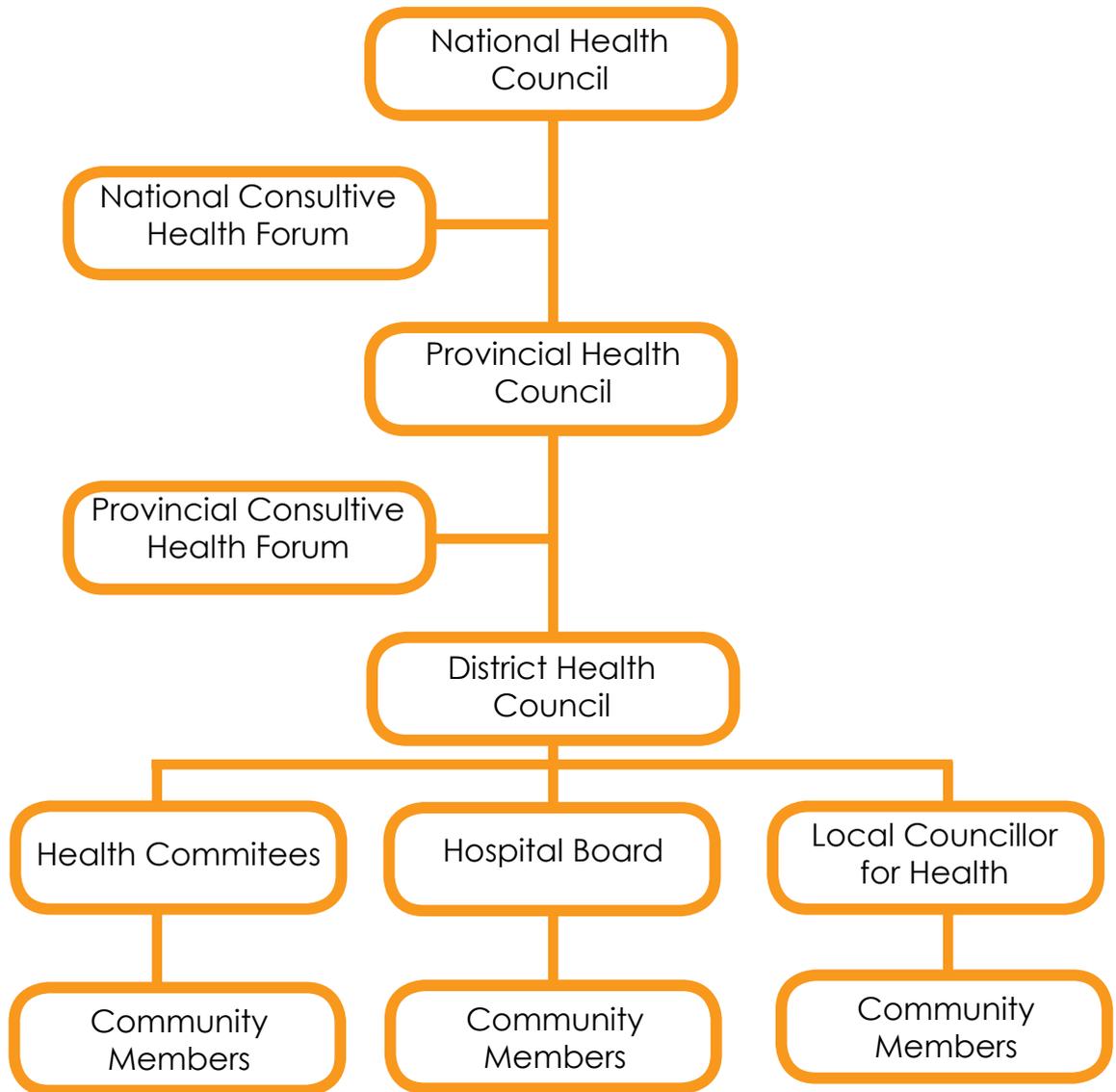


17. Padarath, A & Friedman, I. 2008. *The status of clinic committees in primary level public health sector facilities in South Africa*. Durban: Health Systems Trust.

18. Glattstein-Young, G. 2010. *Community Health committees as a vehicle for community participation in advancing the right to health*. University of Cape Town. Masters thesis.

19. Potts, Helen. 2009. *Participation and the right to the highest attainable standard of health*. University of Essex: Human Rights Centre

Health governance structures



20

In South Africa health management structures are set up to ensure that communities can participate in decision making. The different levels of health management structures have the goal of making sure that the voice of community members can make its way upward to local or provincial health departments.²¹

20. Diagram adapted from Padarath, A & Friedman, I. 2008. *The status of clinic committees in primary level public health sector facilities in South Africa*. Durban: Health Systems Trust.

21. Padarath, A & Friedman, I. 2008. *The status of clinic committees in primary level public health sector facilities in South Africa*. Durban: Health Systems Trust.

Health committees

Health committees were set up by the South African National Health Act 61 of 2003 as the formal structures for community participation in health. It is required by law that all clinics and community health centres should have health committees.

