STEPS for CHANGE

A human rights action guide for health workers

International Federation of Health and Human Rights Organisations

Are you a health worker?

yes →

Is there anything within your healthcare system which negatively affects the ability to provide high quality care to patients?

no →

Do you work with health workers or for an NGO on health?

← yes

no →

Then this guide is not directly meant for you, although you may still find it interesting.

yes / no

So the healthcare system you work in must be absolutely perfect.

no ↓

So there is something that should be changed to improve care to patients.

← yes

yes ↓

Read *Section I* to learn about health and human rights and the role of health workers.

Is it recognized as a problem?

yes / no

no →

Go to *Step 1* and *2* of the guide to learn how health system constraints can be framed as human rights issues.

yes ↓

Do you have a clear picture of what is causing the problem?

no →

Go to *Step 3* of the guide to identify why it is happening.

yes ↓

Is anyone doing anything to change it?

no →

Are you aware of all the actors involved?

no →

Go to *Step 4* of the guide to determine who is involved.

yes ↓

Is it working?

no →

Do you have ideas for change?

yes ↓

no →

Go to *Step 5* of the guide about types of action.

Do you know what your role could be?

yes

no ↓

Excellent! Go ahead and take action!

If you need further ideas and inspiration, or would like to concretize your plans have a look through the guide.

Contents

BACKGROUND & AIM

This is a guide for health workers who want to use human rights to improve their healthcare system. The guide was created in response to a question that often arises when we provide training to health workers on the interrelation between health and human rights:

How can I use human rights to address problems in my own workplace?

Of course the answer to this question is different for every health worker. What exactly an individual health worker can do depends on multiple factors including the abilities, connections and position of the health worker, the context or situation and the human rights issue.

At the same time all health workers have a unique position because they are the ones who directly experience and see the effects of those aspects of a healthcare system that do not conform with human rights. Due to the nature of their profession health workers inevitably play a role in the protection and realisation of health related human rights.

Through our training courses we have helped health workers understand how their profession is connected to human rights; to be able to recognise human rights issues within the healthcare system and know that human rights can help health workers in difficult situations.

This guide goes a step further by approaching human rights as a useful tool; to stop unjust practices, to get people to listen, to mobilise support and to find out what should change.

"When I was first called upon to examine survivors of ruthless beatings and maiming by state security forces, it turned out to be a loud call. Caring for these torture survivors changed from relieving pain and managing their injuries to intervening in gross violations and abuses. My understanding of my role as a clinician changed then. I could have chosen to be a silent clinician or to use my skills to document and stand up against these violations. Every day, I continue to choose the latter."
Dr Joan Nyanyuki, Kenya

"I have noticed that human rights are a powerful tool for realizing the right to health. Being health workers, we are dealing with a huge work load and have limited time for a comprehensive understanding of theories and application of human rights mechanisms. I think one of the main problems is that many doctors have not heard anything about human rights and the right to health during their medical school or residency years. We must emphasize the need for medical school curricula to include human rights."
Dr Nazmi Zengin, Turkey

SETUP & CONTENTS

The guide consists of two main sections, a list of additional resources and a glossary.

Section I provides basic information on the interrelation between healthcare and human rights. This section is not meant to be exhaustive, but serves to support Section II. Reference to publications with more detailed information about human rights and health advocacy can be found under additional resources. Relevant terms that may require further explanation are included in the glossary.

Section II contains a set of practical steps on how to frame healthcare problems as human rights issues and find out what steps to take for change. These steps need to be applied to a specific problem identified within a healthcare system. The steps work sequentially; the outcome of the previous step serving as input for the next step. Templates for each step can be found online at www.ifhhro.org. It is possible to start with the five Steps for Change in Section II and use Section I as reference where necessary.

"As a mental health worker I have been involved with people with mental disorders and disabilities, with war affected and internally displaced people, with torture survivors, prisoners, etc. In all these areas human dignity is generally abused.

Mental health is a field that is full of human misery and ill-treatment, stigma and exclusion. When I found the concept of human rights and started to learn about this mechanism I realized that I had obtained a strong foothold, a structure, an instrument for fighting with an inefficient system and reforming practices.

Human rights have given us a backbone which has become very important in our everyday work with:
- *our beneficiaries; to promote respect, confidentiality, inclusion*
- *the media; to promote rights and non-discriminatory wording*
- *state officials; to advocate for the best possible healthcare delivery or recommend appropriate standards and protocols of care*
- *society; to raise awareness on tolerance, stigma, rights to effective, affordable and available treatment, etc. etc."*

Dr Nino Makhashvili, Georgia

HUMAN RIGHTS FOR HEALTH WORKERS

section I

This section outlines the approach and direction of the guide and provides the background information on the Steps for Change in Section II. The connection between health, human rights and health workers is explained to clarify how this interrelation can be used for action. A list of additional resources with more information on human rights can be found at the end of the guide.

The following four questions are addressed in this section:

❶ What are human rights?
❷ How are human rights related to health?
❸ How can human rights be influenced by health workers?
❹ How can human rights be used for better healthcare?

WHAT ARE HUMAN RIGHTS?

Human rights are freedoms and entitlements that belong to every human being irrespective of origin, status or beliefs. They represent those values that are fundamental to basic human dignity, development and survival. Respect for human rights protects individuals and groups from injustice and prevents abuse of power.

