ALL HUMAN RIGHTS FOR ALL

HEALTH RIGHTS as HUMAN RIGHTS

- DRAFT -

Health Rights as Human Rights

A Resource Package for Health Workers, Policy Analysts and Planners

Prepared for NPPHCN

by Advocacy Initiatives
4th Floor, GlenRand Building
24 Fredman Drive
Sandton 2199
Tel: 011-884 2647 or 082-800 3322
Fax: 011-884 0421
Email: judi@iafrica.com

October 1998

Health Rights as Human Rights
A Resource Package for Health Workers, Policy Analysts and Planners

Contents

Chapter			Page no
1.	**Introduction**		**5**
2.	**Defining Human Rights**		**7**
3.	**A Brief History of Human Rights**		**9**
	3.1	Generations of Rights	9
	3.2	Universal Declaration of Human Rights	10
	3.3	Two International Covenants	11
	3.4	South Africa's History of Human Rights	12
	3.5	Human Rights Today	12
4.	**International Instruments to Protect Human Rights**		**13**
	4.1	Charter of the United Nations (UN)	13
	4.2	International Bill of Rights:	14
	4.2.1	Universal Declaration of Human Rights	15
	4.2.2	International Covenant of Economic, Social & Cultural Rights	18
	4.2.3	International Covenant of Civil & Political Rights	19
	4.3	International Convention on the Elimination of All Forms of Racial Discrimination	21
	4.4	Convention on the Elimination of All Forms of Discrimination Against Women	21
	4.5	Convention on the Rights of the Child	22
	4.6.1	European Convention for the Protection of Human Rights & Fundamental Freedoms	23
	4.6.2	European Social Charter	23
	4.7.1	American Declaration on the Rights & Duties of Man	24
	4.7.2	American Convention on Human Rights	25
	4.8	African Charter on Human and People's Rights	26
5.	**Focus on Health Rights**		**29**
	5.1	Socio-Economic Rights	29
	5.2	Violations by Health Professionals	31
	5.2.1	Nazi Medical Atrocities	31
	5.2.2	American Medical Abuses	32
	5.2.3	Apartheid Medicine	32
	5.3	Health Areas Vulnerable to Violations	33
	5.3.1	Public Health Policies	33
	5.3.2	HIV & AIDS	35
	5.3.4	Reproductive & Sexual Health	41

5.3.5	Discrimination against People with Disabilities	43
5.3.6	Consumerism	44
5.4	Medical Ethics	45
5.5	Health Professional Heroism	46
5.6	Therapy for Survivors	47
5.7	Instruments to Protect Health Rights	48
5.7.1	Hippocratic Oath	48
5.7.2	World Medical Association Declarations:	48
	Declaration of Geneva	49
	International Code of Medical Ethics	49
	Declaration of Tokyo	49
5.7.3	International Council of Nurses Statements:	50
	On Nurses' Role in Safeguarding Human Rights	50
	Position Statement on Nurses & Torture	50
5.7.4	UN Principles on Medical Ethics:	50
	Role of Health Personnel in the Protection of Prisoners Against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment	51
	For Protection of Persons with Mental Illness	51
5.7.5	Amnesty International Declaration on the Participation of Health Personnel in the Death Penalty	51
5.7.6	Declaration of Alma Ata	52
5.8	Health Charters	52
5.9	Patients' Charter, UK	53
5.10	Patients' Charter, Zimbabwe	56
5.11	Patients' Bill of Rights, a Hospital in Arizona, USA	58
6.	**Health Rights in South Africa**	**61**
6.1	The Struggle for Rights	61
6.2	The Constitution of the Republic of South Africa, 1996	62
6.3	The Reconstruction & Development Programme	64
6.4	National Action Plan	65
6.5	National Health Bill	65
6.6	Batho Pele	66
6.7	National Patients' Charter	67
6.8	Other Instruments to Protect Health Rights	68
6.8.1	South African Medical Association's (SAMA) Credo	68
6.8.2	SASA's Code of Conduct	69
6.8.3	SAMDC's Ethical Rules	70
6.9	NPPHCN Advocacy of Health Rights	71
6.10	NPPHCN Health Rights are Human Rights Campaign	71
6.10.1	Applying the National Patients' Charter to Local Health Facilities	75
6.10.2	Practical Steps in Producing a Local Patients' Charter	75
6.11	Enforcing Compliance of Health Rights	80
	Legal Action	81
	Institutions to Monitor and Enforce	81
6.12	When Things Go Wrong...	82
	Basic Complaints Procedure	82
	Mechanisms to Enforce the National Patients' Charter	84

Health Rights as Human Rights

A Resource Package for Health Workers, Policy Analysts and Planners

Chapter 1 Introduction

"The doctor said I was wasting his time..."

On 3 February 1995, Mavis Lehola of Extension 13 in Lenasia gave birth to twins, Thabo and Thabang. A month later she noticed that they both had breathing problems. Despite trips to four different state hospitals and two private ones, both babies died before they were five months old. *The Star* reported Mavis' case (17/3/97), because she was still, two years later, searching for answers.

"I have the right to know what was wrong. They were supposed to tell me if there was nothing they could do and the baby was going to die."

"Modern health professionals working for the State have a dual responsibility: to promote and to protect health, while also promoting and protecting human rights." (Mann, J. Health & Human Rights: Broadening the Agenda for Health Professionals. Health & Human Rights 2: 1: 3)

Health policies, programmes and practices impact on human rights. Yet, few health workers receive any formal training in human rights. So it is hardly surprising that they sometimes, inadvertently, violate patients' rights.

In 1995, the National Progressive Primary Health Care Network (NPPHCN) launched its 'Health Rights are Human Rights' campaign. Since then, thousands of stories about gross abuses at health facilities have flooded in from distressed members of the public. The response to the campaign highlighted the need to improve the interface between health service users - or consumers - and health providers.

Quotes from qualitative research, into people's experiences and ideas about health rights, which was commissioned as part of the NPPHCN's campaign are interspersed throughout this manual as vignettes. The words of the interviewees are sobering reminders of the urgent need to protect human rights in the National Health System.

There is a growing international acceptance that health charters, documents that make health rights explicit, are a good means of improving a nation's health services. In 1997, after much consultation and research, the NPPHCN drafted a Health Rights Charter to help clarify what people's health rights are, and also what responsibilities go hand in hand with these rights. Over-stretched health workers' rights are an important element in this equation.

Much work has since been done by the NPPHCN to raise awareness of health rights and responsibilities and the Health Charter. Much of the latter forms the basis for the Government's National Patients' Charter, which is expected to be launched during 1999.

This Training Manual is aimed at NPPHCN provincial managers and anyone else working in the field of health rights. It offers background information on human rights in general, and health rights in particular. It has been written to provide a context for health rights promotional activities and for future advocacy of the National Patients' Charter (TO ADD: footnote: The National Department of Health launched the Draft on xxxxx).

This Manual aims to save health workers' time and energy by pulling together existing information about human rights. It explores definitions and the history of human rights, reproduces extracts from international and national conventions, examines health professionals' complicity in, or resistance to, human right abuses, analyses areas of health that are particularly vulnerable to violations, such as people with HIV or AIDS and finally, looks at encouraging developments in South Africa such as the National Patients' Charter mentioned above.

This manual aims to illustrate how the care and respect that an individual patient receives slots into the much wider picture of human rights promotion and protection.

Chapter 2 Defining Human Rights

Human rights are a system of laws, codified in the declarations, covenants and conventions which together make up the International Bill of Rights, which are morally binding to all States even if they have not formally ratified them.

Human rights are not just the preserve of lawyers. They are everybody's concern. Human rights are the rights of individuals within society. They define and limit state power.

Human rights reflect individual or group demands for the sharing of power, wealth, enlightenment and other cherished values. Values are people's notions of what is good and worth striving for. Respect for human rights is a prerequisite for individuals' happiness and also for societal ends such as peace and justice.

Human Dignity

Human rights are based on a key principle - human dignity; that is, the idea that there is an innate worth in being human. "Human rights represent one type of conception of human dignity based on equal and inalienable rights held by all individuals against society and the state...(it's) a moral ideal coupled with a social practice to realise that ideal." (Donnelly, J. International Human Rights and Health Care Reform).

"They (human rights) are expressive of both the "is" and the "ought" in human affairs." (Weston, B. 1992. International Human Rights: Overview. Human Rights in the World Community, University of Pennsylvania Press, Philadelphia. pg17) In other words, they represent both the moral and the legal in human affairs.

Inalienable and Universal Rights

All human beings are born with human rights. The Reverend Dr Barney Pityana, Chair of the South African Human Rights Commission has advised, "those who are calling for the iron fist against perceived criminals and suspects should remember that human rights are a birthright. We do not earn them nor do we deserve them. We have them because we are." Human rights are equally possessed by

everyone, everywhere, without discrimination and irrelevant to merit. Another key principle of human rights is this notion of universality.

Rights can only be restricted by law - after due process. They are sometimes, however, limited by the necessity to secure the rights of other people and to protect the common good. Another key principle is that every right brings with it the duty to respect the same right for others.

Indivisible Rights

A narrow definition of human rights might limit their scope to state violations of civil and political liberties. However, there is an important "second generation" of socio-economic human rights - such as the rights to food, shelter, health care, education, employment etc - which are equally important. Socio-economic rights are most important to disadvantaged groups because they aim to address social and economic injustices. This manual will concentrate on this area of human rights as it directly effects health care services.

Human rights are a secular code of ethics for the whole world. "The concept of Human Rights is one of the few moral visions ascribed to internationally. Although its scope is not universally agreed upon, it strikes deep chords of response among many..." (Bunch, B. 1990. Women's Rights as Human Rights: Toward a Re-Vision of Human Rights. Human Rights Quarterly 12: 486).

There is widespread acceptance of the principle of human rights but controversy remains over their nature or scope. Should they be irrevocable or partially revocable, broad or limited? (Weston, B. 1992. International Human Rights: Overview. Human Rights in the World Community, University of Pennsylvania Press, Philadelphia. pg17) Prioritising rights comes down to context.

Enforcement of Rights

For human rights to have meaning they must be enforceable. They must be written into a nation's constitution or laws. In addition, there must be other safeguards; such as South Africa's Constitutional Court, Human Rights Commission, Commission on Gender Equality, Land Claims Commission and Court and the Office of the Public Protector.

Chapter 3 A Brief History of Human Rights

In most parts of the world, respect for human rights has progressed since World War II. This is thanks to the efforts both of lawmakers, and of ordinary people.

3.1 Generations of Rights

Different eras and cultures emphasised different types of rights. It is useful to look at how concepts of human rights have evolved over time.

18th Century

According to one historian, (Reardon, B A. 1995. Introduction : Purposes and Approaches. Educating for Human Dignity: Learning about Rights & Responsibilities University of Pennsylvania pg 8-9) the first generation of rights dates from the end of eighteenth century. The idea of political and civil rights underpinned the American and French revolutions. In their struggles against feudalism and colonialism, the revolutionaries sought restraints on the power of the state over citizens and aimed to establish individual freedoms and the rights of due process.

19th Century

The second generation of rights, dating from the nineteenth century, arose from concern over economic and social hardship. They were generated by international socialist and workers' movements and placed new obligations on States towards their citizens. They aimed to assure economic and social well-being of individuals and groups.

20th Century

The third generation of rights, dating from the mid-twentieth century, could be termed "collective" or "solidarity" rights. They were sought by groups with a common identity or experience in struggles, such as those fighting to end colonialism, racism, sexism and child abuse. They demanded the rights to self-determination, to peace and to a clean environment.

Recent Decades

Finally, the fourth generation of rights, dating from recent decades, involve declared rights on behalf of all humanity. This generation stemmed from the notion of "crimes against humanity". International standards were established condemning atrocities such as genocide and apartheid.

World War II and Beyond

The Allies named the protection of human rights as one of their war aims. When the war was over, Nazi leaders were tried at Nuremberg for crimes against humanity. Partly in response to the horrifying evidence presented at these trials, the United Nations (UN) was founded in 1945. Its principal purpose was to promote respect for human rights through the United Nations Charter.

Since then, numerous declarations and conventions have been passed by the UN and other bodies to promote and protect different areas of human rights.

3.2 The Universal Declaration of Human Rights

The Universal Declaration of Human Rights (1948) was passed by the UN's General Assembly without a single dissenting voice. It was a remarkable achievement for the gathering of representatives from numerous and very diverse cultures to sign a common standard; and accept a broad definition of human rights.

It is not legally binding but has a very real moral and political authority. The UN can investigate, advise, and, in some cases, act on specific human rights situations. For instance, in October 1992, the UN created a Commission of Experts to investigate war crimes in the former Yugoslavia and an International Tribunal was created to prosecute them six months later. A second Tribunal was formed to prosecute war crimes and acts of genocide in Rwanda, between April-July 1994.

3.3 Two International Covenants

In the 1970's, the UN passed two international covenants, which together with the Universal Declaration of Human Rights make up the International Bill of Rights.

The International Covenant on Civil and Political Rights (1976) outlined the limits on a State's encroachment into the sphere of individual freedoms. These are sometimes called "negative" rights as they deal with coercive actions that States cannot take against their members, such as execution, torture and censure.

In the same year, the International Covenant on Economic, Social and Cultural Rights was ratified by approximately the same number of States. It dealt with the more ambiguous, but equally important area of socio-economic, or "positive", rights. These define the State's obligation to create conditions to help ensure human well-being. Their implementation implies more than just refraining from wrongful, coercive actions. Proactive steps are required, "with a view to achieving progressively the full realisation of the rights..." (Article 2)

The implementation of socio-economic rights is harder for countries where resources are scarce. It may require the redistribution and spending of public funds on the State's part, for example, expensive facilities such as hospitals and clinics, to provide health care for those who cannot afford it on their own.

The two covenants stress equality of all human rights. The many rights they describe are interlinked. "The web of rights is unbroken in fabric, simultaneous in operation and all-extensive in character." (Sachs, A. 1990. Protecting Human Rights in the New South Africa pg8). If no health services are made available by the State, then the right to make decisions (such as to terminate a pregnancy) is irrelevant.

President Mandela signed both Covenants in 1994. They have not yet been ratified. Therefore they hold no legal force; only the commitment implicit by his signing.

3.4 South Africa's History of Human Rights (Abuses)

Traumatic pieces of South Africa's pre-1994 history have been exposed at the Truth and Reconciliation Commission (TRC) hearings between 1996-98. The catalogue of appalling human rights abuses has included some perpetrated by members of the medical and scientific professions. "The Truth and Reconciliation Commission has started the ball rolling towards the development of a human rights culture in the medical profession." (*The Star*, 26/11/96)

Referring to a steering committee with representatives from various health sectors, whose dual tasks it was to collect health care-related submissions for the TRC and to initiate a long term process to encourage groups, organisations and Government to start research and transformation in the health field, TRC Commissioner Dr Wendy Orr said, "Things are so bad (in the health sector) at the moment...any (organised) body will be an improvement." This committee's function goes beyond the TRC's mandate and deadline for closure. It aims to continue monitoring the actions of health professionals and disciplining transgressors.