Members of health committees should include:

- one or more local government councillors (e.g. ward councillor)
- the facility manager or head of the clinic
- one or more members of the community who use the health facility²²



Community members can participate in health through being part of health committees. If the health management system is functioning properly then community concerns should be communicated to the District Health Council and from there to Provincial or National Health Councils.

Health committees were set up to:

- Represent the interests of communities at clinics and health centres
- Take steps to ensure that the needs, concerns and complaints of patients and the community are properly addressed by the management of the facility

The Health Act requires provincial governments to put in place laws and policies to formalise the role of health committees. These laws and policies are not yet in place in a number of provinces, and therefore there is currently not enough information on the exact roles and responsibilities of health committees in these provinces.

22.Hassim, A., Heywood, M & Honermann, B. (eds). *The National Health Act 61 of 2003: a guide*. Cape Town: Siber Ink.

Cape Metro Health Forum

In the Western Cape a forum exists for all health committees in the Cape Metro area. Although the Cape Metro Health Forum (CMHF) is not formally recognised by health legislation, it plays an important role in advocacy on health issues, co-ordination and provision of support for all health committees in the Cape Metro area.

Representatives from each health committee in the sub-districts attend meetings of the CMHF. Representatives of the management of City Health and the district health service also attend these meetings.



Hospital Boards

According to the National Health Act each central hospital or group of central hospitals must have a hospital board. These boards must include:

- not more than three representatives of the communities served by the hospital
- one representative from each university associated with the hospital
- one representative from the national Department of Health
- one representative from the provincial department in the province in which the relevant hospital is situated

not more than five representatives of staff and management of the hospital (these representatives may not vote at a meeting of the board)

Hospital boards were set up to:

- ensure accountability of health facility management to the community
- respond to the needs of patients and their families
- get community support for and involvement in health facilities and programmes
- monitor the performance of the hospital against its performance standards
- check that there is responsible financial management of the facility and that the facility is making efficient use of the resources at its disposal
- also raise funds or administer trust funds for the exclusive functioning of the hospital²³

District Health Council

Health districts are managed by District Health Councils, whose function it is to promote co-operative governance and to ensure co-ordinated planning by drawing up district health plans.

In each province, the Member of Executive Council (MEC) responsible for Health, in consultation with the MEC responsible for Local Government and the Municipal Council concerned, must establish a District Health Council (DHC). The DHC consists of a member of the district or metropolitan council, a representative of the MEC for Health, a member of the council of each local municipality in the district, and up to five other people appointed by the MEC for Health.

A District Health Council:

- may consult with or receive representations from any person, organisation, institution or authority on any matter regarding health or health services
- must act in accordance with relevant and applicable laws and policies of the national or provincial government and the municipal council
- must at least annually provide reports as prescribed on its activities to the Provincial Minister of Health

23. Hassim, A., Heywood, M & Honemann, B. (eds). *The National Health Act 61 of 2003: a guide*. Cape Town: Siber Ink.

Provincial Health Council and the Provincial Health Consultative Forum

The function of the Provincial Health Council and the Provincial Health Consultative Forum is to advise relevant members of the Executive Council (premier, ministers and heads of provincial government departments) on matters related to the health of the population.

The Provincial Health Council acts to:

- ensure that the national health policy is implemented in the province
- ensure that the province provides specialised hospital services
- oversee the funding and support of district health councils
- conduct relevant research into health services
- manage the development of human resources
- ensure that appropriate and comprehensive information is disseminated to local communities on the health services in the health district

National Health Council and National Consultative Health Forum

Members of the National Health Council include the Minister of Health, Members of the Executive Council for Health and representatives from local government and the military. The main role of the National Health Council is to advise the Minister on issues relating to:

- responsibilities for health
- financing of health services
- co-ordination of health services
- human resources planning
- development, use of health technology
- proposed laws about health matters
- norms and standards for the establishment of health facilities;
- guidelines for the management of health districts
- the implementation of national health policy
- the national and provincial integrated health plans
- an integrated national strategy for health research

The Minister of Health can call a meeting of the National Consultative Health Forum to co-ordinate national health issues, consult to or advise the Minister on national health matters.

Possible roles for Health Committees

Health committees or similar structures for community participation exist in a number of countries in Southern Africa. The following are some examples of what roles health committees play in countries such as Zimbabwe, Zambia or in South Africa.