Human rights are legally protected by international and regional treaties and national laws. These legal documents impose obligations on governments to respect, protect and fulfil the rights of individuals. This means human rights act as claims on the government.

Human rights are supported by accountability mechanisms which assess how governments carry out their human rights obligations. These courts, committees and other procedures require governments to show, explain and justify what is being done to realize human rights. Accountability mechanisms include national human rights institutes, regional human rights courts United Nations Treaty Bodies and Special Rapporteurs.

HOW ARE HUMAN RIGHTS RELATED TO HEALTH?

The interrelation between health and human rights has three dimensions:
❶ Human rights within the healthcare system
❷ Human rights that influence health
❸ Human rights violations that cause health problems

How do these three dimensions have an impact on the daily practice of a health worker?

❶ Within the healthcare system policies, practices and situations can affect human rights such as the right to health, the right to privacy or the right to information.

❷ Human rights such as the right to adequate food and nutrition, the right to clean water and the right to education influence whether people get ill, what type of health problems they may suffer and if they will find their way to a health facility.

❸ Persons with health problems caused by human rights violations such as torture or violence against women may end up at healthcare institutions and require professional care.

Although each dimension is equally relevant the main focus of this guide is on the first dimension.

The Three Dimensions of Health and Human Rights

The Three Dimensions of Health and Human Rights

- Right to health • Right to information • Right to privacy • Right to liberty
- Freedom from inhumane or degrading treatment • Freedom from discrimination • Right to participation

1 Human rights in the healthcare system

2 Human rights that influence health

3 Human rights violations that cause health problems

- Right to water • Right to education • Right to food • Right to housing

- Torture • Harmful traditional practices • Unsafe working conditions • Violence against women

Diagram inspired by: WHO, 25 Questions and Answers on Health and Human Rights, Health & Human Rights Publication Series Issue No.1, July 2002, page 8 'Examples of the links between health and human rights'

LEGAL SOURCES OF HUMAN RIGHTS WITHIN THE HEALTHCARE SYSTEM

This guide deals with seven human rights that play a role in the healthcare system (see the diagram on page 9). These rights are codified in a number of international and regional treaties. The following overview shows where these rights can be found in the relevant treaties and indicates the corresponding accountability mechanisms. More information on how these rights relate to healthcare can be found under Step 2 of Section II.

Human Rights Treaty	Accountability Mechanism	Human Rights within the Healthcare System
African Charter on Human and People's Rights	African Commission on Human and People's Rights African Court on Human and People's Rights	• Right to health, art. 16 • Right to information, art. 9(1) • Right to liberty, art. 6 • Freedom from cruel, inhuman or degrading treatment, art. 5
American Convention on Human Rights	Inter-American Commission on Human Rights Inter-American Court of Human Rights	• Right to information, art. 13 • Right to privacy, art. 11 • Right to liberty, art. 7 • Freedom from cruel, inhuman or degrading treatment, art. 5 • Freedom from discrimination, art. 1(1), 24
Additional Protocol in the area of Economic, Social and Cultural Rights, American Convention on Human Rights	Inter-American Commission on Human Rights	• Right to health, art. 10
European Convention for the Protection of Human Rights and Fundamental Freedoms	European Court of Human Rights	• Right to information, art. 10(1) • Right to privacy, art. 8(1) • Right to liberty, art. 5(1) • Freedom from cruel, inhuman or degrading treatment, art. 3 • Freedom from discrimination, art. 14
European Social Charter	European Committee of Social Rights	• Right to health, art. 11

Human Rights Treaty	Accountability Mechanism	Human Rights within the Healthcare System
International Covenant on Civil and Political Rights	Human Rights Committee	• Right to information, art. 19(2) • Right to privacy, art. 17(1) • Right to liberty, art. 9(1) • Freedom from cruel, inhuman or degrading treatment, art. 7 • Freedom from discrimination, art. 2(1), 26
International Covenant on Economic, Social and Cultural Rights	Committee on Economic, Social and Cultural Rights	• Right to health, art. 12 • Freedom from discrimination, art. 2(2)
Convention on the Elimination of all forms of Racial Discrimination	Committee on the Elimination of all forms of Racial Discrimination	• Right to health, art. 5 (e)(iv) • Freedom from discrimination, art. 1
Convention on the Elimination of all forms of Discrimination against Women	Committee on the Elimination of all forms of Discrimination against Women	• Right to health, art. 12 • Right to information, art. 10 (h), 16 (e) • Freedom from discrimination, art. 1
Convention against Torture and other forms of Cruel, Inhuman, or Degrading Treatment or Punishment	Committee Against Torture	• Freedom from cruel, inhuman or degrading treatment
Convention on the Rights of the Child	Committee on the Rights of the Child	• Right to health, art. 24, 25 • Right to information, art. 17 • Right to privacy, art. 16(1) • Right to liberty, art. 37 (b)(c)(d) • Freedom from cruel, inhuman or degrading treatment, art. 37 (a) • Freedom from discrimination, art. 2
Convention on the Rights of Persons with Disabilities	Committee on the Rights of Persons with Disabilities	• Right to health, art. 25 • Right to privacy, art. 22 • Right to liberty, art. 14 • Freedom from cruel, inhuman or degrading treatment, art. 15 • Freedom from discrimination, art. 2

HOW CAN HUMAN RIGHTS BE INFLUENCED BY HEALTH WORKERS?