Publicly testifying to violations (whether at the TRC, in a court room or through the pages of a newspaper) validates the reality of the abuse for the person who has been through it. The experience of standing up and telling the terrible truth to an international or national tribunal can be therapeutic. They are, at last, being heard, and believed. It also compels the rest of us to act to try to prevent a repetition of such shameful chapters.

3.5 Human Rights Today

1998 is International Human Rights Year. What is remarkable is that the Universal Declaration of Human Rights, although celebrating its fiftieth anniversary this year, represents a contemporary expression of the human rights idea and the most comprehensive, conceptual statement of rights. It still symbolises a world vision.

Many other declarations and charters have been passed by the UN and other organisations since 1945 on specific areas of rights.

Chapter 4 International Instruments to Protect Human Rights

"The idea of human rights has wings. It has found its way around the globe." (Action-Professionals' Association for the People, an Ethiopian human rights NGO, founded 1993, Guide to Human Rights Education)

Extracts from important treaties have been reproduced to demonstrate how the global culture of human rights has evolved. There are subtle variations in content and scope relating to the provision of socio-economic rights, and more especially the provision of rights to health care.

4.1

Charter of the United Nations (1945)

Preamble

We the Peoples of the United Nations

Determined
To save succeeding generations from the scourge of war, which twice in our lifetime has brought untold sorrow to mankind, and
To reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small, and
To establish conditions under which justice and respect for the obligations arising from treaties and other sources of international law can be maintained, and
To promote social progress and better standards of life in larger freedom,

And for these ends
To practise tolerance and live together in peace with one another as good neighbours, and
To unite our strength to maintain international peace and security, and
To ensure, by the acceptance of principles and the institution of methods, that armed force shall not be used, save in the common interest, and
To employ international machinery for the promotion of the economic and social advancement of all peoples,

Have resolved to combine our efforts to accomplish these aims
Accordingly, our respective Governments...have agreed to the present Charter of The United Nations and do hereby establish an international organisation to be known as the United Nations.

Chapter 1 Purposes and Principles

Article 1

The purposes of the United Nations are:

1. To maintain international peace and security...
2. To develop friendly relations among nations, based on respect for the principle of equal rights and self-determination of peoples...
3. To achieve international co-operation in solving international problems of an economic, social, cultural, or humanitarian character, and in promoting and encouraging respect for human rights, and for fundamental freedoms for all, without distinction as to race, sex, language, or religion; and
4. To be a centre for harmonising the actions of nations in the attainment of these common ends.

Chapter 9 International Economic and Social Co-operation

Article 55

With a view to the creation of conditions of stability and well being which are necessary for peaceful and friendly relations among nations based on respect for the principle of equal rights and self-determination of peoples, the United Nations shall promote:

a. Higher standards of living, full employment, and conditions of economic and social progress and development,
b. Solutions of international economic, social, health, and related problems; and international cultural and educational co-operation, and
c. Universal respect for, and observance of, human rights and fundamental freedoms for all, without distinction as to race, sex, language or religion.

The International Bill of Rights

The International Bill of Rights is comprised of the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights. They are all touchstones for interpreting the human rights provisions of the United Nations' Charter above. The two covenants provided legal substance for the Universal Declaration of Human Rights.

4.2.1

Universal Declaration of Human Rights (1948)

Preamble

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in co-operation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realisation of this pledge,

Now, therefore,

The General Assembly

Proclaims this Universal Declaration of Human Rights as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

Article I
All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2
Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status...

Article 3
Everyone has the right to life, liberty and security of person.

Article 5
No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment...

Article 7
All are equal before the law and are entitled without any discrimination to equal protection of the law...

Article 12
No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation...

Article 13
1. Everyone has the right to freedom of movement and residence within the borders of each State.
2. Everyone has the right to leave any country, including his own, and to return to his country.

Article 18
Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

Article 19
Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 21
1. Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.
2. Everyone has the right to equal access to public service in his country.
3. The will of the people shall be the basis of the authority of government; this shall be expressed in periodic and genuine elections, which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

Article 22

Everyone, as a member of society, has the right to social security and is entitled to realisation, through national effort and international co-operation and in accordance with the organisation and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 23

1. Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment...

Article 25

1. 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.
2. Motherhood and childhood are entitled to special care and assistance...

Article 26

1. Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory...
2. Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups...

Article 29

1. Everyone has duties to the community in which alone the free and full development of his personality is possible.
2. In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

4.2.2.

International Covenant on Economic, Social and Cultural Rights (1976)

Preamble

The States Parties to the present Covenant,

Considering that, in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Recognising that these rights derive from the inherent dignity of the human person,

Recognising that, in accordance with the Universal Declaration of Human Rights, the ideal of free human beings enjoying freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his economic, social and cultural rights, as well as his civil and political rights,

Considering the obligation of States under the Charter of the United Nations to promote universal respect for, and observance of, human rights and freedoms,

Realising that the individual, having duties to other individuals and to the community to which he belongs, is under a responsibility to strive for the promotion and observance of the rights recognised in the present Covenant, including particularly the adoption of legislative measures...

Agree upon the following articles:

Article 1

1. All peoples have the right of self-determination by virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development...

Article 2

1. Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realisation of the rights recognised in the present Covenant by all appropriate means...

Article 9

The States Parties to the present Covenant recognise the right of everyone to social security, including social insurance.

Article 10

The States Parties to the present Covenant recognise that:

1. The widest possible protection and assistance should be accorded to the family...
2. Special protection should be accorded to mothers during a reasonable period before and after childbirth...
3. Special measures of protection and assistance should be taken on behalf of all children and young persons...

Article 11

1. The States Parties to the present Covenant recognise the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions the States Parties will take appropriate steps to ensure the realisation of this right...

Article 12

1. The States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realisation of this right shall include those necessary for:
   a. The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child.
   b. The improvement of all aspects of environmental and industrial hygiene.
   c. The prevention, treatment and control of epidemic, endemic, occupational and other diseases.
   d. The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

4.2.3.

International Covenant on Civil and Political Rights (1976)

The Preamble and first Article are identical to that of the International Covenant on Economic, Social and Cultural Rights.

Article 2

1. Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognised in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status...

Article 6

1. Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.
2. In countries which have not abolished the death penalty, sentence of death may be imposed only for the most serious crimes in accordance with the law in force at the time of the commission of the crime and not contrary to the provisions of the present Covenant and to the Convention on the Prevention and Punishment of the Crime of Genocide. This penalty can only be rendered by a competent court.

Article 7

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

Article 9

1. Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law...

Article 10

1. All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person...

Article 12

1. Everyone lawfully within the territory of a State shall, within that territory, have the right to liberty of movement and freedom to choose his residence.

Article 14

1. All persons shall be equal before the courts and tribunals. In determination of any criminal charge against him, or of his rights and obligations in a suit at law, everyone shall be entitled to a fair and public hearing by a competent, independent and impartial tribunal established by law...

Article 17

1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.

Article 18

1. Everyone shall have the right to freedom of thought, conscience and religion...

Article 19

1. Everyone shall have the right to hold opinions without interference.
2. Everyone shall have the right to freedom of expression...

4.3

International Convention on the Elimination of all Forms of Racial Discrimination (1969)

Article 2

1. States Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races...

Article 5

In compliance with the fundamental obligations laid down in article 2...equality before the law, notably in the enjoyment of the following rights:...

(e) Economic, social and cultural rights, in particular:...

(iv) The right to public health, medical care, social security and social services...

4.4

Convention on the Elimination of all Forms of Discrimination against Women (1981)

Article 10

States Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure to them equal rights with men in the field of education...

(h) Access to specific educational information to help to ensure the health and well being of families, including information and advice on family planning.

Article 11

1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of employment...

(f) The right to protection of health and to safety in working conditions, including the safeguarding of the function of reproduction.

Article 12

1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.
2. Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.

Article 14

1. States Parties shall take all appropriate measures to eliminate discrimination against women in rural areas...
   b. To have access to adequate health care facilities, including information, counselling and services in family planning.

Article 16

1. States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations...
   (e) The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.

4.5

The Convention on the Rights of the Child (1990)

Article 24

1. States Parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right to access to such health care services.
2. States Parties shall pursue full implementation of this right and in particular shall take appropriate measures:
   a. To diminish infant and child mortality
   b. To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care
   c. To combat disease and malnutrition including within the framework of primary health care, through *inter alia* the application of readily available technology and through the provision of adequate nutritious foods and clean drinking water, taking into consideration the dangers and risks of environmental pollution
   d. To ensure appropriate pre- and post-natal health care for expectant mothers
   e. To ensure that all segments of society, in particular parents and children are informed in the use of basic knowledge of child health and nutrition, the advantages of breast-feeding, hygiene and environmental sanitation and the prevention of accidents
   f. To develop preventive health care guidance for parents, and family planning, education and services
3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.
4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realisation of the rights recognised in this article. In this regard, particular account shall be taken of the needs of developing countries.

4.6.1

European Convention for the Protection of Human Rights and Fundamental Freedoms (1953)

Passed by the Council of Europe, this convention dealt exclusively with civil and political rights, making no mention of the right to health. Nor did it outline citizens' duties. It created the European Commission of Human Rights and the European Court of Human Rights.

4.6.2

European Social Charter (1965)

This was signed by the Council of Europe in 1961 and came into force in 1965.

Part 1

The Contracting Parties accept the aim of this policy, to be pursued by all appropriate means, both national and international in character, the attainment of conditions in which the following rights and principles may be effectively realised:...

11. Everyone has the right to benefit from all measures enabling him to enjoy the highest possible standard of health attainable...
13. Anyone without adequate resources has the right to social and medical assistance.

Part 2

Article 11 The Right to Protection of Health
With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed *inter alia:*

1. To remove as far as possible the causes of ill-health.
2. To provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health.
3. To prevent as far as possible epidemic, endemic and other diseases.

Article 13 The Right to Social and Medical Assistance
With a view to ensuring the effective exercise of the right to social and medical assistance, the Contacting Parties undertake:

1. To ensure that any person who is without adequate resources and who is unable to secure such resources by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance and, in case of sickness, the care necessitated by his condition...
2. to ensure that persons receiving such assistance shall not, for that reason, suffer from a diminution of their political or social rights.
3. to provide that everyone may receive by appropriate public or private services such advice and personal help as may be required to prevent, to remove, or to alleviate personal or family want...

4.7.1

American Declaration of the Rights and Duties of Man (1948)

The Pan-American Union adopted this Declaration at the Ninth International Conference of American States in 1948. The Inter-American Commission on Human Rights was created in 1959.

Preamble

All men are born free and equal, in dignity and in rights, and being endowed by nature with reason and conscience, they should conduct themselves as brothers one to another.

The fulfilment of duty by each individual is a prerequisite to the rights of all. Rights and duties are interrelated in every social and political activity of man. While rights exalt individual liberty, duties express the dignity of that liberty...

Chapter 1

Article 7
All women, during pregnancy and the nursing period, and all children have the right to special protection, care and aid.

Article 11
Every person has the right to the preservation of his health through sanitary and social measures relating to food, clothing, housing and medical care, to the extent permitted by public and community resources.

Chapter 2

Article 35
It is the duty of every person to co-operate with the state and the community with respect to social security and welfare, in accordance with his ability and with existing circumstances.

Article 36
It is the duty of every person to pay the taxes established by law for the support of public services.

4.7.2

American Convention on Human Rights (1978)

The American Convention on Human Rights was signed by the Organisation of American States in 1969 and entered into force in 1978. It makes no mention of health care. It established the Inter-American Court of Human Rights.

Chapter 3 Economic, Social and Cultural Rights

Article 26
The States Parties undertake to adopt measures, both internally and through international co-operation, especially those of an economic and technical nature, with a view to achieving progressively, by legislation or other appropriate means, the full realisation of the rights implicit in the economic, social, educational, scientific and cultural standards set forth in the Charter of the Organisation of American States...

Chapter 5 Personal Responsibilities

Article 32
1. Every person has responsibilities to his family, his community and mankind.
2. The rights of each person are limited by the rights of others, by the security of all and by the just demands of the general welfare, in a democratic society.

4.8

The African (Banjul) Charter on Human and People's Rights (1986)

This Charter was adopted by the Eighteenth Assembly of Heads of State and Government of the Organisation of African Unity (OAU) in 1981, and ratified in 1986 by a majority of the 50 OAU States. It established an African Commission on Human and People's Rights to which anyone can file a complaint. However it did not establish a Human Rights Court because its emphasis was on mediation, counsel and consensus rather than the more adversarial procedures of Western legal systems.

Chapter 1 Human and People's Rights

Article 4
Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right.

Article 5
Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of this legal status...

Article 7
1. Every individual shall have the right to have his cause heard...

Article 9
1. Every individual shall have the right to receive information.
2. Every individual shall have the right to express and disseminate his opinions within the law.

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.

Article 18
1. The family shall be the natural unit and basis of society. It shall be protected by the State, which shall take care of its physical and moral health...
2. The aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs.

Chapter 2 Duties

Article 27

1. Every individual shall have duties toward his family and society, the State and other legally recognised communities and the international community.
3. The rights and freedoms of each individual shall be exercised with due regard to the rights of others, collective security, morality and common interest.

Article 28

Every individual shall have the duty to respect and consider his fellow being without discrimination, and to maintain relations aimed at promoting, safeguarding and reinforcing mutual respect and tolerance.

Summary

These conventions, and the organisations that formulated them, are the instruments of human rights. They have aided a global shift towards the acceptance of a broad definition of human rights. This is also due to the work of the International Labour Organisation and NGO's like Amnesty International, human rights education in schools, and some countries' foreign policies being motivated by human rights considerations.

These instruments have instilled expectations about proper human rights behaviour. (The full documents can be found in Twenty-five Human Rights Documents 1994. Center for the Study of Human Rights, Columbia University, New York) Europe, the Americas and Africa have all created supervisory bodies to enforce the provisions of their regional charters. The Middle East has not followed suit.

The United Nations' General Assembly holds primary responsibility for promoting human rights internationally. It has many sub-committees such as the Committee on the Elimination of Discrimination against Women or the Economics and Social Council, which submit reports with recommendations on the progress of rights implementation by the signing nations.

The Economics and Social Council has created a Commission on Human Rights with a Sub-Commission on Prevention of Discrimination and Protection of Minorities which makes recommendations and dispatches

special representatives and envoys, on an ad hoc basis, to act as additional means of enforcement.

Establishing common ground on human rights is an amazing feat, given the spectrum from individualism to collectivism of nations' political ideologies. This consensus highlights the moral power of the idea of inalienable rights.

Chapter 5 Focus on Health Rights

"You will organise the transport you've got the pains...say no it's too far go back again. When you come again, you got a lot of pains. You must get more money that you pay for transport you go back again." (Female, urban interviewee from Rights & Realities: Pre-campaign Report NPPHCN Media & Training Centre. 1996)

5.1 Social and Economic Rights

"Moving beyond the boundaries defined in (evolving) formal law, we use the principles of human rights as the lens through which to analyse...conceptions of health...we use standards of human rights to examine the actions of a wide range of actors, from families and community institutions to health care providers..." (Freedman, L. 1995. Censorship & Manipulation of Reproductive Health Information. The Right to Know: Human Rights and Access to Reproductive Health Information, University of Pennsylvania Press, Philadelphia pg4)

A state which decides not to recognise a right to health care violates no international legal obligation. However, the International Covenant on Economic, Social and Cultural Rights, the International Convention on the Elimination of all Forms of Racial Discrimination, the Convention on the Elimination of all Forms of Discrimination against Women and the Convention on the Rights of the Child all explicitly guarantee a right to health. By doing so, they are making it an international human rights standard. This chapter will examine what a right to health means, the various instruments that have been created to uphold it and how it may be better implemented in practice.