If health committees are intended to be structures for community participation in governance or management of health, they should be involved in:

1. Planning and decision making related to health issues

It is important for health committees to be involved in decision-making and problem-solving at the health-systems level. They could do this by:

- actively participating in the Health Department's drawing up of annual health plans
- informing government of urgent health problems (through meetings, submissions to Parliament)
- liaising with other health groups (e.g. Hospital Boards, District Councils)
- making linkages with ward and municipality health structures



At a clinic level health committees can:

- identify health related problems in the community for purposes of planning
- give information on local priorities for action
- become involved in clinic-level decisions regarding how budget and resources are distributed
- give information to authorities on community health needs for inclusion in the budget²⁴

2. Monitoring and evaluating health services or health issues

Health committees should be involved by:

- making sure that there is good quality of care at health facilities by dealing with community complaints and holding clinic or health centres accountable

24. Padarath, A & Friedman, I. 2008. *The status of clinic committees in primary level public health sector facilities in South Africa*. Durban: Health Systems Trust.



ensure patients' rights are upheld and that clinics conform to the Patients' Rights Charter
assisting in monitoring that drugs and other clinic materials are available at all times
checking that health policies are being implemented correctly
monitoring health in people's working situations (e.g. factories, plantations, bus and taxi ranks)²⁵



Case Study

A health committee in South Africa helped to reduce excessively long waiting periods at a clinic. Committee members would ask patients how long they had been waiting and respond to unusually long wait times by investigating further and informing the facility manager. Another committee noted that patients were being questioned about health problems in an open area. They argued that patient privacy was not being respected and, as a result of their objections, the facility manager corrected the situation.²⁶

3. Advocating for the community

Health committees are supposed to act as the connection between community members and the clinic or health committee. An important part of this role is for them to look after the interests of the community by:

- Making sure there is a supply of safe drinking water for communities
- Advocating for improved housing for communities
- Taking up sanitation issues with the local municipality
- Ensuring that refuse is collected regularly

25. Loewenson, R & Rusike, I. 2004. *Assessing the impact of health centre committees on health system performance and health resource allocation*. EQUINET discussion paper 18.

26. Glatstein-Young, G. 2010. *Community Health committees as a vehicle for community participation in advancing the right to health*. University of Cape Town. Masters thesis.

Case Study



A health committee in the Eastern Cape approached the municipality about illegal dumping in their community. The municipality agreed to clean the dump site and the community was warned about not dumping in the area again.

“

Now it's the community members who are monitoring that site. They are very determined that no-one should dump there again. That was a really big achievement for us.²⁷

(Community Health Committee, sub-district B) ”



initiating or supporting nutrition projects (e.g. for schools, old people)
running community vegetable gardens at the clinics
making community members aware of the availability of health services
assisting community members to identify priority health problems in the community
fundraising for additional services and health programmes at the clinic required by the community
organising community health actions and campaigning for better government health services (distributing leaflets, holding demonstrations, organising petitions)
identifying groups in the community and the area that don't have access to health services
working with traditional midwives to refer people to the clinic
keeping a register of disabled children or people needing periodic home visits
making home visits to the sick and providing health information, food and medicine during home visits
embarking on income generating projects to provide home based care for HIV-affected families
having regular meetings with the community to identify health needs
giving regular feedback to community members and being accountable to the community²⁸

27. Boule, T., Makhamedela, N., Goremucheche, R & Loewenson, R. 2008. *Promoting Partnership between Communities and Frontline Health Workers: Strengthening Community Health Committees in South Africa*. Community Development Unit, Nelson Mandela University South Africa. Harare: EQUINET

28. Ngulube, T.J., Mdhluli, L., Gondwe, K & Njobvu, C.A. 2004. *Governance, participatory mechanisms and structures in Zambia's health system: An assessment of the impact of Health Centre Committees (HCCs) on equity in health and health care*. EQUINET discussion paper



Case Study

A health committee in the Cape Town area in South Africa gave patients information about what services the clinic offers and told patients when there were staff shortages at the clinics so that patients were aware when they would have to wait longer than usual.²⁹

4. Providing support to the clinic/health centre

In South Africa a number of health committees play a supportive role at clinics or health centres. Although it can be part of improving a community's sense that they are "owners" of the clinic, there is also a danger in the work of health committees being limited to this supportive role only. Health committees provide support to the clinic by:

- bringing community views to health workers
- negotiating for additional health care workers/nursing staff at the clinic
- helping to improve supplies of essential medicines for clinics/ community health centres
- raising funds to contribute to purchases of medicines for the clinic
- notifying the clinic of outbreaks of disease in the community
- being actively involved in the planning and implementation of health campaigns (in collaboration with the clinic)
- assisting with monitoring that TB patients are taking their medicines
- volunteering their services in the facility
- organising broader community groups to undertake work activities at their clinics or health centres
- assisting the department in ensuring the security and safety of clinic premises and staff³⁰



Case Study

In Zimbabwe a health committee at the Mwanza clinic in Goromonzi district raised funds within the community in order to improve health services at the clinic. The fundraising started when they wanted to hire a guard to protect the clinic from thefts. The health committee then had a meeting with community members where they discussed the idea of charging a small fee to all community members and users of the clinic. The funds they raised were not only used to hire a guard for the clinic, but also to build toilets, purchase benches for patients to sit on and to supply transport costs for health staff having to travel to fetch essential medicines. The health committee decided with

29. Glatstein-Young, G. 2010. *Community Health committees as a vehicle for community participation in advancing the right to health*. University of Cape Town. Masters thesis.