This guide adopts three different spheres in which health workers (can) influence human rights within the healthcare system as illustrated by the diagram on the next page.

The primary role of a health worker lies in individual patient care. Health workers providing the highest possible standard of care are already upholding human rights. Upholding human rights in the patient care sphere includes:[1]
- providing all necessary care without discrimination
- respecting the autonomy and dignity of all patients
- obtaining informed consent from patients before treatment
- providing all information necessary for patients' decision-making
- respecting patient confidentiality
- taking the background of the patient into account
- maintaining professional skills at the highest possible level

The inner circle of patient care is, however, not isolated from the outside world. There can be issues both within and outside the work sphere that negatively influence human rights in patient care and create obstacles for health workers to provide the highest possible standard of care. When health workers experience pressure to comply with obligations of a third party that compromise their ability to provide the best care to the patient the situation can be described as a dual loyalty conflict.

Possible obstacles affecting human rights in patient care include:
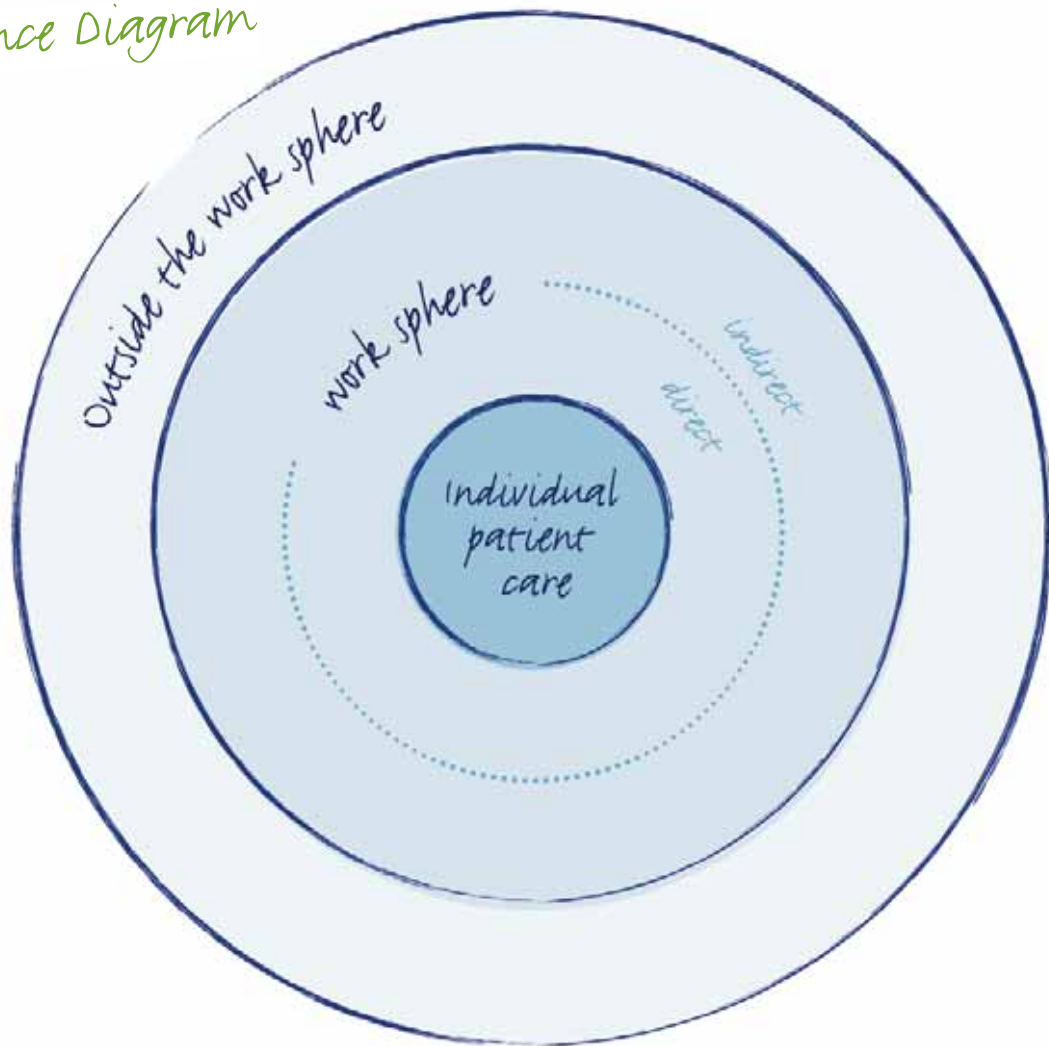
Work sphere
- institutional rules and regulations
- lack of knowledge of health workers
- personal beliefs and attitudes of health workers
- unequal power relations between health worker and patient
- institutional discrimination

Outside the work sphere
- health laws and policies
- denial or lack of necessary resources
- societal beliefs and attitudes

The existence of such obstacles means that action in different spheres can be necessary for health workers to be able to respect human rights within their own work. Section II of this guide focuses on how to arrive at such points for action.

spheres of influence Diagram

The diagram shows concentric circles labeled from outside in: **Outside the work sphere**, **work sphere** (with **indirect** and **direct** zones divided by a dotted line), and at the center **Individual patient care**.