Is the right to health care a basic human right? Many other rights are dependent on it. "Good health is the precondition to individuals' excise of rights to equal participation in communal and social life. At the same time, an individual's capacity for participation in activities of their choice enhances their health status." (Cook, R. Gender, Health & Human Rights. Health & Human Rights 1: 4: 361) Protecting human dignity should be at the heart of good health care.

As with other economic, social or cultural rights, there is debate as to whether health can be claimed as a universal human right or whether it is simply a social ideal. Jack Donnelly argues that denial of access to

certain kinds of health care can result in death, therefore, the right to health protection may be classified under "the right to life and security of the person". The latter civil right provides protection from state violence (a "negative" right) and also protection by police from 'private' violence (a "positive" right). To allow a person to die (when intervention is possible) is as negligent on the State's part as to allow a person to be harmed by other means. (Donnelly, J. International Human Rights and Health Care Reform)

The definition of human rights has evolved. Most people now consider health to fit under its broad, protective umbrella. "The concept of human rights, like all vibrant visions, is not static or the property of any one group; rather its meaning expands as people reconceive of their needs and hopes in relation to it." (Bunch, C. 1990. Women's Rights as Human Rights: Toward a Re-Vision of Human Rights. Human Rights Quarterly 12:486)

The right to health could never - sadly - guarantee perfect health for all. It implies more a right to health protection; the availability of health care facilities and healthy conditions to live and work in. "The human right of health does not imply a right to be healthy; rather it pertains to access to healthcare in case of need." (Amollo. 1997. Human Rights Implications of the HIV Pandemic in Africa pg2)

Human Development

"At the core of human dignity lies the ability to be an effective agent in guiding the course of one's own life." (Freedman, L. Reflections on Emerging Frameworks of Health and Human Rights, Health and Human Rights 1: 4: 324)

Human development is a process of enlarging people's choices. Without the three requirements for it (a long and healthy life, the acquisition of knowledge and skills and access to resources needed for a decent standard of living), other opportunities such as the chance to be creative and productive in cultural, social, political or leisure realms and to enjoy self-respect will remain out of reach. Health is a vital component in allowing people to be able to participate and contribute to their maximum potential and capacity within society.

Defining Health

How broadly should health be defined? What is the scope of health professionals' responsibility?

The World Health Organisation's Constitution (1946) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

By defining health narrowly, and concentrating only on physical symptoms, some health professionals have neglected the social conditions. "By medicalizing suffering, doctors unintentionally maintain dominance over patients, encourage conforming social behaviour and attitudes and marginalise patients' concerns and social problems...If human suffering is simply reduced to objective disease concerns, the opportunity for health professionals to recognise human worth and dignity may be eclipsed by emotional and moral dissociation. Such moral disengagement may be a critical factor in abusive behaviour." (Iacopino, V. 1995. Human Rights: Health Concerns for the Twenty-First Century. Medicine and Health Care into the Twenty-First Century, Philadelphia: Pennsylvania Academy of Science pg378)

5.2 Violations by Health Professionals

It is a terrible irony that abuses of patients' rights are sometimes committed by health professionals, whose responsibility it is to care and heal them.

Extreme violations of human rights have been perpetrated by health professionals in the past, and in some parts of the world continue today. Atrocities such as genocide and political torture are somehow *even* more abhorrent when carried out by people who have taken the Hippocratic Oath and aligned themselves with the 'caring' professions.

5.2.1 Nazi Medical Atrocities

During the Nuremberg Trials, physicians were tried for their complicity in human experimentation and racial medicine. Many more had been involved. The Tribunal revealed details of doctors' participation in torture, mass killings, euthanasia of the mentally ill and disabled, sterilizations and medicalized "racial cleansing" in Nazi concentration camps.

5.2.2 American Medical Abuses

The use of human beings as expendable subjects, in the name of scientific research, has gone on elsewhere too. During the Second World War, the US Armed Forces Chemical Defense Research Programme made 4,000 US servicemen participate in tests involving high concentrations of mustard gas and other dangerous chemicals. Some were told little about the nature of the research. Others were told lies. It took until the early '90's, for the Department of Veterans' Affairs to demand that the Institute of Medicine appoint an investigative committee to look at the dreadful effects on the men's health.

Between 1932 and 1972, the US Public Health Service, through its Tuskegee Syphilis Study, conducted research on a group of black men in Alabama, without their knowledge. The doctors studied syphilis, from inception to death, in their 400 research subjects. When Penicillin became available in the '40's, it was deliberately withheld from these patients. They were, unknowingly, being observed, and not treated, by their doctors.

5.2.3 Apartheid Medicine

An American medical delegation in consultation with many progressive groups, (TO ADD: footnote on NAMDA, NPPHCN) visited South Africa in 1989, to investigate the intersection of apartheid, health and human rights. Based on their observations of marked differences in health conditions for different racial groups, they recommended that the South African Government end apartheid and desegregate all health facilities immediately.

They reported that health care for blacks was grossly inferior and commented, "(It's a) system that attempts to subordinate their (health professionals') professional and ethical responsibilities to political decisions about appropriate health care for each legally defined "race" group." (Apartheid Medicine: Health and Human Rights in South Africa, 1990 from the American Association for Advancement of Science Mission of Inquiry to South Africa, April 1989). Funds for medical services were unequally appropriated, with overcrowding in black hospitals and under-utilisation of white ones. 50% of all health expenditure served just 18% of the population. They also recorded extreme violations of

human rights in prisons; torture, detentions without due process and a lack of health care.

In the Biko case (1977), three South African doctors examined him during his terminal illness and recorded a diagnosis of malingering, despite clear evidence of extensive brain injury from beatings during his detention.

5.3 Health Areas Vulnerable to Violations

There have been far fewer extreme human rights abuses since the '94 election of a Government committed to human rights.

However there are controversial areas of health care, where rights remain vulnerable to violation.

These include:

- treatment of people with HIV/AIDS
- health rights of prisoners and psychiatric patients
- allocation of health care resources
- levels of emergency care
- health care in rural areas
- mother and child services
- reproductive health care and abortion legislation
- environmental issues around housing, water and sanitation provision
- health care for the disabled, elderly and terminally ill
- genetically inherited disorders
- formulation of public health policies and numerous others.

5.3.1 Public Health Policies

Finding the balance between collective public health and individual rights is at the crux of making public health policies. "All governmental policies in general and health policies in particular, have the potential to burden human rights to a greater or lesser degree, whether by restricting freedoms, discriminating against individuals or population groups...Few public health officials are familiar with human rights doctrines...and the human rights community has rarely written or litigated in the area of public health." (Gostin, L and Mann, J. Towards the Development of a Human Rights Impact Assessment for the Formulation and Evaluation of Public Health Policies. Health & Human Rights 1: 1: 59-78)

Gostin and Mann have developed a Human Rights Impact Assessment; a step-by-step method for formulating public health policies without violating human rights.

Step1: Clarify the public health objective.

Step2: Evaluate the likely effectiveness of the policy.

Step 3: Consider whether the policy is well targeted.
Over or under inclusion can reflect discrimination if a group is to be targeted for coercive public health measures and they are chosen for reasons not directly related to public health.
eg Quarantining someone based on assumptions about the high risk of their group transmitting diseases.

Step 4: Examine each policy for possible human rights burdens.
The potential benefits to community health have to be balanced with repercussions to human rights. Some human rights are absolute regardless of the public health crisis (eg the right to life). Others are not (eg All societies tolerate some restriction on the rights to privacy and liberty).

Step 5: Consider whether the policy is the least restrictive alternative that can achieve the public health objective.
An overly coercive policy may backfire and discourage infected people from seeking a test or treatment.

Step 6: If a coercive public health measure is truly the most effective, and least restrictive, alternative, use the "significant risk" standard which must be determined case-by-case and not by generalities.
eg Excluding children who are HIV-positive from school based on the minuscule risk of transmission during sports activities would not meet this criteria. The only "significant risk" for AIDS involve unprotected sex and shared needles.

Step 7: If a coercive measure is truly necessary to avert a "significant risk", guarantee fair procedures to all affected people.
eg "Due process" prior to committing someone with severe mental illness to an institution.

Drafting new public health policies is a mine field. Sometimes they have been half implemented before abuses they are generating come

to light. Policies that respect human rights will encourage individuals and communities to trust and co-operate with public health authorities.

Promotion of human rights, particularly among previously disenfranchised groups increases their ability to protect their own health.

5.3.2 HIV and AIDS

"AIDS intimately touches upon our ideas about sexuality and societal divisions, social responsibility and individual privacy, order and instability and above all, health and the prospect of happiness." (Fee, E and Krieger, N. Thinking and Rethinking AIDS: Implications for Health Policy. AIDS: The Politics of Survival, Gaywood Publishing Co, Amityville, NY pg 227).

HIV/AIDS is more than a medical issue. It has raised numerous ethical, legal and health policy problems. Prejudice and discrimination have made it a human rights issue too. People talking about AIDS sometimes adopt a language of guilt and innocence; those infected through blood transfusions are innocent; those infected through sex, somehow deserve what they get.

Respect for human dignity is the first casualty in the debate between individual rights and public interest, when cries defending the latter are irrational. It undermines public health by driving the disease underground. People will simply not come forward for a test if they fear that their right to privacy will be violated.

The attitudes of judgmental health workers also put people off getting tested and counselled.

"They (nurses) are rude and it creates problems of people becoming lazy to go to the clinics." (Zulu-speaking female in Gauteng. Qualitative research commissioned by NPPHCN into responses to the 'Reach for your rights' radio social action spots)

Protecting human rights is part of an effective response to tackling the epidemic, especially as it is spreading most rapidly amongst society's vulnerable groups.

Fear and Confusion

AIDS is surrounded by fear and confusion. This obstructs people with the virus being treated in a fair, compassionate and life-affirming way. Many health professionals, employers and insurance companies are guilty of treating people with AIDS differently from others with comparable life-threatening conditions.

As universal precautions must be taken when dealing with any patient's blood, there are no excuses for health workers' violations of HIV-positive people's rights to privacy, autonomy and dignity.

Social Discrimination

The stigma surrounding the disease has led to social discrimination against groups such as gay men, sex workers and the poor. HIV-positive children have been sent home from school. Hospital patients and prisoners have been segregated.

Blood Testing

HIV testing, particularly when conducted without consent, is a test for human rights. The notion of mandatory screening of an entire population would be expensive and invasive of the rights of a huge group for minimal benefit. Employers such as the SA Police, SA Defence Force and Correctional Services have violated their employees' rights with pre- and post-employment testing. Such actions are condemned by the World Health Organisation. Many insurance companies have discriminated against potential clients by imposing pre-insurance testing. (TO ADD: a case study - from the AIDS Law Project?)

Allocation of Resources

There is blatant discrimination in the allocation of resources (health care or otherwise) to people with AIDS. Pre-employment testing closes the door to obtaining an income. Insurance companies deny HIV-positive people health cover.

Health authorities deny people with HIV/AIDS access to expensive treatments because they have short life expectancy and it would impoverish the health system. The Health Minister has recently announced that pregnant women will not be given AZT for a period

prior to labour (although it would reduce the chance of their baby being born HIV-positive), because of insufficient resources. (TO ADD: a recent media quote?) Regardless of the size of the health budget, it is discriminatory to conserve health resources by denying a specific group, or people with a particular terminal disease, equal access to medicines.

Other areas of controversy have been ethical problems in the area of testing of experimental drugs, the use of placebos and the approval of new drugs.

Confidentiality

There have been breaches of confidentiality in hospitals, clinics, insurance companies, prisons, the police service; in fact, anywhere that HIV testing is carried out or is mandatory. The Constitution gives everyone the right to personal privacy and dignity. It is up to the individual what parts of their life they want to keep private. In May 1996, the policy of segregating HIV-positive prisoners at night was scrapped, so their right to privacy could be maintained. (TO ADD: exact details of the act by the Correctional Services)

The fear of stigma inhibits people from revealing their illness, even to their family, friends and colleagues. They fear discrimination and isolation. An individual must be in control of passing on such private information.

Without unprotected sex or the sharing of hypodermics, AIDS is hard to pass on. Therefore, the argument that public interest justifies breaches of confidentiality does not hold water. **With only the smallest risk of casual transmission, there is no need for colleagues to know a person's HIV status.**

People reveal their HIV status to health professionals because they trust them. They trust the notion of medical confidentiality, as a right guaranteed by the South African Medical & Dental Council (SAMDC) and South African Medical Association (SAMA). Even after death.

The SAMDC also requires express informed consent to be obtained before a HIV test is done, and before information about someone's HIV status can be passed on. Health professionals cannot assume

that a person with AIDS is practising unsafe sex or that the public is not responsible for protecting itself.

The only situations where confidentiality may be breached is when a court orders disclosure of information or when a person with HIV/AIDS confides that they are intending to continue having unsafe sex with a named third party ie there is a clear threat to an identified individual's life. In which case, the professional must try to counsel them. Failing to persuade them, they must inform the patient that it is a doctor's ethical and legal obligation to warn the third party.

Government Responses

Some countries for example the United States of America, have curbed the movement of people with HIV/AIDS' by placing restrictions on travel. (TO ADD: the exact details of the US document prohibiting HIV+ travel)

Only in Cuba has a government chosen to instigate a policy of quarantining people with HIV/AIDS. Initially only a small number of HIV-positive war veterans were put in semi-quarantine (those returning infected from Africa). Later, all sexually active Cuban nationals were screened. The government stopped short of demanding the screening of foreign tourists.

The Cubans' unique response subordinated HIV-positive individuals' rights to State control. Medical disciplines (routine testing, contact tracing with partner notification, close medical surveillance and partial isolation and recommending that HIV-positive women terminate pregnancies) verge on a culture of punishment. They has been criticised by the World Health Organisation for violations of privacy and liberty. Yet, the Cubans have had some success in controlling the epidemic on their island. Other factors that may have contributed to this success are US embargo-induced isolation, very little intravenous drug abuse, easy access to abortions and the emigration of many, oppressed gay men prior to the public health issue arising.