30. Padarath, A & Friedman, I. 2008. *The status of clinic committees in primary level public health sector facilities in South Africa*. Durban: Health Systems Trust.

community members on how funds were spent and all have benefited from the improvements at the clinic.³¹

5. Health promotion in the community

Health care is not only about the treatment of illness, but also about preventing illness and promoting healthy behaviours. Health committees become involved in health promotion in communities by:

- providing health information to communities (healthy nutrition, the importance of hygiene)
- using effective methods to spread health messages at their clinics (community drama providing information on HIV& AIDS in their communities)
- participation in health promotion activities in things such as promoting community hygiene, refuse disposal
- promoting healthy living in their communities by encouraging positive changes to improve health (e.g. not drinking alcohol during pregnancy or giving up smoking)

Case Study



In South Africa one health committee created their own pamphlets and used a free local newspaper to circulate health information and any news from the health facility.³²

What can community members do if they want to join a health committee?

Members of health committees are normally chosen by patients and community members at the annual general meeting of the existing health committee. Health committee members can also be chosen (by a show of hands) at a community meeting specially called to establish a committee if there is no existing health committee.

Sometimes members of the community volunteer to join the health committee; members may be elected by the facility manager or staff at the clinic; or even selected by the local councillor. These methods are not as effective as allowing community members to elect the

31. Loewenson, R & Rusike, I. 2004. *Assessing the impact of health centre committees on health system performance and health resource allocation*. EQUINET discussion paper 18.

32. Glatstein-Young, G. 2010. *Community Health committees as a vehicle for community participation in advancing the right to health*. University of Cape Town. Masters thesis.

health committee and may even lead to excluding important potential members from the community. A health committee is only really representative of the community if the members have been chosen by the community and are supported by it.³³

How do I start a health committee?

If there is no health committee at your clinic or community health centre there are a variety of strategies you could use to try and get a health committee started. You could:

Contact the chairperson of the metro health care forum to find out what you need to do

Attend a sub-district health forum meeting to enquire about what the procedure is for starting a new health committee in that area

Contact the manager of the clinic, the sister in charge or the ward councillor about starting a health committee

Advertise locally to call a community meeting to choose members to serve on a health committee (e.g. through pamphlets in the clinic, community radio or community newspapers)



Activity 3

Purpose

Process

(Time 20 minutes)

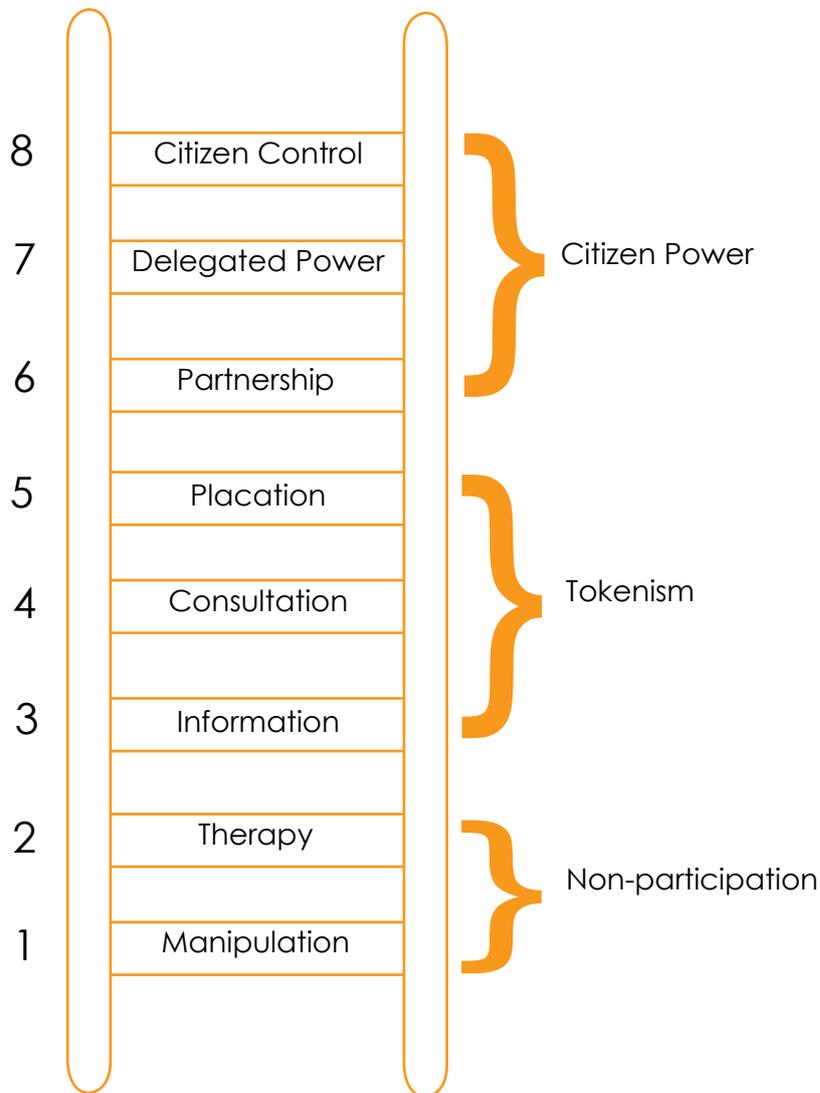
1. Divide participants into small groups and ask each group to identify one health problem in their community.
2. Their task is to start an NGO that will work to solve this health problem.
3. Each group should decide on a name for the NGO, the mission or main goal of their NGO and some tasks (3-5) the NGO must tackle to meet its main goal.³⁴

33. Padarath, A & Friedman, I. 2008. *The status of clinic committees in primary level public health sector facilities in South Africa*. Durban: Health Systems Trust.