- The **inner circle** comprises health workers providing care to individual patients.

- The **middle circle** up to the dotted line (direct work sphere) covers the areas of work where a health worker is active including colleagues, superiors, patients and their families. The section past the dotted line (indirect work sphere) covers those areas of the work environment in which a health worker is not directly involved. Possible actors in this sphere are hospital management and professional associations. The exact content of the direct and the indirect work sphere will be different for each health worker, depending on position, responsibilities and professional activities.

- The **outer circle** includes any actors, institutions and communities that lie beyond the work sphere such as government officials, the media or society.

Three examples of obstacles faced by health workers

A health worker is unable to adequately treat an old man with diabetes because insulin has been out of stock at pharmacies for the last months.

A health worker cannot provide a young woman with information about contraceptives because it is against the law to do so for unmarried couples.

A health worker is not able to get his patient with HIV at the top of the waiting list for kidney dialyses because people without HIV have priority.

HOW CAN HUMAN RIGHTS BE USED FOR BETTER HEALTHCARE?

There are many different ways in which human rights can help address deficiencies and abuse in healthcare systems. This guide takes a practical approach by viewing human rights as tools which can be used to improve healthcare. These 'human rights tools' have been subdivided into five categories of action that are described below. Concrete examples of types of action for each category can be found under Step 5 of Section II.

Protection

Human rights can be used to protect individuals against shortcomings or mistreatment in healthcare systems. As an internationally recognised and legally guaranteed set of values human rights provide strong arguments to stop, prevent and remedy unjust situations or practices.
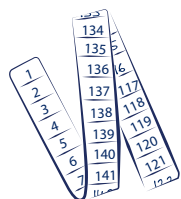
Documentation

Health related human rights provide an indication of what the ideal healthcare system should look like. In this way human rights serve as a framework for the collection of evidence on what should or should not be happening within a healthcare system.

Human rights indicate what type of information is needed to monitor progress in healthcare systems. Similarly, human rights can act as an instrument to measure the impact of health policies and programmes on individuals.

Dissemination

One way to gain broader attention for a problem in the healthcare system is to frame it as a human rights issue. Human rights add weight to a discussion and send a strong message that what is happening cannot be ignored.

Human rights offer new avenues for spreading information about difficulties in healthcare systems. Among human rights institutions at the international, regional and national level there is a high demand for details about what is taking place in practice to be able to bring governments to account.

Human rights can be a basis for education and awareness-raising about specific issues within the healthcare system. By bringing an alternative perspective human rights can be used to clarify why changes are necessary.
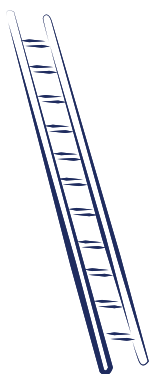
Mobilisation

When trying to gain support to address problems in healthcare systems human rights can bring together different stakeholders by creating a common issue to rally around. Human rights can be used to uncover multiple causes of an issue to show that cooperation between different people and groups is necessary for change.

Human rights are a legitimate claim and as such can provide access to forums and individuals that can be influential in bringing about changes within a healthcare system.

Creation

The human rights framework provides standards for both the end result and process needed to achieve this result. In this way human rights can give direction to the development of new practices and procedures within healthcare systems.
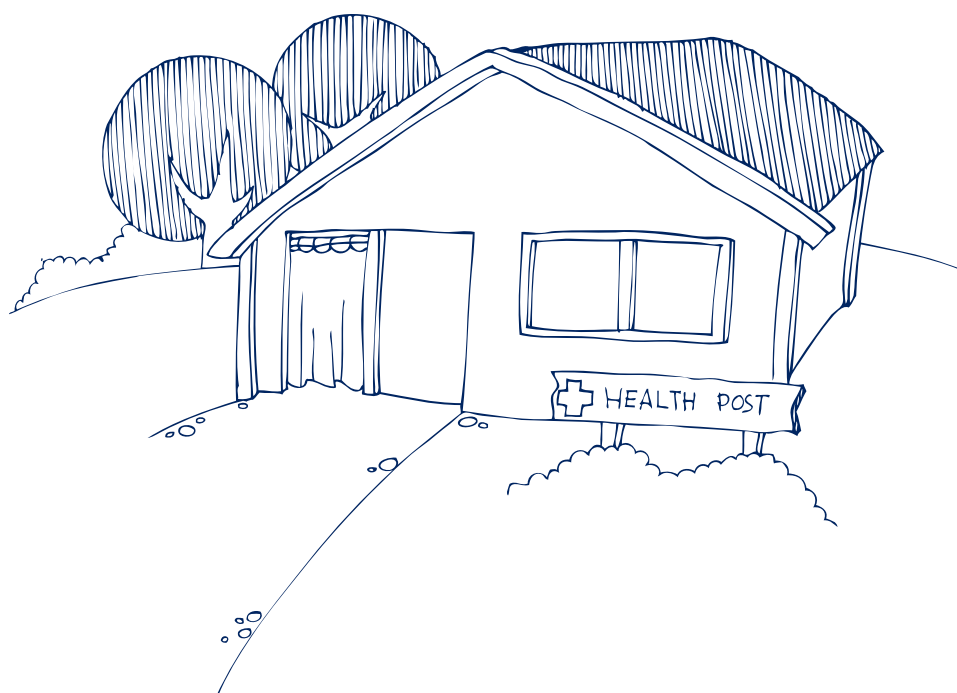
STEPS FOR CHANGE

section II

Any action for change within a healthcare system starts with a realization that something is happening which should not be taking place. Sometimes the problem and its solution are crystal clear, but often there are so many attributes to a problem that it becomes difficult to know where to start. This section describes how to use a human rights approach to pick apart the problem in order to identify entry points for action. By looking at the issue from a human rights perspective the problem is brought back to the ones that are directly affected, why it is happening and which actors are involved.