In America and Western Europe, individual rights were deemed important, right from the start of the epidemic. Scheper-Hughes writes, "AIDS was viewed as a crisis in human rights (that had some public health dimensions) rather than as a crisis in public health that had some important human rights dimensions..." She believes,

"because of the severe limits on the measures that public health institutions could possible take, most democratic nations found themselves necessarily flying blind into the eye of the storm, their instrument panels dismantled." (Scheper-Hughes, N. 1994. AIDS and the Social Body. Social Science and Medicine 39: 7: 992)

Scheper-Hughes's concern is for that "vast unorganised, 'non-community' of sexually dominated women for whom the best line of defence might come in the form of widespread and routine testing with follow-up through partner notification." .(Scheper-Hughes, N. 1994. AIDS and the Social Body. Social Science and Medicine, 39: 7: 992)

There should be no problem defining AIDS-specific rights. A number of instruments are available for this purpose. "The application of basic human rights to the predicament of HIV/AIDS is no more than another instance of the invocation of fundamental rules which have been developed and expressed by nation States and the international community, particularly since 1945." (Kirby, M. Life's Dominion - Closing Reflections at the First National Conference in South Africa on AIDS and the Law)

The United Nations' Economic & Social Council Commission on Human Rights' Second International Consultation on HIV/AIDS and Human Rights (Geneva 1996) produced guidelines to assist States in dealing with the crisis. It stated, "The protection of human rights is essential to safeguard human dignity in the context of HIV/AIDS and to ensure an effective, rights-based response to HIV/AIDS...Public health interests do not conflict with human rights."

The challenge AIDS presents is to translate international human rights norms into national, and more importantly, locally-practised observance.

Dakar Declaration (1994) by the African Network on Ethics Law and HIV.

This declaration outlined 10 principles to fight the epidemic:

- responsibility
- engagement
- partnership and consensus building
- empowerment

- non-discrimination
- confidentiality and privacy
- adaptation
- sensitivity in language
- ethics in research
- prohibition of mandatory HIV testing

Charter of Rights on AIDS & HIV (1992)

This Charter was produced by The Aids Consortium ***(TO ADD: a footnote on who the AIDS Consortium are),*** to outline rights for all citizens that should not be denied to HIV-positive people: liberty, autonomy, security of the person, freedom of movement, privacy and confidentiality. It drew on international documents including the Montreal Manifesto of the Universal Rights and Needs of People living with HIV Disease and the UK's Declaration of the Rights of People with HIV & AIDS.

Article 6 Health & Support Services

6.1 Persons with HIV or AIDS have rights to housing, food, social security, medical assistance and welfare equal to all members of our society.

6.2 Reasonable accommodation in public services and facilities should be provided for those affected by HIV or AIDS.

6.3 The source of a person's infection should not be a ground for discrimination in the provision of health services, facilities or medication.

6.4 HIV or AIDS should not provide the basis for discrimination by medical aid funds or services.

Other Articles in the Charter deal with rights to liberty, autonomy, security of the person, freedom of movement, privacy and confidentiality, testing, employment, media, insurance, gender and sexual partners, prisoners, equal protection of the law, access to public benefits and duties.

Section 12: Duties of Persons with HIV or AIDS

Persons with HIV or AIDS have the duty to respect the rights, health and physical integrity of others and to take appropriate steps to ensure this where necessary.

Patients' rights are not absolute, inevitably they are limited by the resources available (but allocation of these should be based on empirical data not on discrimination). "If there is a duty upon the State to provide treatment, there must be a right upon someone - the object of that duty - to demand treatment or to demand admission to a hospital. However the State's duty and consequently the individual's

right is very limited...It is not the place of the medical professional to judge his patients, and to determine whether or not a patient lives or dies according to the moral accountability of that patient...(health workers are) under an ethical obligation to treat all who require his services." (Leech, B. The Right of the HIV-Positive Patient to Medical Care in SA. Journal Of Human Rights, 9: 1: 44)

The **SAMDC** has produced **'Guidelines on the Management of AIDS and HIV-Positive Patients' (1989)** and the **SAMA** has published **'AIDS - Guidelines for Discussion' (1992).** These guidelines are available. The problem lies in overcoming ignorance and fear and putting them into practice.

As new challenges emerge - like the AIDS epidemic - new legal responses are needed in order to protect human rights. Obligations of health care systems need to be made explicit.

Medical professionals (and employers) are central to eliminating discrimination and irrational responses to people with HIV/AIDS.

5.3.3 Reproductive and Sexual Health

"First they tell you that people from the shacks are irresponsible they have a lot of children." (Sotho-speaking male in Gauteng. Qualitative research commissioned by NPPHCN into responses to the 'Reach for your rights' radio social action spots)

Issues of control and dignity are inherent in any discussion of reproductive health rights.

Some governments have censored and controlled information concerning reproduction and sexuality in order to enforce demographic targets and enforce moral codes about sexuality and women's "proper" role. People's, particularly women's, health and humanity is effected. Depriving people of the knowledge and information they need to make decisions about sex and reproduction is a human rights abuse.

Reproductive rights include the ability to negotiate the kind of sex a person wants, freedom from rape, coercion, forced reproduction or abortion. Control over their own reproduction and sexuality is a precondition for women's ability to exercise other rights. Only with

access to information can women make informed choices about safe abortions and labour, STD's and contraception.

Health workers are, more often than not, the conduit through which people receive family planning advice and information. The importance of their maintaining a non-judgmental attitude is vital. Lynn Freedman writes of "domination by health professionals who present "risk" as if the only thing at stake in deciding whether or not to conceive or give birth is the possibility of physical injury; who obsess about reproduction but ignore sexuality; who preach about "personal responsibility" but fold on questions of power and resources, of vulnerability and discrimination...The right not to be alienated from one's own reproductive and sexual capacity...is the essence of the search for human dignity and social justice that is the basic motivation for human rights advocacy." (Freedman, L. Reflections on Emerging Frameworks of Health and Human Rights. Health & Human Rights 1: 4: 325)

Women's HIV status often impacts on their reproductive rights. Health professionals may assume that a HIV-positive woman should terminate a pregnancy. AIDS does not abolish a woman's right to control her body.

Programme of Action of the United Nations International Conference on Population Development (1994)

This is not a binding international law but it was endorsed by the United Nation's General Assembly. It states, "Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capacity to reproduce and the freedom to decide if, when and how often to do so."

Principle 8
Everyone has the right to the enjoyment of the highest attainable standard of physical and mental health.

States should take all appropriate measures to ensure...universal access to health care services including those related to reproductive health care, which includes family planning and sexual health. Reproductive health care programmes should provide the widest range of services without any form of coercion. All couples and individuals have the basic right to decide freely and responsibly the number, spacing, timing of their children and to \have information, education and the means to do so.

5.3.4 Discrimination against People with Disabilities

"Nurses don't care about injured (disabled) people." (Zulu-speaking female in Gauteng. Qualitative research commissioned by NPPHCN into responses to the 'Reach for your rights' radio social action spots)

The Department of Health estimates that at least 13% of the population have physical or mental impairments. However equal training and employment opportunities are regularly denied people with disabilities and so they are also denied the opportunity to develop their skills and abilities.

Within the context of health care, people with disabilities may experience difficulties accessing health facilities' premises and the patronising or cruelly impatient attitudes of some health workers.

"(Nurses) making jokes about (disabled) patients and screaming at them." (Zulu-speaking female in Gauteng. Qualitative research commissioned by NPPHCN into responses to the 'Reach for your rights' radio social action spots)

Often, people are afraid of talking to people with disabilities. They alter their voices and do not talk normally with them. Such awkward behaviour is due to lack of contact with disabled people. The opportunity to 'normalise' social interaction is reduced by families keeping their disabled relatives out of sight or in segregated medical or other institutions.

People with disabilities are sometimes treated as if a particular disability affects all their other faculties. People in wheelchairs, with purely physical disabilities, are sometimes treated as if they are unintelligent.

All human rights, including the right to making decisions, and provide informed consent for medical procedures, are applicable to all people.

Vienna Declaration and Programme of Action from the World Conference on Human Rights (1993) produced Standard Rules on the Equalisation of Opportunities for Persons with Disabilities.' It reiterated that "All human rights are universal, indivisible, interdependent and interrelated."

The Human Rights Act (1993) made discrimination on the grounds of disability unlawful in South Africa. It covers physical and mental disabilities and illnesses including HIV/AIDS.

The Interim Constitution (1993), Labour Relations Act (1995) and the Bill of Rights all have equality clauses against discrimination on grounds of disability. (TO ADD: update this with the Equity Act, etc)

The Disability Rights Charter of South Africa

This charter was produced by the Disabled People South Africa, draws on principles from the Universal Declaration of Human Rights, Declaration on the Rights of Disabled Persons, World Programme of Action Concerning Disabled Persons and International Labour Organisation conventions on vocational rehabilitation and employment.

Article 3 Health & Rehabilitation
Health & rehabilitation services and facilities shall be effective, accessible and affordable to all disabled people in South Africa.

5.3.5 Consumerism

not a great source for reference

In July 1998, former Superintendent of Chris Hani Baragwanath Hospital, Dr Bernard Rabinowitz went public, accusing his colleagues of "not giving a damn" about up to 40 patients dying at the hands of junior doctors performing surgery without supervision.

"Disciplinary action must be instituted against the administration who are now literally being dragged to an inquiry, kicking and screaming," he told *The Star* (6/7/98). Cases of alleged negligence included the death of a young girl after doctors had allegedly directed a breathing

tube to her stomach instead of her lungs, and the death of an elderly woman who had died after surgeons allegedly turned her away without diagnosing a hip fracture.

At times, health professionals are open to criticism over competence, neglecting problems of access and quality of service and cost effectiveness. Some are guilty of putting their financial interests and practice conditions above concern for their patients' interests.

The issue of rights for 'consumers' of health services is no different to the rights of consumers of other 'products'. People expect, and deserve, to get what they pay for, and what they are entitled to. When things go wrong due to negligence or serious misconduct, there must be procedures for redress that are timely and efficient.

The South African Medical and Dental Council receives between 1,400-1,500 written complaints a year, mainly against private doctors. Inquiries take 12-18 months to resolve. About 10% of the doctors charged with professional misconduct are struck off by the council's six member committee, which weighs up the evidence. (*The Star*, 17/3/97)

Consumers or patients - consumer advertising is powerful way to stimulate public interest in health. The question raised in Europe and in America is whether patients can be simultaneously asked to take more responsibility for their own health and denied access to some information that may help them to do so? The European Commission and many European governments talk loftily of the need for "patient empowerment": Greater public awareness and understanding about diseases and their therapies. For, if patients are to take more responsibility for their health, they do deserve reliable information on available treatments." (*The Economist*, 8/8/98) (TO ADD: more from Judi?)

5.4 Medical Ethics

Medical ethics and patients' rights overlap. Modern concepts of medical ethics include principles of patient autonomy and informed consent. These concepts should protect patients from over-zealous health workers.

The idea of informed consent, for instance, protects patients from research, testing and treatments. This was a principle of the Nuremberg Code, which informed subsequent guidelines such as the International Covenant on Civil and Political Rights. An individual's consent to participate in research must be legally competent, voluntary, informed and comprehending.

However, consent should be more about a process of communication with the patient than stark legal requirements. This principle provides an opportunity to counsel patients. It preserves health professionals' integrity and patients' dignity.

5.5 Health Professional Heroism

This manual has previously examined the subject of medical personnel complicity in human rights abuses. On the other side of the coin, there are numerous circumstances where the conscience of health professionals has helped fight against atrocities.

In Chile, Guatemala, Mozambique and Nicaragua, there is evidence that health professionals have been killed because of their political beliefs or human rights work. "Respect for the rights of the individual and the protection of the health of human population are deeply rooted in the traditions of medicine whether in peacetime or during armed conflict." (Geiger, J and Cook-Deegan, R. 1993. The Role of Physicians in Conflicts and Humanitarian Crises: Case Studies from the Field Missions of Physicians for Human Rights 1988-93. JAMA 270: 5: 616)

Their Health professionals may be among the first to witness violence and human rights violations. They provide care for the victims of torture. Their forensic skills may produce damning evidence. By investigating and documenting human rights abuses, they can help reveal atrocities to the world. Sometimes this mobilises international intervention. "Witnesses may die or disappear but the physical evidence still will speak powerfully for them." (Geiger, J and Cook-Deegan, R. 1993. The Role of Physicians in Conflicts and Humanitarian Crises: Case Studies from the Field Missions of Physicians for Human Rights 1988-93. JAMA 270: 5: 619)

Progressive organisations such as the Chilean Medical Association, the National Medical and Dental Association of South Africa, (ADD FOOTNOTE: on NAMDA) Physicians for Human Rights and Amnesty International (which has a Health Professionals Network of about

10,000 health workers) champion the cause of human rights and defend medical ethics against repression.

In 1986, after a township demonstration, police requested patients' files from the Alexandra Clinic. The Clinic Director, Dr Tim Wilson refused on grounds of medical confidentiality but the files were seized anyway. It was example of political violence and the abuse of human rights directly impacting on ordinary health care provision. Political violence also disrupted transport, water, sanitation and street lighting. Scarce health resources were diverted from primary care to care for the injured and disabled.

5.6 Therapy for Survivors

"Victims may better become survivors if some part of the legacy of the past can be addressed." (Summerfield, D. 1996. Addressing Human Response to War and Atrocity. Beyond Trauma, Plenum Press, New York pg26)

Patients may be reluctant to reveal torture to physicians because of fear; fear of reprisal, fear of being overwhelmed by reliving the humiliation and retrieving painful memories, fear of stigma or not having their experiences validated by their medical confidante.

When caring for survivors, there is a tendency of people, including health professionals, to withdraw. Some have found their health workers unwilling or unable to deal with their stories; emotionally unprepared to listen to their accounts of torture. By minimalizing their experiences, the health professional is unintentionally revictimizing the person.

Patients' Fears

It is vital to understand and gently confront patients' fears. There are parallels between the way health workers should treat victims of torture and victims of abusive treatment in the health care system. In varying degrees, patients may mistrust health staff, hold back or transfer anger to them, because of past abuses by health workers. A vicious circle starts if health workers react with hostility to the patient's aggression or frustrating timidity. This, in turn, generates more apprehension, fear and suspicion in the patient. The result is an on-going absence of trust.

The patient's past experiences need to be heard. They may need empathy, reassurance and have their previous mis-treatment acknowledged.

It is a slow process but trust has to be built before the interface between patients and health providers will improve.

5.7 Instruments to Protect Health Rights

The declarations below apply the "laws of humanity" to the medical context. Since the Hippocratic Oath, other instruments have been developed to define the ethical and legal limits of health workers' interactions with patients. Produced by professional associations such as the World Medical Association or the International Council of Nurses, they offer guidance to health workers who may, at times, be placed in difficult ethical dilemmas.

5.7.1

The Hippocratic Oath (5th Century BC)

From 4th Century AD, this oath became obligatory for new doctors.

"...The regimen I adopt shall be for the benefit of the patients according to my ability and judgement, and not for their hurt or for any wrong...Whatsoever house I enter, there will I go for the benefit of the sick, refraining from all wrongdoing or corruption...In my attendance of the sick, or even apart therefrom, whatsoever things I see or hear, concerning the life of men, which ought not to be noised abroad, I will keep silence thereon, counting such things to be as sacred secrets..."

5.7.2 World Medical Association (WMA) Declarations

The WMA was founded in 1947 because of the medical-related atrocities exposed during the Nuremberg Trials.

Declaration of Geneva (1948)

With various later amendments, the WMA revised the Hippocratic Oath in this Declaration.

"...The health of my patient will be my first consideration;
I will respect the secrets confided in me, even after the patient has died...
I will not permit considerations of age, disease or disability, creed, ethnic, origin, gender, nationality, political affiliation, race, sexual orientation or social standing to intervene between my duty and my patient;
...I will not use my medical knowledge contrary to the laws of humanity..."

really, done in 1948?