34. This exercise has been adapted from Claude, Richard P. 2000. *Popular Education for human rights: 24 participatory exercises for facilitators and teachers*. Cambridge: Human Rights Education Associates

Levels of Participation

Arnstein's Ladder of Citizen Participation



According to Arnstein there are degrees or levels of participation. There could be little or no community participation in decision-making or there could be a situation where community members have complete control of decision making. Situations exist where participation falls between these two extremes (of no power for communities or complete power for communities).³⁵

35. Arnstein, Sherry. (1969). A Ladder of Citizen Participation. *Journal of the American Institute of Planners*, 35(4) 216-224

When she speaks of **Non-Participation** Arnstein includes:

1. **Manipulation** which involves situations where the support of citizens is used by officials to get what they want. Officials persuade and advise citizens who have no real understanding of the issues and citizens simply do what those in power suggest.



For example when community members are invited to participate in a planning meeting, but don't really understand the plans being discussed. Yet they are persuaded to agree with what is being planned and officials can claim that there was community participation in all the planning for the project.

2. **Therapy** as a form of participation exists where officials work with community members to help them 'adjust' to problems such as high levels of crime or poor access to health care. The focus is moved from the community or societal problem to changing the individual or teaching them to cope with or adapt to these problems.



A father took his sick baby to the clinic. At the clinic the father was told to take baby home and feed it sugar water. That same day the baby died of pneumonia and dehydration. When the father wanted to lodge a complaint he was invited to attend child-care sessions for parents (therapy). No attempt was made to start an investigation of the child's death or to take any action to prevent similar cases that could lead to the death of more children.³⁶

When she speaks of **Tokenism** Arnstein includes:

3. **Informing** which involves officials giving people information about alternatives or decisions that they have made. This could be a step in the direction of genuine citizen participation. But if the officials don't ask for feedback from citizens and citizens have no power to negotiate or change things, then it amounts to tokenism.

36. Arnstein, Sherry. (1969). A Ladder of Citizen Participation. *Journal of the American Institute of Planners*, 35(4) 216-224

An example of this would be if health officials made an announcement to all community members in Khayelitsha that a decision had been made that they were going to close all existing clinics in the area and build one new larger clinic which would be about 20kms outside of the township.



4. Consultation involves asking citizens about their concerns and ideas (through surveys, neighbourhood meetings or public hearings) and could also be a step towards real citizen participation. It is not real participation if nothing is done with the needs and concerns identified by citizens and consultation is about going through the motions of participation by gathering information from communities, but not doing anything with this information.

An example of consultation could be when people come and do research surveys about what problems are in the community. Those who participate in the survey never hear anything about the results and no change happens as a result of the information community members provided.



5. Placation involves a situation where citizens have some degree of influence. They can advise or participate in planning, but officials still have the final say whether they will use the input or advice of community members or not. Placation is when people are consulted, but officials modify their plans based on this consultation only if it is absolutely necessary.

For Arnstein, real **Citizen Power** and instances where officials collaborate with communities in a meaningful way include:

6. Partnership which means that real negotiation and collaboration takes place between citizens and power holders where they share in both planning and decision making. Officials may have a tentative plan, but are open to change this plan based on the input of those who are affected (community members).

7. Delegated power requires that there is more equality in the relationship and that citizens have power over certain agreed functions or decisions and officials cannot influence these decisions. In this kind of situation a problem is presented to the community and officials stipulate how much money can be spent or set other limits on the project. The community makes the decisions and comes up with a plan and officials need to negotiate with them about the plan.



8. When there is complete **Citizen control** of participation then citizens handle the entire job of planning and managing a programme or project without any interference at all from officials. The community identifies the problem and makes all decisions while officials are called on to provide help or input where needed.



Activity 4

Purpose

To apply knowledge on the different degrees to which people actually participate and how much decision-making power is involved for communities on each of these levels.

Process

(Time 30 minutes)

1. Photocopy and enlarge the cards with stories below. Divide the larger group into small groups and give each group a copy of the ladder of participation.
2. Ask the groups to place each card where they feel the story fits on the ladder of participation.
3. Create a flipchart with the eight rungs of the ladder of participation. After the small groups are finished ask one group to volunteer to place their participation cards along the ladder on the flipchart. Ask for some discussion from the larger group of whether they agree with how the cards are placed and why



A health committee is asked to attend a meeting to participate in planning and budgeting for a clinic. They are given no information on the budget or what they will be planning for, but have to agree to the budget at the meeting.

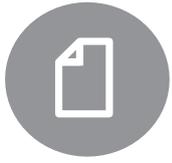
Community members are unhappy that there is no medicine for high blood pressure available at the clinic. The clinic responds by inviting them to a talk on how to manage their high blood pressure.