The section contains five steps:

❶ defining the issue
❷ determining which human rights are affected
❸ unearthing the causes
❹ identifying the actors involved
❺ taking action

▶ *Before walking through these five steps it is necessary to first select a problem within the healthcare system that needs to be addressed.*

A case study is included which shows how each step should be applied. Templates which can be used to complete the steps are available online at *www.ifhhro.org*

STEP 1 WHAT IS THE ISSUE? – THE PEOPLE'S PERSPECTIVE

In order to frame the healthcare problem from a human rights perspective it is necessary to determine who is directly affected, in what way these individuals are affected and where this is taking place.

Who are affected? ▶ Determine which people are affected by the problem.

Identify whether these people belong to a vulnerable group based on specific grounds such as their ethnicity, sex, socio-economic status or health status.

How are they affected? ▶ Describe how these people are affected by the problem.

Distinguish this from possible causes such as lack of services, ineffective policies, or structural discrimination. Instead, the focus should be on the experience of the people that are directly affected.

Where is this taking place? ▶ Establish whether the problem is taking place across the whole country, in a rural or urban area, or in a specific health institution.

What is the human rights issue? ▶ Complete this step by formulating the issue in one sentence including the answers to the above three questions.

This central issue is the *symptom* or *signal* of all the underlying concerns which will be looked at during Steps 2 and 3.

Steps for change by a health worker from Nigeria
COMPLETED STEP 1 - WHY IS THIS HAPPENING?

Who are affected? ▶ People with a low socio-economic status.

How are they affected? ▶ They are suffering and dying from highly preventable illnesses.

Where is this taking place? ▶ This is taking place in the rural hospital in Sahon-Rami village. And the other 10 basic health facilities in rural Mashegu, Nigeria

What is the human rights issue? ▶ In health facilities in rural Mashegu people with a low socio-economic status are dying from highly preventable illnesses

The Situation

"After graduation from medical school I was posted to a rural hospital in Mashegu, northern Nigeria, to serve as primary care physician under the National Youth Service Scheme. I met the hospital in dilapidated condition. Within a few months I discovered that most of the rural people who were supposed to be served by the hospital were not attending.

There was a case of a three year old little girl who was brought to the clinic, she was severly dehydrated and too weak to even cry, having been suffering from diarhea since five days before her parents decided to bring her to the hospital. Unfortunately, the girl died within minutes of stepping into the clinic. From that moment, I felt I must act to stop further deaths from highly preventable illnesses. As a doctor, I felt a deep sense of responsibility not to allow this to happen again, after all I am trained to save lives and not watch people die. I felt compelled to do everything within my power to raise the health status of people in rural Mashegu."

This example was provided by Dr Igboekwu Chukwumuanya from Physicians for Social Justice.

## STEP 2 WHICH HUMAN RIGHTS ARE AFFECTED?

After completing Step 1 the healthcare problem has been defined taking the individuals that are affected as a starting point. The next step is to determine which human rights are being compromised because of what is happening.

This step helps to clarify that what is happening is not just an unfortunate situation but that it is a human rights issue which requires change. The relevant human rights provide the first indication of what this change should accomplish.

The tables on the following pages contain information on the right to health and six other human rights which are relevant within healthcare systems. For each right a general definition is provided as well as details on how this right is related to healthcare.
Information on corresponding human rights treaties and accountability mechanisms can be found under Section I on pages 10-11 .