International Code of Medical Ethics (1949)

This code expanded the scope of the Declaration of Geneva.

"A physician shall...be dedicated to providing competent medical services in full technical and moral independence, with compassion and respect for human dignity;...respect the rights of patients...and safeguard patient confidences...give emergency care as a humanitarian duty..."

Declaration of Tokyo (1975)

This declaration dealt specifically with doctors' treatment of those imprisoned or detained.

"...The utmost respect for human life is to be maintained even under threat, and no use made of any medical knowledge contrary to the laws of humanity...The doctor shall not countenance, condone or participate in the practice of torture or other forms of cruel, inhuman or degrading procedures..."

5.7.3 Statements by the International Council of Nurses

Statement on the Nurse's Role in Safeguarding Human Rights (1983)

"...Health care is a right for all individuals. Everyone should have access to health care regardless of financial, political, geographical, racial or religious considerations. The nurse should seek to ensure such impartial treatment...A patient/prisoner has the right to refuse to eat or to refuse treatments. The nurse may need to verify that the patient/prisoner understands the implications of such action but she should not participate in the administration of food or medications to such patients...informed consent is a patient's right and must be ensured."

Position Statement on Nurses and Torture (1989)

"The nurse shall not countenance, condone or voluntarily participate in...any treatment which denies to any person the respect which is his/her due as a human being."

5.7.4 United Nations Principles on Medical Ethics

Principles of Medical Ethics relevant to the Role of Health Personnel, particularly Physicians, in the Protection of Prisoners and Detainees against Torture and other cruel, inhuman or degrading Treatment or Punishment (1982)

"It is a gross contravention of medical ethics, as well as an offence under applicable international instruments, for health personnel...to engage...in acts which constitute participation in...torture or other cruel, inhuman or degrading treatment or punishment...There may be no derogation from the foregoing principles on any grounds whatsoever, including public emergency."

Body of Principles for the Protection of all Persons under any Form of Detention or Imprisonment (1988)

"No detained or imprisoned person shall, even with his consent, be subjected to any medical or scientific experimentation which may be detrimental to his health...medical care and treatment shall be provided whenever necessary..."

Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (1991)

"All persons have the right to the best available mental health care...treated with humanity and respect for the inherent dignity of the human person."

5.7.5

Amnesty International's Declaration on the Participation of Health Personnel in the Death Penalty (1981)

"*Recalling* that the spirit of the Hippocratic Oath enjoins doctors to practice for the good of their patients and never to do harm,

Considering that the Declaration of Tokyo of the World Medical Association provides that "the utmost respect for human life is to be maintained even under threat, and no use made of any medical knowledge contrary to the laws of humanity"...

Noting that the United Nations' Principles of Medical Ethics enjoin health personnel, particularly physicians, to refuse to enter into any relationship with a prisoner other than one directed at evaluating, protecting or improving their physical and mental health,

Conscious of the ethical dilemmas posed for health personnel called on to treat or testify about the condition of prisoners facing capital charges or sentenced to death, where actions by such personnel could help save the prisoner's life but could also result in the prisoner's execution...Declares that the participation of health personnel in executions is a violation of professional ethics..."

5.7.6

Declaration of Alma-Ata (1978) from the International Conference on Primary Health Care

This International Conference entrenched health as a fundamental human right by committing participating countries to working to achieve health for all by the Year 2000. They made a commitment to community participation and intersectoral action, both fundamental to health promotion programmes. The Primary Health Care founding document inspired the creation of the National Progressive Primary Health Care Network in 1987.

5.8 Health Charters

"They (nurses) are bound to help you whether it's the right day or not." (Zulu-speaking female in Gauteng. Qualitative research commissioned by NPPHCN into responses to the 'Reach for your rights' radio social action spots)

A health charter is a written declaration of rights and a description of an organisation's functions. It is a vehicle for change as it highlights injustice and suggests ways of improving the situation. Their aims are to promote consultation, participation, service standards, courtesy, information, openness and transparency, responsiveness and value for money. They put consumers first.

A health charter does more than just spell out a patient's right to good treatment. It also outlines the two way process required to create a culture of caring. This involves fair treatment of patients by staff, and staff by patients. Both parties must try to empathise more with the other. Health workers must aspire to creating an environment, which offers time, space and respect to their patients who are entitled to be treated with dignity, sympathy and care.

"We must also have patience, for the nurses also have problems at the hospital." (Xhosa-speaking female in Gauteng. Qualitative research commissioned by NPPHCN into responses to the 'Reach for your rights' radio social action spots)

In order to achieve a culture of caring it is important that health workers feel that their rights are respected and that patients are treating over-stretched health resources responsibly.

The balancing act of rights and responsibilities is the basis for health charters, which are increasingly being drafted and adopted by governments, district health authorities and individual hospitals and clinics.

"Patients should know their rights but they also have a duty to behave well."
(Zulu-speaking male in Gauteng. Qualitative research commissioned by NPPHCN into responses to the 'Reach for your rights' radio social action spots)

Health charters represent part of a global move to endorse health rights. It is also an effective means of advocating them. International human rights law is mainly dependent on the voluntary consent of nations. Likewise, any health charter will depend on the voluntary participation health professions and communities.

Below are three case studies of health charters: the English Patients' Charter, the Zimbabwean Patients' Charter and a Hospital Charter from Arizona, USA.

5.9 Case Study of a European Country's Health Charter

The 'Patients' Charter', UK, 1991

The UK's 'Citizens' Charter' was produced by the Conservative Government in 1991. It aimed to make the citizen the 'customer' of British public services. By paying for services through taxes, the 'customer' was entitled to high quality services and more accountability. New management strategies were introduced which tried to treat staff with more consideration and respect. The idea being that they would then treat customers better.

The Patients' Charter was part of this initiative. Now, under a Labour Government, the programme continues under the title 'Service First'. It aims to help the National Health Service (NHS) listen to, and act on, people's views and needs, be setting clear standards of service. The Charter has been produced in Bengali, Gujarati, Hindi, Punjabi, Urdu, Chinese, Vietnamese, Greek, Turkish, Somali, Polish, Braille, large print, sign language video and audio cassette.

The Charter makes a clear distinction between rights (what all patients will receive, all the time) and expectations (standards of service which the NHS is aiming for, but which may not always be achieved). The nature of its contents is comprehensive

and very specific. It tells the public exactly how many days a particular service will take and how to complain if the service they receive falls below that stated.

1. Access to services:

Patients have the right to:
- Receive health care on the basis of their clinical need, not on their ability to pay or any other factor.
- Be registered with a General Practitioner (GP) (the health authority will find you one within 2 days) and be able to change doctors easily if you want to (they'll send you a list of doctors within 2 days).
- Get emergency medical treatment at any time.
- Be referred to a consultant when your GP thinks it is necessary, and to get a second opinion if you and your GP agree it's desirable.

Patients can expect:
- The NHS to make it easy for everyone to use its services including children, elderly and people with disabilities.
- Children to be on a children's ward with a consultant paediatrician.

2.Personal consideration and respect

Patients have the right to:
- Choose whether to participate in medical research or medical student training.

Patients can expect:
- All staff to wear name badges.
- The service to respect your privacy, dignity and religious/cultural beliefs at all times.

3. Providing information

Patients have the rights to:
- Have any proposed treatment including any risks involved clearly explained before you decide whether to agree to it.
- Have access to your health records and knowledge that everyone working for the NHS is under a legal duty to keep your records confidential.
- Have any complaint about the NHS investigated and to get a quick, full written letter from the relevant chief executive or general manager within 4 weeks.
- Receive detailed information on local health services including information on standards of service you can expect, waiting times etc.

4. Health checks

Patients have the rights to a health check:
- When you join a GP practice for the first time.
- Every 3 years if you're between 16-74 years.
- Once a year if you're over 75 – in your home if you prefer.

5. Drugs and treatment

Patients have the rights to:
- Prescribed appropriate drugs and medicines.

- Free medicine if you're in specific categories (eg pensioner, over 60, under 16 or under 19 and in full time education, pregnant, nursing mother, suffering one of a group of specific conditions, on income support or family credit).
- Waiting time for hospital admissions guaranteed 18 month maximum.
- To be told in advance if you're going into a mixed sex ward.

Patients can expect:

- If you call 999, an ambulance within 14 minutes in an urban area and 19 minutes in a rural area.
- Waiting time for your first appointment as an outpatient, when you've been referred to a hospital consultant by your GP, 90% within
- 13 week maximum, 100% within 26 weeks.
- A home visit by a community nurse, health visitor or midwife, by appointment, within a 2 hour time band.
- A home visit by a district nurse or mental health nurse within 4 hours, if you've been referred to them as urgent, and within 2 days if you've been referred to them as non-urgent.
- Seen immediately to have your treatment assessed in an accident & emergency department.
- Single sex washing and toilet facilities.
- Written explanation of the hospital food, nutrition and health policy.
- Enquiry points and clear signposting in hospitals.
- A clean and safe hospital environment.

Monitoring Charter Performance

Health Authorities produce annual reports on local hospitals' Patients' Charter performance. The first annual "League" table was published in June 1994, showing how local hospitals and ambulance services were doing against national standards. Patients can nominate their local hospital, community trust or GP practice for a Charter Mark Award.

Many GP practices, health authorities and hospitals have their own charters, adding to and improving on national standards. The act of writing their own charter and displaying it in a public place inspires ownership of the standards set. This also provides an opportunity for making clear how patients can help. Their responsibilities can be politely spelt out, such as asking patients to cancel appointments with as much notice as possible, inform doctors or hospitals of a change of name or address, return equipment like wheelchairs, walking sticks etc, give blood regularly, carry a donor card, and use out-of-hours GP services, 999 and accident & emergency departments appropriately.

The Charter also offers a procedure for comments and complaints. It explains that you should go straight to the relevant health professional if possible, of if the complaint is about a particular member of staff, to contact the health authority, or if it is about a hospital or community service then to go to their general manager or chief executive, or to the Health Service Commissioner for England. Finally the Charter offers an invitation to write to the Chief Executive of the entire NHS if you think your Charter rights are being denied or if you have comments or suggestions to help improve the service.

5.10 Case Study of an African Country's Health Charter

The Patients' Charter, Zimbabwe, 1996

Produced by the Ministry of Health and Child Welfare in collaboration with the Consumer Council of Zimbabwe, its stated aim was to improve the relationship between patients and health care providers. The Charter explains what kind of service the public can expect from the health care system, where further information and treatment is available and what to do if things go wrong.

Patients can expect:

- To be treated with care, consideration and respect in all your dealings with health care providers.
- To receive emergency care and treatment at anytime on the basis of need regardless of your ability to pay.
- To give or withhold your consent to medical or other care and treatment
- To choose whether to take part in research or student training.

1.Patients' Rights

All Zimbabweans have a right of access to health care services in time of need:

- As non-paying patients
- As paying patients

1.1 **Hospitality:** You have the right to be accorded courtesy and to be treated with respect, in a safe and clean environment.

1.2 **Confidentiality**: Save for the requirements of the law, all information concerning your illness and personal circumstances will be kept in confidence and used only for the purposes of your treatment.

1.3 **Privacy:** you have the right to privacy during consultation, examination and treatment.

1.4 **Discrimination:** You have the right to be received and attended to without regard to sex, age, religion, colour, creed, tribe, race or socio-economic status.

2. Services

2.1 **Admission and your stay in hospital**: In the event of an accident, illness or emergency, you will be attended to by competent health workers. You will be assessed and dealt with appropriately and immediately upon arrival. Whether you are admitted as an emergency case or not, hospital staff shall: inform your relatives/next of kin, keep your clothes and valuables in a safe place, give you clear information about your illness and treatment plan...

2.2 **Consent:** In the event that surgery is anticipated in your treatment plan you have the right to be consulted and to be informed about the nature of the operation. Where risks are known, you will be informed. If you are 18 years of age and above you have the right to give your consent to surgery...You have a right to be consulted and to give consent to any research or teaching to be carried out on you.

2.3 **Children in hospital:** As a parent/guardian you have a right to: information concerning the nature and treatment of your child's illness, to freely interact with your child provided this does not interfere with the treatment of your child and others and to accompany your child to hospital if feasible.

The Charter makes suggestions about how to avoid inconveniences and delays:
- Get to know your local health services and what they offer.
- Have the relevant documents with you when you visit a health facility
- Ask health workers when you need assistance or information.

3. Patients and their families when seeking health services

Whilst you have the right to be heard, you also have the obligation to listen to medical advice and instruction concerning your treatment.
Give staff all the information they require to plan your stay and treatment adequately.
Know your medical history so you can tell those who need to know about the treatment you are receiving or if you are allergic to some medicines etc.
Follow the referral chain (Visit your local health centre or GP first unless you are in an accident or emergency when you can go to your nearest hospital without a referral) and ensure you have the necessary documents to effect your access into hospital.
Keep your hospital notes safe and clean
Ask questions so you can make decisions based on better knowledge and understanding.
The patient and family shall inform the health professional if the patient is currently consulting with, or under the care of, another health professional including traditional medical practitioner in connection with same complaint or any other complaint.
Keep your appointments or notify the doctor as soon as possible if you are unable to attend.
Do not expect a prescription at every visit, remember you do not need a pill for every illness.
Take you medicines exactly as instructed and complete any course of treatment.
Do not share prescribed medicines.
The health service aims to ensure that all the drugs and other sundries required for your treatment are available.

3.1 **Care in the community:** You have a right to communicate with health workers on matters which concern your health. You do not have to wait till you are ill. You have the right to continuing care at home where there is need (eg invalidity, old age, recuperation etc). In the event that you request for an ambulance it will be

dispatched to you as soon as possible. However, arrival time will depend on distance, conditions of the roads and availability of ambulances.

3.2 **Securing your health and that of others in the community:** Attend and participate in health promotion activities organised in your area. Get your views and opinions known through your hospital board, health centre committee or community health workers. Always ensure a high standard of personal hygiene.

4. Free services in Zimbabwe

Immunisation for children and pregnant women
Treatment for TB, leprosy and mental illness.
You are entitled to a disease free environment through free disease control measures and other public health measures from community health workers.

5. If things go wrong

Complaints provide a useful means of monitoring the quality of services and how they meet the needs of patients...You may also want health workers to know if you have been treated well. This allows those caring for you to know that what they are providing is the right kind of service and also that their efforts are being appreciated by those who matter most...In most cases it is possible to solve complaints on the spot by speaking directly to the person providing the services or their immediate superior. ...You may be asked to make a formal complaint in writing and send it to the PR Unit at the Office of the Medical Director, Medical Superintendent, Administrator, Chair of the Hospital Board or Ministry of Health and Child Welfare.

The Charter's final words are, "Your health is your responsibility, health workers are there to assist you where necessary."

5.11 Case Study of an American Hospital Charter

The Patients' Bill of Rights, USPHS Indian Hospital, Fort Defiance, Arizona, USA

The purpose of the document was to set forth the official policies of the Navajo Area regarding the rights of patients.

General Rights of Patients:

1. The patient in the Fort Defiance, Indian Hospital has the right to considerate and respectful care. This requires the providers to develop a sensitivity to Indian culture and traditional values (religious beliefs, native healing practice, mores, etc).