The health committee is informed that the health centre/day hospital is going to reduce the hours they are open. There is no opportunity for either community members or the health committee to respond. The decision has already been made.

Community members are asked to answer questions and give their opinion on what their main health problems are. Even though they give useful input, officials decide not to use the information and stay with their idea of what the main health problems are.

A health committee is asked to come up with a plan to shorten waiting times at the clinic. The committee had identified this as a problem and they decide there is a need for extra staff. They go back to the clinic to convince the facility manager to motivate for two additional nurses at the clinic. The facility manager is able to get one new nurse.

Community members are worried about litter and pollution in their community. A number of people volunteer their time to clean up certain areas. The city council is also asked to remove refuse more regularly and they agree to do this.



Workshop Handouts

The pages that follow can be photocopied to give to workshop participants as handouts during the workshop



“
The will of the people shall be the
basis of the authority of government... ”
(Universal Declaration of Human Rights)

What is participation?

Participation is a process in which individuals and groups in communities discuss and reach agreement with government and other interested parties on:

how to take the needs of communities into consideration when making decisions

how information is shared

responding to comments and requests for changes in laws

how goals and policies are set and implemented

decisions that affect their lives

how tax resources are allocated

how benefits are parcelled out

how government programmes are operated

how government programmes are evaluated



Being a representative

Some definitions:

A **representative** is someone who has been chosen to speak, act and make decisions on behalf of a large number of people

A **constituency** is the group of people that the representative speaks for

A **mandate** is the strength of support that a representative has for a particular course of action

A good representative:

Represents an agreed point of view

Represents all parts of their community

Reports back to community members

Includes hard to reach members of the community in discussions (elderly, HIV-positive, people with disabilities, immigrants and refugees)



The right to participation

Article 25 of the **International Covenant on Civil and Political Rights** (ICCPR) includes:

the right to participate in public affairs (directly or through chosen representatives)

voting rights

the right of equal access to public services

The right to participate is also set out in the **South African Constitution** which stipulates that:

“
People’s needs must be responded to, and the public must be encouraged to participate in policy-making.”

“
Transparency must be fostered by providing the public with timely, accessible and accurate information.”

Rights related to the right to participate

Right to access to information

Right to free political choices

Right to stand for election

Right to vote

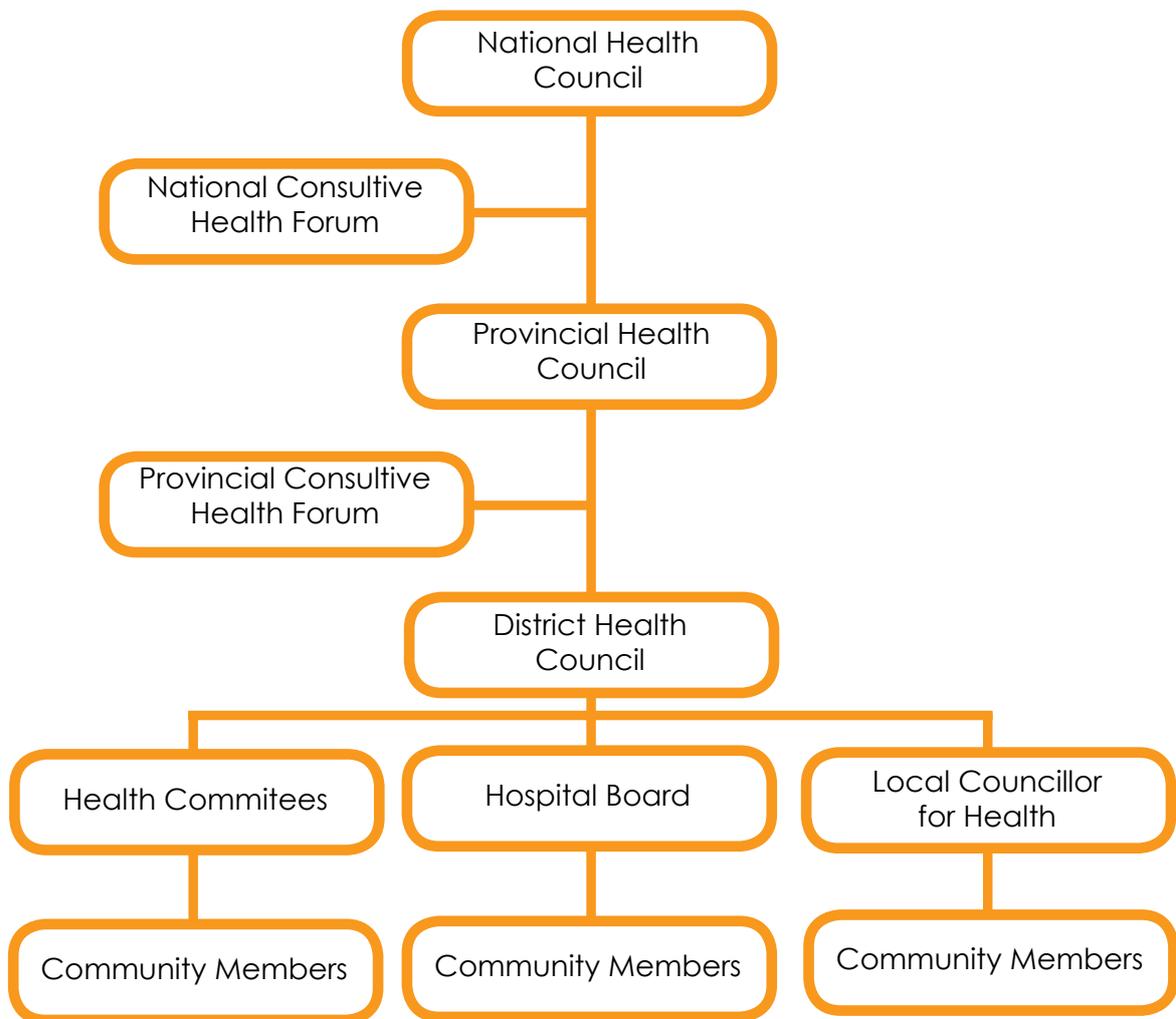
Freedom of assembly, demonstration, petition and picket