Use the tables to find out which human rights are affected by the problem and for each right describe why it is relevant to the issue.
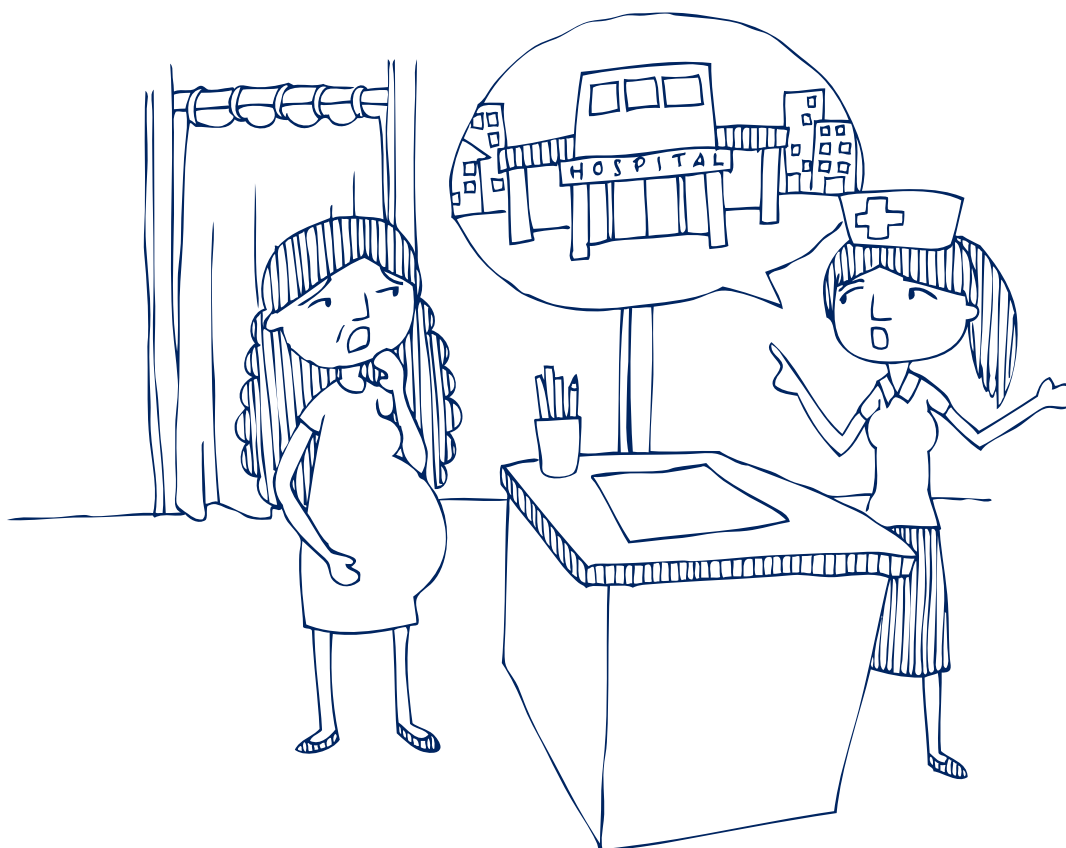
RIGHT TO HEALTH[2]

The right to the enjoyment of a range of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health. These include both *healthcare* and *underlying determinants* of health such as safe water and sanitation.

RELATION TO HEALTHCARE

According to this right health facilities, goods and services need to be:

Available in sufficient quantity
This includes availability of:
• healthcare facilities such as hospitals and clinics
• trained health workers
• essential medicines
• medical equipment and supplies
• underlying determinants

Accessible to everyone
This covers:
• *physical accessibility* - within safe physical reach of all sectors of the population access to buildings for persons with disabilities
• *financial accessibility* - affordable for all
• *non-discrimination* - accessible to all without discrimination
• *access to health information* - the right to seek, receive and impart information on health issues this should not be at the expense of privacy and confidentiality

Acceptable
This requires that :
• medical ethics are respected
• services meet local needs
• services are sensitive to gender and life-cycle requirements

Good quality
This involves:
• health workers with up to date skills and knowledge
• scientifically approved and unexpired medicines and equipment
• safe water and adequate sanitation
• constant electricity and sufficient lighting

RIGHT TO INFORMATION

DEFINITION

The right to seek, receive and impart information. This includes a government obligation to ensure access to information.

RELATION TO HEALTHCARE

This covers:
- information on available healthcare services
- information on health promotion, disease prevention and treatment
- information in different languages, for illiterate, blind and deaf people
- information free from discrimination, stigma or stereotypes
- patients' access to personal medical records
- information about personal diagnosis and prognosis
- information necessary for informed consent

RIGHT TO PRIVACY

DEFINITION

The right to be protected against arbitrary or unlawful interference with individual privacy. This covers information privacy, bodily privacy, communications privacy and territorial privacy.

RELATION TO HEALTHCARE

This requires:
- confidential treatment of medical records
- confidentiality concerning a person's health status
- privacy during medical examination and treatment
- full, free and informed consent for medical treatment

RIGHT TO LIBERTY

DEFINITION

The right not to be deprived of liberty arbitrarily. This means deprivation of liberty must not be manifestly disproportionate, unjust, unpredictable or discriminatory. Deprivation of liberty should be in accordance with procedures prescribed by law.

RELATION TO HEALTHCARE

This prohibits:
• detainment of patients without a set procedure
• delays in reviewing the institutionalisation of patients
• delays in releasing institutionalised patients
• unnecessary quarantines
• excessive restraints of patients

This requires:
• legal procedures for institutionalisation
• means to challenge involuntary admission

FREEDOM FROM CRUEL, INHUMAN OR DEGRADING TREATMENT

DEFINITION

The right to be free from treatment that causes severe physical pain and mental suffering and treatment that is grossly humiliating and undignified.

RELATION TO HEALTHCARE

This prohibits:
• physical or mental abuse of patients
• gross neglect of patients
• inadequate living conditions in health institutions
• non-therapeutic and prolonged seclusion or solitary confinement
• medical and scientific experimentation without informed consent
• intrusive and irreversible medical treatment without informed consent
• denial of or delays in treatment

This requires:
• independent medical services for detainees

FREEDOM FROM DISCRIMINATION

DEFINITION

This is a cross-cutting principle relating to all human rights.