2. The patient has the right to get all information concerning his health care from his physician or other primary care provider.
3. In the case of minors, non-English speaking patients, or patients whose condition is such that they could not understand, the information should be given to an appropriate member of the patient's family.
4. The patient and his representative have the right to know the physician that is responsible for his/her care.

Rights for Services:

1. Services will be provided to the extent the facility and its resources can provide the services. These include:
   a) Evaluation - diagnosis of the patient's general health condition.
   b) Treatment or procedures to prevent, control or cure, the illness. This includes effective management of pain.
   c) Referral - providing additional physician or other appropriate services as required and when unavailable at the facility.
   d) The patient has the right to expect that his referring physician, or other appropriate person(s) designated will secure up-to-date reports of his care and progress where he is receiving care in a referral or contract hospital...

3. The patient has the right to know what other choices, if any, he may have instead of the treatments or procedures indicated by the physician.

4. The patient has the right to know the name and qualification of the person(s) who will be responsible for his procedures and treatments.

5. In emergency situation (life threatening or possibility of personal loss of limbs, eyesight, or other critical functions) the physician would not be responsible for providing extensive information because giving such information may be taking vital time and therefore, could be more dangerous for the patient. After the emergency situation has been relieved, the patient or an appropriate representative has the right to full knowledge about the diagnosis and prognosis.

Right to refuse treatment

The patient has the right to accept or refuse treatment, and has the right to refuse to take part in any research projects.

General patient responsibilities

1. Each patient is ultimately responsible for:
   a) Understanding his or her own general treatment plan, including medicines, diet, activity and exercise.
   b) Asking questions if instructions are unclear.
   c) Keeping appointments or rescheduling appointments.
   d) Not running out of medicines that are important and taken daily.
   e) Learning the name of your care provider.

2. Each patient has the responsibility to respect other patients' privacy, confidentiality and safety needs.

Grievance Rights

The patient has the right to take complaints on health services to the Chief Executive Officer. Named individuals in each department are given with their telephone extensions.

Summary

Declarations of medical ethics from the Hippocratic Oath of the Fifth Century BC, to those of the late Twentieth Century, all echo the same principles. They place a high value on such patients' rights as privacy, confidentiality and autonomy.

Health charters put health-related human rights into a practical context. Whether local or national, they inform the public what they can expect at their clinic or hospital – and what, in return, is expected of them.

Chapter 6 Health Rights in South Africa

"Everybody must be free. So if I'm working for you, I must feel free. I must feel at home, I must feel, I must, you must, you must take me like you sister and I will take you like my mother or my sister, like family." (Female, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

6.1 The Struggle for Rights

South Africa has some catching up to do. Isolation from "the family of nations", during the apartheid era, meant removal from progress made by the international human rights movement over the last 50 years.

South Africa abstained on the Universal Declaration of Human Rights in 1948.

After the '94 elections, South Africa signed The International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the International Convention on the Elimination of all Forms of Racial Discrimination, and the African Charter on Human and People's Rights was ratified.

"No one gives us rights. We win them in struggle. They exist in our hearts before they exist on papers. Yet intellectual struggle is one of the most important areas of the battle for rights. It is through concepts that we link our dreams to the acts of daily life. We are not used to the idea of rights, certainly not of constitutional rights. Our debates are about power rather than rights. We speak about human rights only in terms of how they are violated and not in terms of how they can affirm and legitimise a new society. If we can agree upon the basic rights, freedoms and relationships we want in a new South Africa, then the question of formulating precise governmental structures and electoral procedures will not be difficult." (Sachs, A. 1990. Protecting Human Rights in a New South Africa pg vii)

New South Africa must strive to make rights a reality for all. Inequalities in health rights are part of Apartheid's legacy.

Government Commitment

The new, democratically elected government is committed to protecting and promoting human rights. It delivered a Constitution, inspired by the International Bill of Rights, to drive transformation and help make new political freedoms meaningful. It also established impartial and independent bodies such as the Office of the Public Protector and the South African Human Rights Commission to protect and promote human rights.

SAHRC provide a local definition of human rights: "Human rights are those rights which are listed in the Bill of Rights which is Chapter 2 of the Constitution."

The New Constitution (1996) contains more detailed provision of socio-economic rights than the Interim Constitution (1993) which had made no specific mention of the right to health (except for children's right to basic health). The New Constitution has given social-economic rights equal status with other rights and emphasises that responsibilities come with these rights.

6.2

The Constitution of the Republic of South Africa (1996)

Preamble

We, the people of South Africa,
Recognise the injustices of our past;
Honour those who suffered for justice and freedom in our land;
Respect those who have worked to build and develop our country; and
Believe that South Africa belongs to all who live in it, united in our diversity.
We therefore, through our freely elected representatives, adopt this Constitution as the supreme law of the Republic so as to -

Heal the division of the past and establish a society based on democratic values, social justice and fundamental human rights;
Lay the foundations for a democratic and open society in which government is based on the will of the people and every citizen is equally protected by law;
Improve the quality of life of all citizens and free the potential of each person; and
Build a united and democratic South Africa able to take its rightful place as a sovereign state in the family of nations...

Chapter 2 Bill of Rights

Section 7 - Rights

1. This Bill of Rights is a cornerstone of democracy in South Africa. It enshrines the rights of all people in our country and affirms the democratic values of human dignity, equality and freedom.
2. The state must respect, protect, promote and fulfil the rights in the Bill of Rights...

Section 9 – Equality

1. Everyone is equal before the law...
2. Equality includes the full and equal enjoyment of all rights and freedoms...
3. The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth...

Section 10 – Human dignity

Everyone has inherent dignity and the right to have their dignity respected and protected.

Section 11 – Life

Everyone has the right to life.

Section 12 – Freedom and security of the person

1. Everyone has the right to freedom and security of the person which includes the right -
   a) Not to be deprived of freedom arbitrarily or without just cause;
   b) Not to be detained without trial;
   c) To be free from all forms of violence from either public or private sources;
   d) Not to be tortured in any way; and
   e) Not to be treated or punished in a cruel, inhuman or degrading way.
2. Everyone has the right to bodily and psychological integrity, which includes the right -
   a) To make decisions concerning reproduction;
   b) To security in and control over their body; and
   c) Not to be subjected to medical or scientific experiments without their informed consent...

Section 14 – Privacy

Everyone has the right to privacy...

Section 24 – Environment

Everyone has the right to an environment that is not harmful to their health or well-being...

Section 27 – Health care, food, water and social security

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.

Section 28 - Children
Every child (under 18) has the right...to basic nutrition, shelter, basic health care services and social services...

The above rights are not dissimilar to the demands framed by the Freedom Charter - a vision for a democratic South Africa. The Freedom Charter, which was adopted by the Congress of the People in 1955, was well ahead of its time. It preceded the International Covenant on Social, Economic and Cultural Rights by over twenty years. However, the reality of apartheid laws ensured that the disenfranchised had almost no rights to land, housing, water, welfare benefits and basic education.

The success of the New Constitution rests on developing a human rights culture, to entrench democracy.

6.3 The Reconstruction and Development Programme

"We must try to talk to our leaders and tell them what we want. What rights...like building the hospitals, houses...Something like that." (female, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

The Constitution provided the guiding principles for the Government's Reconstruction and Development Programme (RDP), the socio-economic policy framework aimed at mobilising people and resources towards addressing inequities of the past.

In the area of health, the RDP reinforced the need to unify the fragmented health services, to create an integrated National Health System, which promotes equity, access and utilisation of health services, extend availability and ensure appropriateness of health

services, develop health promotion activities and the human resources available to health sector and improve planning and monitoring in the health services. Under the umbrella of the RDP - Presidential Lead Projects - a number of initiatives were launched eg. free public health care services for under 6 year olds and pregnant and lactating women and the unemployed, a National Primary School Nutrition Program, and in 1996, 102 new rural clinics were built as part of the Clinic Building Programme.

6.4 National Action Plan

1998 is International Human Rights Year and the UN is encouraging nations to review their progress in the field of human rights. Governments are being advised to adopt National Action Plans (NAP) as instruments for evaluating performance on human rights. NAP's were proposed in the Vienna Declaration and Programme of Action at the World Conference of Human Rights (1993), as a means of setting goals and prioritising the promotion of human rights. The Declaration emphasised "All human rights are universal, indivisible, interdependent and interrelated", thus confirming the importance of socio-economic rights, and called for a "system of indicators to measure progress in the realisation of the rights set forth."

On International Human Rights Day 1997 (10/12/97), President Mandela announced that South Africa would lodge its NAP with the UN by Human Rights Day 1998 (12/12/98)

The NAP process by the SAHRC, involved analysing South Africa's constitutional democracy and the effectiveness of its institutions since 27 April 1994. The Commission had to analyse the values expressed in the Constitution and establish what further legislation was required to meet its obligations, and international treaties yet to ratify. They had to identify what major human rights challenges still face the country and set strategic goals in order to meet them. Please see Appendix III for its section on health rights.

6.5 National Health Bill - *awaiting clarification on exact status!*

At the moment a draft a new Health Bill is being prepared. It is likely that it will contain extensive provisions for guaranteeing other health

rights for South Africans. Similar legislation is also being prepared by several provincial governments to provide policy at provincial level. Please see Appendix IV for the latest draft of Chapter 2 (on Health Rights) of the National Health Bill.

6.6 Public Service Delivery - Batho Pele

"The nurses are ill-treating the people...they always chasing them away, they don't want to listen (to) the patients. And they only care about those they know." (Female, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

The quality of public service delivery is an important issue in the context of fulfilling socio-economic rights. Systems and attitudes have to be improved in order to produce a more efficient, equitable and accountable public service. 1997 was named 'The Year of Delivery' by the Department of Public Services & Administration. They launched 'Batho Pele' ('People First'), a public service delivery initiative.

Public sector reform requires customers' needs and priorities to be established. The gap between those needs and what is actually being offered has to be identified. Standards can then be set and the system geared up to deliver them. Customers need to be told what they can expect so that they can demand no more, but certainly no less, than their rights. Progress needs to be monitored and results published for accountability.

The Department of Health, Department of Home Affairs and North West Provincial Department of Local Government have been pilot departments for an initiative to improve standards and service delivery. The results are due to be published by the end of 1998.

"It is my rights to say, "You must help me, because you told me at five o'clock, I must be here. So I'm here. You must help me." (Female, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

As health policies, programmes and practices inevitably impact on human rights, public health sector employees are responsible for promoting and protecting human rights, or at the very least avoiding

violations. Plans to implement a National Patients' Charter are an important part of urgently needed reform in the public health sector.

6.7 National Patients' Charter (to be launched in 1999)

"At Site B Day Hospital...some will come early as four o'clock...they did not get to be cared for anyway. So you have to go home without being cared. So some use to die there in the chairs." (Female, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

Section 234 of the New Constitution makes provision for the adoption of charters by stating, "In order to deepen the culture of democracy established by the Constitution, Parliament may adopt Charters of Rights consistent with the provisions of the Constitution."

In April '97, the Department of Health recommended that a Charter of Patients' Rights and a national campaign to improve the culture of caring within health services should be undertaken. "As part of the democratisation of society and in view of its powerful symbolism, the rights of patients should be entrenched in a Charter." (Department of Health report, 1995. Towards a National Health System. Ch 5.3).

It is envisaged that the introduction of a Patient's Charter will bring about the following potential outcomes:

- Improved consumerism within the National Health System.
- Raised awareness amongst both the consumers and the providers of health care.
- Raised expectations of patients and their empowerment in terms of them participating in health matters.
- Changed attitudes of health care providers.
- Strengthened partnership between consumers and providers.
- Improved quality of care provided.

The contents of this Charter are being finalised. Please see Appendix II for the latest draft. It will clarify and promote South Africans' health rights. It will consolidate all the work done on health rights over the past few years by professional bodies and NGO's such as NPPHCN.

The National Patients' Charter has been influenced by the New Constitution and its Bill of Rights, the RDP, the White Paper for the

Health Transformation of the Health System, the "Batho Pele" Initiative, The National Health Bill and the NPHHCN's Health Charter. It contains references from the Department of Health's 'A Handbag of Women's Health Rights', the Geneva meeting on mother to child transmission of HIV and The Rights of Parents and Children, Lawyers for Human Rights' 'Disability Rights Charter of South Africa', The South Africa Nursing Council's 'The Rights of the Patient', South African Medical Association's 'Patients' Rights' and Addington Hospital 'Charter of Patients' Rights'.

Government backing for a single health charter will increase consumers' expectations and empower citizens to demand their rights. Gradually, this will effect the attitudes of those providing the service.

6.8 Other Instruments to protect Health Rights

"You rather stay at home than being treated by the doctors who say something that you don't know or you don't agree with." (Female, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

6.8.1

CREDO of South African Medical Association (SAMA)

I, a doctor and member of the South African Medical Association,
Believe in the sanctity of life and in the promotion of optimal quality of life for all.
I will therefore strive:

To use my knowledge and skills to promote and protect the health of my fellow human beings,
To place medical care above consideration of race, gender, creed, social standing, political allegiance or nature of disease,
To foster a good relationship with my patients, based on mutual respect, communication and trust,
To respect the rights of my patients, including the right to informed consent,
To respect the confidentiality of information entrusted to me,
To recognise my limitations and to consult with, or refer to, my colleagues when necessary,

To maintain and improve my professional skills,
To respect and protect the rights of my colleagues,

To sustain and promote integrity, insight and a caring nature within the medical profession.

6.8.2

Code of Conduct of SAMA

The South African Medical Association believes that... doctors should:

1. Dedicate themselves to the health and service of mankind.
2. Promote health for all by sharing responsibility for the health and health education of society.
3. Strive to ensure that everyone has equal access to affordable health care.
4. Strive to provide medical care to disadvantaged and vulnerable groups.
5. Strive to improve the standards and quality of health services in the community.
6. Not condone or participate in torture or any other form of cruel, inhuman or degrading procedure, towards any person.
7. Treat persons held in custody in the best interests of their health and with the same concern as other patients.
8. Endeavour to influence non-medically qualified practitioners to adopt safe practices.
9. Place medical care above consideration of race, gender, creed, social standing, political allegiance or nature of disease.
10. Foster a good relationship with their patients based on mutual respect, communication and trust...
11. Respect the desire of a patient to die in dignity and comfort and allow the natural process of death to follow its course in the terminal phase of sickness when the patient requests this...
12. When determining professional fees, consider the financial position of their patients and be prepared to discuss fees with them.
13. Respect the rights of patients, including the right to informed consent.
14. Make available to a patient a brief factual written report regarding his or her health status if the patient has reasonable grounds for requesting this.
15. Respect the confidentiality of information entrusted to them, unless law or ethical duty prevents this.
16. Recognise their own limitations and recommend to a patient that other opinions and services be obtained when this is considered in the best interests of the patient...
17. Make all relevant information available to the colleagues concerned.
18. Report their findings and recommendations back to a colleague when asked to consult about a patient.
19. Take reasonable steps to consult the doctor in charge of a case before superseding that doctor.