Freedom of association

Freedom of speech and expression



Health Governance Structures





What is a health committee?

Formal structure for community participation in health

The law (National Health Act) says that every clinic or community health centre must have a health committee

The law (National Health Act) says that every hospital must have a Hospital Board

Health committees should be made up of:

- a ward councillor
- one or more members of the community
- the facility manager/sister in charge

Community members serving on health committees are volunteers

Health committee members should be elected or chosen by the community



Possible roles for health committees

Planning and decision making related to health issues

- actively participating in the Department of Health's drawing up of annual health plans
- informing government of urgent health problems (through meetings, submissions to Parliament)

- liaising with other health groups (e.g. Hospital Boards, District Council)

- making linkages with ward and municipality health structures

At a clinic level health committees can:

- identify health related problems in the community for purposes of planning

- give information on local priorities for action

- become involved in clinic-level decisions regarding how budget and resources are distributed

give information to authorities on community health needs for inclusion in the budget

Monitoring and evaluating health services or issues

making sure that there is good quality of care at health facilities by dealing with community complaints and holding clinic or health centres accountable

ensure patients' rights are upheld and that clinics conform to the Patients Rights Charter

assisting in monitoring that drugs and other clinic materials are available at all times

checking that health policies are being implemented correctly

monitoring health in people's working situations (e.g. factories, plantations, bus and taxi ranks)

Advocating for the community

making sure there is a supply of safe drinking water for communities

advocating for improved housing for communities

taking up sanitation issues with the local municipality

ensuring that the collection of rubbish or general cleanliness of the community is improved

initiating or supporting nutrition projects (e.g. for schools, old people)

running community vegetable gardens at the clinics

making community members aware of the availability of health services

assisting community members to identify priority health problems in the community

fundraising for additional services and health programmes required by the community at the clinic

organising community health actions and campaigning for better government health services (distributing leaflets, holding demonstrations, organising petitions)

identifying groups in the community and the area that don't have access to health services

working with traditional midwives to refer people to the clinic

keeping a register of disabled children or people needing periodic home visits

making home visits to the sick and providing health information, food and medicine during home visits

embarking on income generating projects to provide home based care for HIV-affected families

having regular meetings with the community to identify health needs

giving regular feedback to community members and being accountable to the community

Providing support to the clinic/health centre

bringing community views to health workers
being actively involved in the planning and
implementation of health campaigns (in
collaboration with the clinic)

bringing community views to health workers
negotiating for additional health care
workers/nursing staff at the clinic

helping to improve supplies of essential
medicines for clinics/community health
centres

raising funds to contribute towards purchases
of medicines for the clinic

notifying the clinic of outbreaks of disease in
the community

being actively involved in the planning and
implementation of health campaigns (in
collaboration with the clinic)

assisting with monitoring that TB patients are
taking their medicines

provide community-based data for the
attention of health workers

volunteering their services in the facility

organising broader community groups to
undertake work activities at their clinics or
health centres

assisting the department in ensuring security
and safety of clinic premises and staff

Health promotion in the community

providing health information to communities (healthy nutrition, the importance of hygiene)

using effective methods to spread health messages at their clinics (community drama providing information on HIV&AIDS in their communities)

participation in health promotion activities in things such as promoting community hygiene, refuse disposal

promoting healthy living in their communities by encouraging positive changes to improve health (e.g. not drinking alcohol during pregnancy or giving up smoking)



How do I start a health committee?

If there is no health committee at your clinic or community health centre there are a variety of strategies you could use to try and get a health committee started. You could:

Contact the chairperson of the metro health care forum to find out what you need to do

Attend a sub-district health forum meeting to enquire about what the procedure is for starting a new health committee in that area

Contact the manager of the clinic, the sister in charge or the ward councillor about starting a health committee

Advertise locally to call a community meeting to choose members for the health committee (e.g. through pamphlets in the clinic, community radio or community newspapers)



Levels of participation

Manipulation

People do what those in authority suggest they do. Communities participate to support officials to get what they want.