Discrimination means any distinction, exclusion or restriction on the basis of prohibited grounds which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise of human rights.[3]

Prohibited grounds of discrimination include race, sex, age, language, religion, political or other opinion, health status, disability, national or social origin, sexual orientation, socio-economic or other status.

RELATION TO HEALTHCARE

Freedom from discrimination covers every aspect of healthcare including:
• access to healthcare services
• access to health information
• quality of healthcare services
• health service delivery
• attitudes of health workers

RIGHT TO PARTICIPATION[4]

DEFINITION

This is a cross-cutting principle relating to all human rights.

Participation means the active and informed involvement of people and groups in decision-making that affects them.
Participation needs to be accessible and inclusive, fair and transparent.

RELATION TO HEALTHCARE

Participation in health-related decisions is necessary so that healthcare systems can be responsive to the needs and concerns of specific groups.

COMPLETED STEP 2 - WHICH HUMAN RIGHTS ARE AFFECTED?

Five human rights have been found relevant to the issue identified during Step 1. For each of these rights details have been added to specify how it is relevant.

Right to health ▶ People in rural Mashegu face financial barriers in accessing healthcare

The hospital is too far away

The negative attitude of health workers makes people feel unwelcome

Right to information ▶ People in rural Mashegu lack information about health services

Right to privacy ▶ Not directly relevant in this case

Right to liberty ▶ Not directly relevant in this case

Freedom from cruel, inhuman or degrading treatment ▶ People are denied treatment because they cannot afford user fees

Freedom from discrimination ▶ People suffer from discrimination based on their socio-economic status

Right to participation ▶ People were not consulted when the "user fee" policy was formulated, though they are the ones that are directly affected
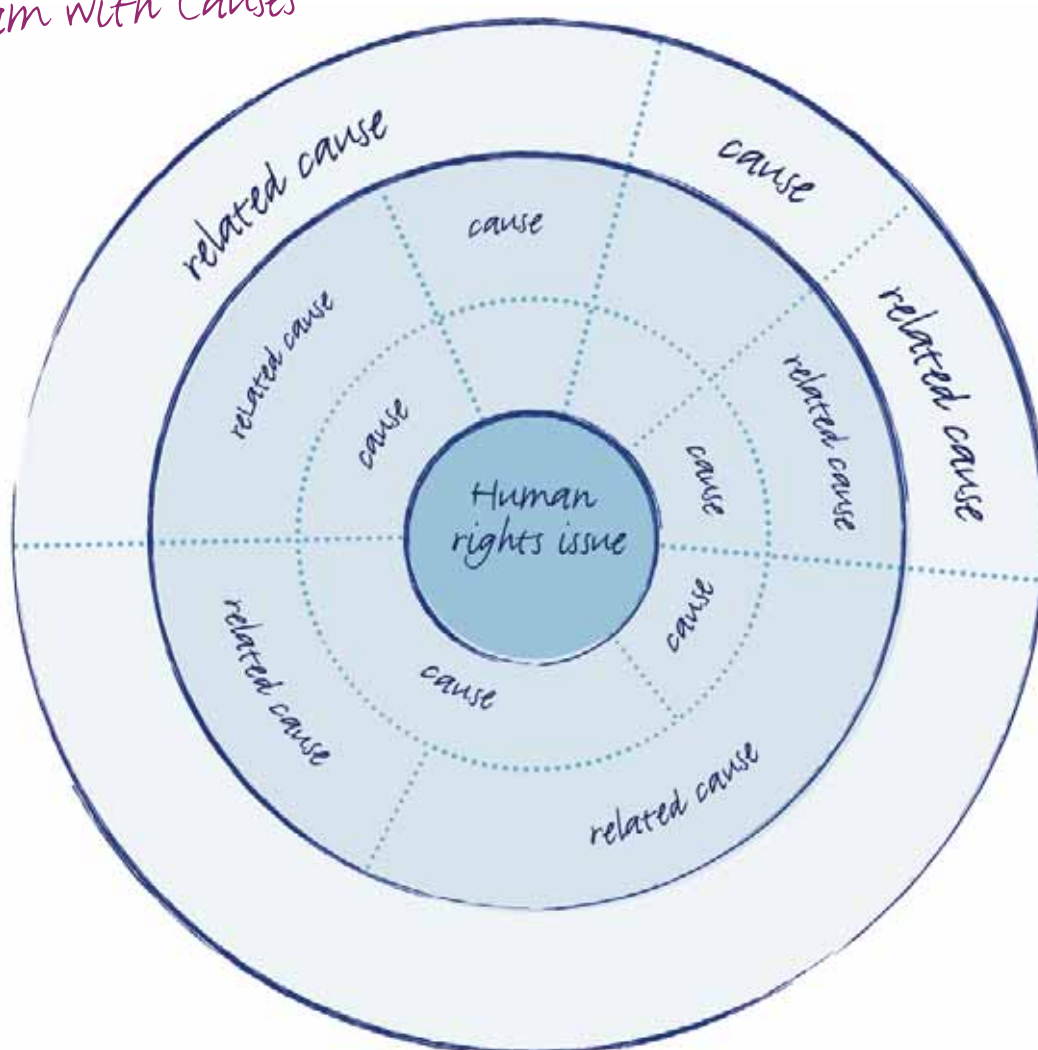
This example was provided by Dr Igboekwu Chukwumuanya. See page 19 for a description of the case.