20. Participate in continuing education so as to improve the standard of medical care.
21. Conduct themselves in a professional manner that is beyond reproach, and take any necessary steps to correct unethical behaviour by colleagues.
22. Ensure that they maintain their professional independence and integrity when entering into any contract regarding professional services; recognise that they remain personally responsible to their patients for care; and ensure that the terms and conditions of their contract are fair.
23. Ensure that information about themselves given in the course of presenting medical topics to the media or to audiences does not imply that they are the only, the best, or most experienced practitioners in a particular field. They should also avoid activities that could be regarded as canvassing or touting for patients.

6.8.3

Ethical Rules of the South African Medical and Dental Council (SAMDC)

Rules specifying the acts or omissions in respect of which the SAMDC may take disciplinary steps:

1. Advertising his services in an unprofessional manner...
2. Canvassing or touting for patients personally, through agents or in any other manner.
3. For a practitioner to carry on a regularly recurring itinerant practice at a place where another practitioner is established...
6. For a practitioner to accept commission from a person...in return for the purchase, sale or supply of any goods, substances or materials used by him in the conduct of his professional practice.
7. Paying commission to any person for recommending patients...
10. Practising in partnership or association with a person not registered in terms of the Medical, Dental and Supplementary Health Service Professions Act, 1974...
13. Employing as an assistant or *locum tenens* any person not registered as a practitioner.
14. In any way helping or supporting any illegal practice or conduct...
15. Employing a person whose name has been removed from a register kept by the council...
16. In cases where he should be aware that a patient is under treatment by another practitioner, superseding such other practitioner without taking reasonable steps to inform the practitioner originally in charge of the case.
17. Impeding a patient...from obtaining the opinion of another practitioner...

18. Unjustifiably casting reflection on the probity or professional reputation or skill of a person registered under the Act.
19. Divulging any information on a patient that ought not to be divulged, except with the express consent of the patient or, in the case of a minor under the age of 14 years, with the written consent of his parent or guardian...
20. Granting a certificate of illness without such certificate containing the following information: (i) the name, address and qualifications of the practitioner; (ii) the name of the patient (iii) the employment number of the patient (if applicable) (iv) the date and time of the examination...(vi) a description of the illness, disorder or malady in layman's language...
24. Making use in the conduct of his practice of any form of treatment, apparatus or technical process that is secret or is claimed to be secret...
25. Sharing consulting or waiting rooms with a person not registered...
29. The performance, except in any emergency, of a professional act for which he is inadequately or insufficiently experienced...
31. Permitting himself to be exploited in a manner detrimental for the public or professional interest.
32. Participating in the manufacture for commercial purposes, or the sale, advertising or promotion of any medicine as defined in the Medicines and Related Substances Control Act 1965...
34. Where a practitioner has a financial interest in a private clinic or hospital, referring a patient to such a clinic or hospital without displaying a conspicuous notice in his waiting room indicating that he has a financial interest...

6.9 NPPHCN's Advocacy for Health Rights

"They (health workers) treat you as if you are stupid, they just give you hell and harass you." (Zulu-speaking female in Gauteng. Qualitative research commissioned by NPPHCN into responses to the 'Reach for your rights' radio social action spots).

Non-governmental organisations, particularly the National Progressive Primary Health Care Network (NPPHCN), have been at the vanguard of pushing for improved health rights.

NPPHCN was created out of the belief that health care is a basic human right and vital to development, and that apartheid health services violated basic human rights.

6.10 NPPHCN's Health Rights are Human Rights Campaign

Since 1995, NPPHCN (footnote: This has been made possible by generous support from the Kaiser Family Foundation) has been running a high profile campaign called 'Health Rights are Human Rights.' Its aims are to improve health care by improving the service provider-consumer relationship, raise awareness of health rights, develop a Health Charter and get the Government on board.

Phase One

The First Phase, in early 1996, was a media campaign involving *The Sowetan* and *New Nation* to raise awareness of the concept of health rights. It focused on rights to confidentiality, communication and full information from your health worker.

Ulwazi Radio Education Project produced radio advertisements in five languages which were put out on all major commercial stations. It was the first time "social action spots" had been used for health promotion in South Africa. The advertisements were ordinary people talking about their experiences of the public health sector. Listeners were asked to ring a helpline (run by Sowetan Help Centre) to share their stories of abuses at health facilities and to suggest what they thought should be health rights. 'Reach for your rights' was the slogan.

Qualitative research was commissioned to evaluate pre- and post-campaign perceptions and attitudes to health rights and also to evaluate the radio spots.

Phase Two

The Second Phase, launched on Human Rights Day 1997 (21 March '97), was drafting a health charter. Through a series of workshops, NPPHCN had received a mandate (from government, other NGO's, traditional healers, private sector and labour organisations) to draft this charter. It was launched in December 1997 together with a toll-free helpline number (0800 114010) manned by trained NPPHCN staff. Please see Appendix I for a copy of NPPHCN's Health Rights Charter.

Research carried out by NPPHCN's Media & Training Centre revealed that access to basic socio-economic rights is still beyond the reach of a large percentage of the population. Health organisations need to provide communities with knowledge of their rights; to empower them to participate more in matters affecting their health.

In people's minds, the concept of rights is associated with hard-won democracy and equality.

"Before the ANC got the independence, we could...at the clinics maybe you don't get the... You couldn't tell them what to do. They just give injection. You couldn't tell them that you don't want Depo injection. But now you can tell them that you want this and this..." (Female, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

However, "...in some contexts the use of the concept "rights" suggested that rights are seen as something that you have or do not have based on the particular circumstances of your life." (Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996 pg 15)

The idea of "inalienable" rights is countered by the reality concept of rights. Many of the interviewees in the focus groups indicated that they felt that, although you might be entitled to something, reality dictates whether you really have it or not.

Disadvantaged people do not perceive that health rights are for them. Many have low expectations of health care. Their experiences are of travelling long distances, waiting for hours, being sent home to return another day for consultations that are too short to be effective and disrespect from health workers. A lack of information about where, when and how to access health services has effectively disempowered those who feel that they have too little money to afford anything better.

"Without a clear and vigorous concept of rights, non-racial democracy is like a fountain with water, beautiful but stony." (Sachs, A. 1990. Protecting Human Rights in a New South Africa, pg vii)

Some interviewees had no idea of what a health right means or of the existing mechanisms to claim redress for violations within the health sector. They had little faith that they would be listened to if they tried to complain.

People's perceptions of health rights revealed how they saw socio-economic issues interconnecting. Inaccessible, low quality health services were just part of a wider picture involving unhealthy environmental conditions, unemployment, crime, and lack of rights and opportunities for women and children.

"We haven't got yet the rights. We must still try to get our rights from them...from our husbands. We black women. We haven't got rights yet. That's why it is up and down..." (Female, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

It is the most vulnerable people, living in conditions detrimental to their health, who are also the ones having greatest difficulty accessing health care. They are also the group treated the most unfairly by health workers.

A previous NPPHCN survey: 'Hearing the People: a national household survey of health needs' by Hirschowitz, R & M Orkin (1994) revealed that 63% of Africans and 25% of Coloureds thought that there were environmental things wrong where they lived that affected their health such as unsafe water, dirty streets and inadequate toilet facilities.

"Discrimination against blacks, I mean if they are very ill, they must take you to any hospital." (Sotho-speaking male in Gauteng. Qualitative research commissioned by NPPHCN into responses to the 'Reach for your rights' radio social action spots)

Of those interviewed, 45% of Africans and 17% of coloureds had avoided going for health care because of the cost. 22% of Africans had been refused medical treatment because they could not afford it.

Blacks wait longer for service than whites: half of Africans got service within an hour but a third waited between 2-3 hours. Half the Africans had consultations lasting five minutes or less.

"If they don't know you, you going to sit there for the whole blessed day..." (Female, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

Phase Three

Phase Three of the 'Health Rights are Human Rights' Campaign will popularise the Government's National Patients' Charter utilising multi-media and face to face initiatives.

6.10.1 Applying the National Patients' Charter to Local Health Facilities

Important as it is to have the National Patients' Charter, it will only become meaningful if its contents are expressed as real rights that people can expect when visiting their local facility.

One way to achieve this is for the consumers at a specific health facility to get together with the staff to discuss the rights and responsibilities of users and providers there. Then, together, they could formulate a local charter to consolidate their ideas.

If the planning, implementation and evaluation of a negotiated local charter, is the joint responsibility of the community health committee (representing users) and management staff (representing providers), there is a much better chance of compliance with it. With joint ownership, all parties will be committed to it.

From the community health committee's point of view, negotiating a charter provides an additional tool to supplement policy critique and formulation, as participation in decision-making for governance helps assure a reasonable level of quality in the health service provided.

6.10.2 Practical Steps in Producing a Local Patients' Charter

A meeting or workshop between community health committee and facility management team could be arranged in order to:

- Discuss achievements for the service and wishes for the type of service that is desired.
- Learn about health rights as they apply to both patients and providers.
- Prioritise health rights in terms of their applicability to the facility.

- Produce a joint written document representing the agreed local health charter.
- Agree on how to jointly measure the extent to which the charter is being implemented.
- Produce a poster or brochure to explain health rights to all the other users of the service and staff.
- Implement the charter and evaluate it at monthly meetings of the community health committee.

Example of a Workshop to develop a Local Patients' Charter

Objectives of the workshop:

- Increase mutual tolerance between staff and community health committee.
- Improve the understanding of services provided by a facility as well as unmet needs or concerns.
- Deepen awareness of health rights and how a charter could be used to improve the quality of care.
- Prioritise important sections for the local charter.
- Write a simplified local charter.
- Determine tools to measure implementation of the charter.
- Produce agreement on implementation of the charter.

Target Group for the Workshop

- Members of community health committees, hospital boards, clinic committees etc
- Management of facilities, whether hospital, health centre, clinic etc
- Personnel of health facilities who come into contact with users.
- Personnel from other sectors who need to interact with the health sector.

Examples of educational sessions to train communities

Session Activity

1 Ice-breaker - introductions - name and an action starting with the first letter of the name, that would improve the health of others. Tell the story of "The Unhappy Clinic" (see below). Break into mixed user/provider groups to discuss its implications.

2 Keynote input on health rights.

3 Health rights game - getting through the system.

4 Wishes for the service. The users and providers sit in separate groups. The first task is to list the achievements of the service. The second task is to list wishes for a better service.

5 Role play - users play providers and vice versa.

6 Reading the charter together. Ranking rights within the charter in order of importance or grouping them and ordering the groups.

7 Writing a list of practical examples at the facility level of important rights.

8 Choosing appropriate indicators and how to measure.

9 Compiling a local charter.

10 Designing a poster for the facility.

11 Planning further action.

Case Study for use in Workshops - "The Unhappy Clinic"

Angilondolozi Clinic is a clinic that was erected in 1982 to provide separate services for blacks living in Solani Township a few kilometres down a dusty road from the white town of Golden Acres. Solani had a population of 20,000 people and was growing rapidly, whereas Golden Acres had a population of about 5,000 which was somewhat static.

The reason for the clinic being erected there was that the majority of white ratepayers in Golden Acres were becoming worried about the rapid growth of Solani. This was costing the municipality a great deal to service. Increasingly Golden Acres residents were also dissatisfied with dirty, drunk and disorderly township residents using the town's Curewell Hospital. This was dragging its standard of care down by overcrowding it.

Curewell had an international reputation for its superb neurological intensive care unit and sophisticated MRI scanner that was state of the art. All this had been inspired and built up by Dr Brain, one of Golden Acre's most famous citizens. It was felt that if a clinic was

built which could provide more effective family planning services, then the population wouldn't grow so fast, and residents would have enough money to pay for their own services. Immunisation services were also provided to prevent contagious diseases, which could spread.

Conditions in Solani, were very different from those in Golden Acres. There were a series of water taps near the entrance to the township that were erected when the clinic was built. For the most part, residents who lived five to ten kilometres further down the road collected water from the Umnyama Stream which ran from the industrial area on the outskirts of Golden Acres, past the clinic, along the road through the centre of Solani, and on to the main residential areas of the township. Although the stream was sometimes reduced to a trickle, there was usually enough clear drinking water there to collect if a person was prepared to be patient.

Fortunately there was also a small dam where the stream was at its widest near the centre of Solani. It was here that women could bring their laundry to wash and share experiences, while children could bathe on hot sunny days. Refuse was also collected from an open container next to the clinic, at the entrance to the township. After a scare of cholera in the early 1980's, approximately two thirds of the residents of Solani built pit toilets after warnings issued by the Health Inspector in Golden Acres. The rest used the wooded and secluded areas along the banks of the stream. About half the people in Solani worked in one or two big factories in the industrial area on the outskirts of Golden Acres. There was some talk of retrenchment as there had been a downturn in the economy.

Morale among the staff at Solani Clinic was not very high. Many of them had been trained at Curewell and did not like the facilities at Solani. The matron who was in charge of Solani was determined to model the clinic on the hospital. She had persuaded the authorities, which had once made the service free to encourage people to use the family planning services to allow the clinic to charge a fee. This money was used to improve facilities at the clinic. For example, a recreation room was built for the staff and this did a little at least to improve their morale.

To improve efficiency in the clinic, the clerk at reception had instructions to chase away those who did not have enough money.

After taking the money, and people's names and addresses, he was then to write down the main thing that the person was complaining of, and send them to the appropriate part of the clinic, for example where they treated STD's. The clerk was an elderly man, who had many years of experience in dealing with malingerers and was known for only allowing those who were genuinely sick to attend the clinic. The staff appreciated this, as it kept the numbers of people attending the clinic reasonable and allowed them to knock off early, which was a good thing for their families. Because they could easily attend to the people who attended the clinic during the day, it was also not unreasonable to start a little later than some other clinics. This the staff also thought was a good thing because it gave their patients time to reach the clinic leaving at a reasonable time instead of daybreak.

The clinic mainly dealt with preventive care such as family planning and immunisations. As part of the transformation of the health system towards district care, it was also treating minor ailments now. Very sick people could be referred to Curewell Hospital. An ambulance would be sent out of town to the clinic, to pick up sick people a few times a day. It would even come out at night, for someone who was desperately ill, if the matron phoned to call the ambulance, but the staff, who lived in Golden Acres, refused to go into the township which was dangerous.

The family planning sister, the only staff member in the clinic who was not African, had once worked for a religious order and was also responsible for the STD clinic which was a new service that had been started to cope with the advent of AIDS. She spoke with an English accent that many of her patients couldn't fully understand, and although she was well known for her kindness, she believed strongly that young people should be firmly told to avoid having sex until they were married. She never missed the opportunity of advising everyone who came to the clinic about this. As a reward for good behaviour, she reserved the more expensive forms of family planning and treatment for those who behaved responsibly and had decent lifestyles. For those who were promiscuous or who had many babies, she recommended tugal ligation.

Despite the short hours, during the times that it was open, the clinic was always crowded. There wasn't always enough room for everyone to

rights...here in Khayelitsha." (Female, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

'Apartheid medicine' left health resources unevenly distributed. Many people are still deprived from enjoying their fundamental socio-economic rights and freedoms. It will take some time, but The New Constitution intends the right to health to be a justifiable right, not just a distant hope.

Legal Action

If medical confidentiality is breached by a health worker, you can complain. If your complaint is justified, the doctor could be struck off the medical register. You could also sue for damages.