Therapy

Those in power work individually with community members to help them cope and adjust to societal problems like high levels of crime.

Informing

Officials give community members information, but if there is no opportunity given to communities to respond to the information this is not real participation.

Consultation

People are asked to say what they think or identify their needs, but there is no guarantee that any action will be taken based on their needs.

Placation

Community members can influence decisions to some degree by advising or participating in planning, but officials still have the final say about decisions made.

Partnership

Community members have the power to really negotiate with officials and there would have to be agreement from both officials and community members on the decisions that are made.

Delegated power

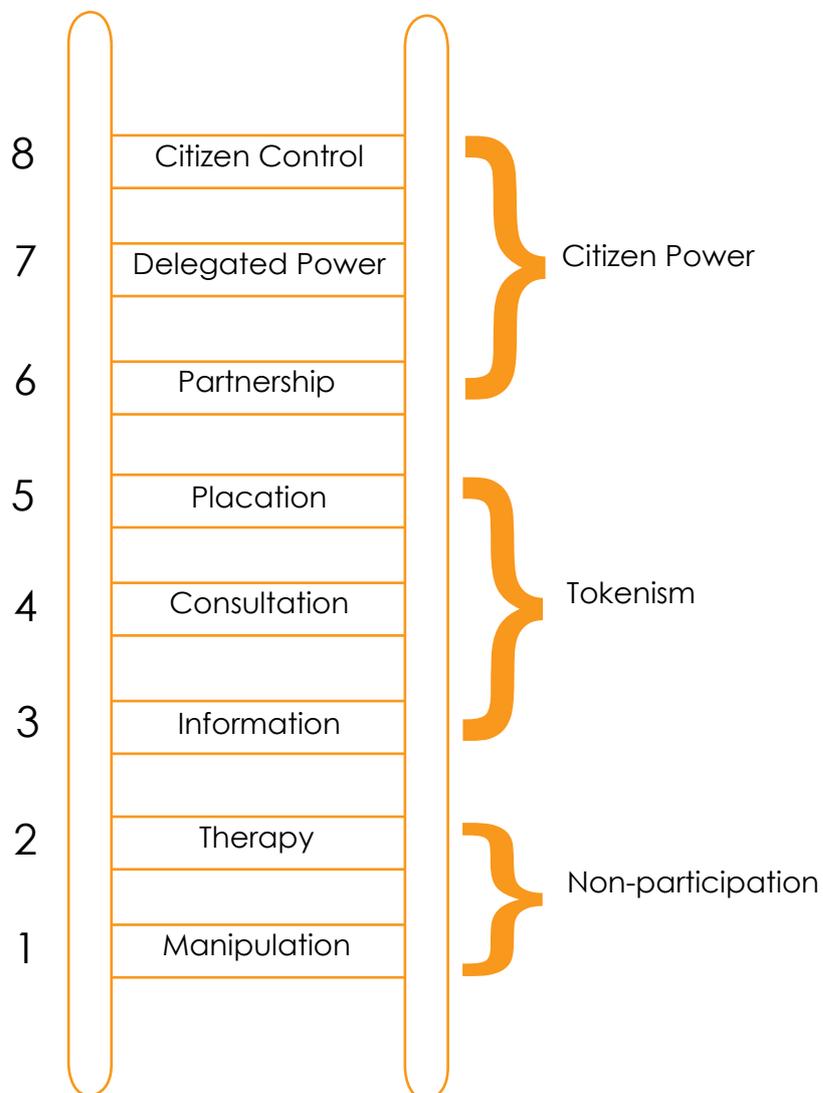
Community members have complete control over certain agreed on decisions, within certain limits. The community makes the decisions and comes up with a plan and officials need to negotiate with communities in order to change the decision or plan.

Citizen control

The community identifies the problem, makes all decisions independently and runs the project. Officials may be called on to provide help or input if it is needed.



Ladder of Participation (Arnstein, 1969)



Conclusion

This toolkit has given you an overview of the right to health: how to claim these rights; identify violations; deal with those violations; and also participate effectively in the realisation of the right to health. It has provided you with some tools to better understand and work with human rights concepts, specifically the right to health.

As a result we hope that you will be:

- Better informed about what the right to health is
- Empowered to claim your rights
- Able to hold government and other parties accountable for violations
- Able to assist in getting satisfactory answers and responses for victims of violations
- Able to effectively participate in planning, policy making and evaluating the implementation of issues related to health

The toolkit has also provided you with materials you can use to empower others in your organisation or community to build their understanding of the right to health - so that they too can take action.

It's important to remember that the ideas and strategies on realising the right to health in this toolkit could be applied to other rights issues, such as education, food security, housing or social assistance.

Now it's time for you, your organisation or your community to take action in starting to claim rights and protesting violations. It's up to you to make certain that violations of health rights are responded to effectively, and that people are able to see rights as something that are real and not just promises on a piece of paper.

So, stand up, speak out, do something!



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