In Jansen van Vuuren v Kruger (1993), Barry McGeary's doctor told him he was HIV-positive after an insurance test and then breached confidentiality by telling another doctor and a dentist on the golf course. The judge ruled that the doctor had been justified because the other doctors were involved in McGeary's treatment. Later, the result of 'The McGeary Case' was challenged by HIV/AIDS and human rights organisations and overturned by the Appellate Division.

The Constitution is supreme law. There is a Constitutional Court and a number of impartial institutions to implement socio-economic rights, which are more complex than enforcing civil and political rights.

Institutions to Monitor and Enforce

The South Africa Human Rights Commission (SAHRC) has a Constitutional mandate to establish a human rights culture in South Africa. It is obliged to obtain information from all relevant state departments (such as housing, health care, education etc) on the progress they are making to implement the Bill of Rights. It checks that active steps are being taken to achieve a more equitable society. Its annual report is tabled in Parliament.

The Office of the Public Protector, also set up in 1995, is concerned with administrative irregularities, corruption in the public service, inefficiencies, wastage and complaints from the public in regard to treatment by the state.

The Commission on Gender Equality, established in 1997, safeguards women's rights and deals with inequality and discrimination.

There is also a Land Restitution Commission and Youth Commission.

NGO's also play an important part in monitoring human rights and protecting democracy.

"The greatest challenge we face in promoting and protecting human rights in South Africa is this environment of selective and partial accountability and the widespread cynicism about government, taking government for granted, a culture of resistance which is a throwback from the past." (Revd Dr N. Barney Pityana, Human Rights in South Africa: Setting the Context, SAHRC)

6.12 When things go wrong in the Health Sector...

When Mavis Lehola's twins died, she went to the Legal Aid Board. They told her that because the babies were dead, there nothing that could be done. She was advised to complain to the hospital.

When people's health rights have been violated, they do not know what to do. Who should they complain to? If they fail to be satisfied by the response of the first person they talk to, who should they go to next?

"We are not sure who is superior between the doctor and the matron. We must be well informed where we are supposed to report." (Zulu-speaking female in Gauteng. Qualitative research commissioned by NPPHCN into responses to the 'Reach for your rights' radio social action spots)

Basic Complaints Procedure

First, talk to the person directly involved in your health care problem - the nurse, the midwife, the doctor,

If they are unavailable, unapproachable, or the reason for your complaint, talk to their manager - the matron or consultant on the hospital ward, the practice manager or senior partner in the GP's clinic...

If you still receive no satisfaction, contact the person in charge of the facility: the Superintendent of the hospital or the Health District Manager responsible for your clinic. You could make an appointment to go in person or put your case in writing to them

You should also involve your community health worker, health committee, and your elected community structures at any stage in the process...

You could make a complaint to the health worker's professional organisation. For instance if you wish to make allegations about a physician's misconduct, you can contact the Ombudsman of the South African Medical Association (tel: 0800 11 9820 or 011-465 9577) or the Professional Conduct Department at the South African Medical & Dental Council (SAMDC) (tel: 012-328 6680). If you wanted to make a complaint against a nurse, midwife or auxiliary staff you can contact the Professional Conduct Department at the South African Nursing Council (SANC) (tel: 012-343 0121). They require complaints in writing and certified by the police. The SANC write to the hospital to gather all relevant information and a statement from the nurse involved. If you cannot remember the name of the nurse, they are able to source it through the hospital's duty roster.

The case is considered by the SAMDC's Committee for Preliminary Inquiry or by the SANC's Committee for Preliminary Investigation. These bodies decide whether there is a case to answer. If there is, the case is passed on to the SAMDC's Professional Conduct Committee or the SANC's Committee for Inquiry. The case is then tried like a court of law. They have the power to impose penalties ranging from a caution to a fine or removal from the professions' registers. If a health professional is struck off, their name is published in the *Government Gazette.*

The SAMDC's official grievance procedure is attached as Appendix V.

Other options include approaching the South African Human Rights Commission, the Consumer Court or the Constitutional Court.

Advice and support is available on NPPHCN's toll-free helpline. (tel: 0800-114010)

Mechanisms to enforce the National Patients' Charter

TO ADD - A paragraph on any special mechanisms to address breaches of the National Patients' Charter? Should this be available at the time this draft is finalised

Chapter 7 Conclusion

"It's my right to express myself that that pain is still there or that wound is not even yet been cured." (Male, urban interview from Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996)

Good health is vital to secure human dignity, happiness and fulfilment. Human dignity requires respect from your neighbour and your health worker as well as from the state. Even collectively, the power of international conventions, national laws, medical professions' codes of conduct and health charters cannot ensure everyone's respect for others' health rights. However, these instruments do help less assertive people enjoy their rights. They offer moral support to those trying to improve the health system and when problems occur, they assist those who have been wronged.

7.1 What next?

In order to build a human rights culture everyone needs to understand exactly what human rights are and value them. Then, voters need to demand that they guide all government laws, policies and programmes.

This is dependent on human rights education.

7.2 Human Rights Education

Education is a basic human right; so is the right to know your rights. People cannot defend their rights unless they know what they are. Human rights education allows a person to make decisions that protect their own health. The resulting dignity and autonomy in turn contribute to their health and well-being.

The UN General Assembly announced 1995-2005 to be the 'Decade of Human Rights Education'. "Every citizen of the 21st century should have the knowledge of the fundamental human rights upheld by the international legal standards that provide the norms for a just and peaceful world community." (Reardon, BA. 1995. Introduction: Purposes and Approaches. Educating for Human Dignity: Learning about Rights and Responsibilities, University of Pennsylvania pg 3)

South Africa's National Action Plan (NAP), National Health Act and National Patients' Charter will all be finalised within the next year. They will provide useful platforms for the promotion of health and human rights, aided by the on-going human rights education efforts of SAHRC, consumer groups and NGO's like NPPHCN.

The messages will only reach grass roots by the efforts of health professionals. Health advocacy, through protecting human rights, is part of their duty to alleviate suffering. "The institutional and societal context of health, and the professional practices and methods employed in seeking to ensure the well-being of individuals and populations, create additional human rights-related roles and responsibilities for health professionals..." (Mann, J. Health & Human Rights: Broadening the Agenda for Health professionals. Health & Human Rights 2: 1:1-3)

Health professionals need to educate themselves about broader health rights as part of their health promotion activities. They will then be in a position to educate the public about health rights as a means of improving the health of the nation.

NPPHCN is currently producing a health rights education kit and hopes to use the media to reach audiences that workshops alone cannot. The Human Rights Institute of South Africa (HURISA) and a number of other organisations offer training in health rights as part of their socio-economic rights training packages.

7.3 Co-operation

The United Nations Charter called for co-operation "in promoting and encouraging respect for human rights and fundamental freedoms." If abuses are to be eradicated in the health sector, co-operation is required between patients and health workers, between health managers and staff and between government and other organisations working to improve health provision. Patients must know their rights and responsibilities. Health workers must strive to change some of their practices and attitudes despite being over-stretched and under-resourced.

Much work is required to transform the National Health System so that everyone has equal access to basic health care and is treated with the same respect. "No amount of idealistic health rights education can have a substantial impact on people's conceptualisation of health rights if the system does not allow for a basic need to be perceived as a right instead of an unattainable privilege." (Rights & Realities: Pre-campaign Report, NPPHCN Media & Training Centre, 1996 pg4-6).

Health rights should not just belong to those who are able to realise them.

Appendices

1. Health Rights Charter (NPPHCN), 1997.
2. National Patients' Charter (Draft), Department of Health, 1998
3. NAP Health Rights Section (Draft), SAHRC, 1998
4. National Health Bill, Department of Health, 1998
5. SAMDC, Official Complaints Procedure

APPENDIX I

HEALTH RIGHTS CHARTER, NPPHCN, 1997

Many organisations and individuals' inputs have been compiled into this set of health rights.

This section contains what a large number of South Africans identified as being their health rights. These rights should be read in conjunction with the body of rights that protect the rights of women, children, people with disabilities, health providers, prisoners and people with specific diseases, as outlined in the Bill of Rights.

Health rights are a concept, which includes the rights of patients, health promotion and prevention and incorporates factors such as access to clean water, sanitation, nutrition and housing.

Access to Care

You have the right to:

- Access to health care services in time of need, irrespective of your ability or inability to pay. The health service is there to respond to your needs and this requires your co-operation, respect and support. The National Department of Health has expressed its commitment to provide equitable health care to all South Africans.
- Reasonable expectations in terms of a range of services and the quality of care.
- Affordable health care.
- Information about health care services, health policy and referral mechanisms to ensure that access to health care services is efficient.

Care in the Community

- The health service is based on the referral chain. This means that you are required to visit your local health centre or general practitioner when you are not feeling well. However, if you are involved in an accident or emergency you can go to the nearest hospital without referral.
- Home visits should be provided.
- You have the right to have community health care workers available in your locality to assist you with your health care needs.
- You have the right to consult community health care workers on matters which concern your health. You do not have to wait till you are ill.

Choice

You have the right to exercise your choice without fear of moral or ethical reprisals from health workers.

Communication

You have the right to:

- Be communicated with in a manner that puts you at ease.
- Be communicated with in a language that you can understand. Interpreters should be available when necessary.
- Have complicated and complex medical issues simplified.

Complaints and Redress

You have the right to:

- Express your views and opinions through your hospital board, health centre committee or community health worker.
- Take a complaint on health services to immediate managers.
- Have your complaint investigated and to receive a full and prompt reply.

Confidentiality

Save for the requirements of the law, all information concerning your health or personal circumstances, will be kept in confidence and used only for purposes of your treatment on condition that it does not place others at risk.

Courtesy, Patience, Honesty and Transparency

You have the right to:

- Be accorded courtesy and to be treated with patience, with health care providers allowing sufficient time to undertake thorough examination and to take correct patient history, in a clean environment.
- Be treated with empathy and tolerance by health workers.
- Be assertive and to express your needs in a language of your choice, and to have your cultural and religious beliefs respected.

Dignity, Respect, Privacy and Confidentiality

You have the right to:

- Privacy and dignity concerning your illness and medical management of that illness. Case discussions, examinations and treatment shall be conducted in confidence.
- Refuse permission for the presence of health science students and allied health personnel trainees if they are not directly involved in your care. They should always be introduced to the patient.
- Expect that all health records and other information will be kept confidential.

Discrimination

You have the right to be received and attended to irrespective of sex, age, religion, colour, tribe, race or socio-economic status.

Doctors, Dentists and Specialists

You have the right to:

- Have access to a doctor, a dentist and other health specialists.
- A brief factual written report regarding your health status if requested on reasonable grounds.

Drugs and Medicine

You have the right to:

- Have appropriate drugs and medicines prescribed.
- Have all the information about the effects of prescribed drugs explained in a language that you can understand. The health service aims to ensure that all drugs and other sundries required for your treatment are available.
- Request information about medicines prescribed to you, even though some pre-packaged medicines carry comprehensive information concerning the use of the medicines and their effects.

Fees

You have the right to discuss fees and related medical costs with a health provider.

Health Promotion

A range of health promotion activities were identified as a need in communities. These include breast-feeding demonstrations, exercise for pregnant women, exercise for the elderly, substance abuse education, care groups, adequate food security, to be taught about health rights and to re-establish confidence in the public sector.

Information

You have the right to:

- Information regarding prevention, diagnosis, prognosis and treatment.
- Have access to your health records and to know that everyone working for the NHS has a legal duty to keep your records confidential.
- Receive information on local health services. Your health facility should openly display information on their charter.

Informed Consent

You have the right to:

- Receive all the information needed to reach a decision on whether or not to agree to the treatment or procedure. Options should also be included in the information.
- A second opinion.
- Be consulted and to give consent on any research or teaching to be carried out on you.
- Know what other choices, if any, you may have instead of the treatments or procedures indicated.

The information provided should include:

- An explanation of the procedure and/or treatment involved.
- The associated risks that go with the procedure or treatment.
- How the treatment or procedure may affect your lifestyle (will you be able to work and function normally).
- The right to know the names and qualifications of the person/s who will be responsible for the treatment and/or procedures.
- In emergency situations health providers are not responsible for providing extensive information because giving such information may take vital time and therefore, endanger their patients' lives.

Palliative Care

You have the right to:

- Die with dignity and in comfort.
- Receive or decline spiritual care and moral comfort, including the help of a minister of religion, as well as the support of family, relatives and friends during the course of care and treatment.

Safety and Security

You have the right to be protected from all forms of danger, including gangsterism and hijacking when entering a health facility. Premises must be protected with reasonable security measures to protect health care users and providers.

Services – Hospitals, Ambulances and Accommodation

Admission and your stay in hospital:

- In the event of an accident or emergency you have the right to be attended to by competent health workers.

- You have the right to be assessed and dealt with appropriately, immediately upon arrival.

Whether you are admitted as an emergency or not, hospital staff shall:

- Inform your relatives/next of kin or whomever you wish, where practical.
- Keep your clothes and valuables in a safe and clean place.
- Give you clear information about your illness and condition and the treatment plan for your recovery.
- Give you clear information about domestic arrangements and any other information relevant to your stay in hospital.

Ambulance and Transport:

You have the right to:

- The provision of ambulances or other transportation when needed.
- Expect an ambulance to arrive if you call for one. You can help by remembering that the ambulance is there to help people in emergency. Irresponsible use can lead to a loss of lives.

Treatment

You have the right to:

- Emergency medical treatment. This right is guaranteed in the Constitution of South Africa.
- Be treated according to generally accepted medical standards.
- Continuity of care in respect of co-operation between health care workers or establishments which may be involved in treatment or care.
- Discontinue a relationship with any health provider or health facility without any fear of reprisals or prejudice.
- Refuse treatment with the full knowledge of your right to take action against providers not fulfilling your request.
- Participate in decisions about your treatment regime.

Water, Sanitation and Waste

You have the right to adequate water supply, sanitation and waste disposal.

Other Services

You have the right to:

- Free primary health care for pregnant and nurturing mothers, and children under the age of five.
- Free immunisation for your children.
- Reproductive choice.

Health Responsibilities

With every right there is a responsibility. As users of the health care system we are required to take on some responsibilities to ensure that our rights are met. Your health rights will only be achieved if you balance your role and contribution.

You have the responsibility to:

- Have realistic expectations of the health service
- Take care of your health
- Be sensitive to others
- Be courteous to providers
- Help your community meet the needs of the disadvantaged
- Provide accurate information to providers

- Take care of health records
- Respect the privacy and dignity of health providers
- Present yourself on time and comply with treatment procedures
- Be constructive in your complaints
- Pass on information to your communities
- Refrain from smoking in health facilities
- Be in a sober and coherent state when presenting yourself at health facilities
- Ensure the safety of providers
- Exercise choice
- Support fair remuneration of health workers
- Be non-discriminatory, non-racist and non-sexist
- Avoid inconvenience and delay, get to know your local health services and what they offer.

APPENDIX II

National Patients' Charter (Draft), Department of Health, 1998

APPENDIX III

National Action Plan
Health Rights Section (Draft),
SAHRC, 1998

APPENDIX IV

National Health Bill, Department of Health, 1998

APPENDIX V

SAMDC
Official Complaints Procedure