STEP 3   WHY IS IT HAPPENING? – THE CAUSES

Having defined what is happening in human rights terms, the next step is to identify why this is happening. During this step the Spheres of Influence Diagram will be used to create a map of different concerns affecting the human rights issue. The explanation of the diagram can be found on page 13 of the guide.

Start with the human rights issue defined during Step 1 and think about all possible factors both within and outside the work sphere which influence this situation. Place the issue at the centre of the Spheres of Influence Diagram. Include all known causes in the diagram to create a structural overview of the factors that contribute to the central issue. Go into as much detail as possible and with each additional cause keep asking why this is the case to identify more underlying causes. Write the causes into the applicable sphere and link causes that lead to each other, as indicated below.
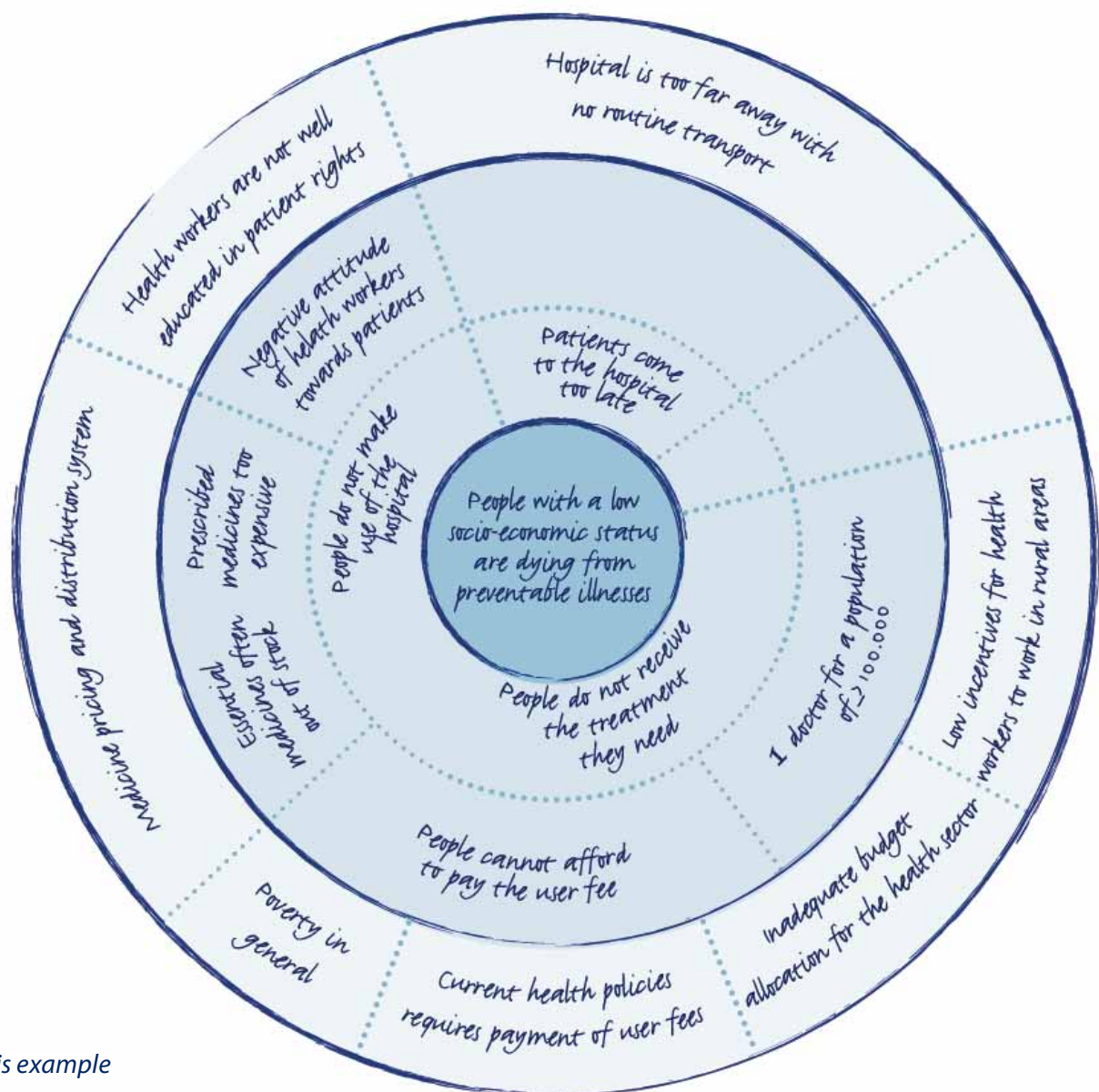
Spheres of Influence
   Diagram with Causes

Steps for change by a health worker from Nigeria
COMPLETED STEP 3 - WHY IS THIS HAPPENING?

This diagram contains all causes known to the health worker involved. The issue identified during Step 1 is included in the centre of the diagram. As can be seen several causes have more than one related cause.


People with a low socio-economic status are dying from preventable illnesses

Patients come to the hospital too late

People do not receive the treatment they need

Hospital is too far away with no routine transport

Negative attitude of health workers towards patients

People do not make use of the hospital

Health workers are not well educated in patient rights

Prescribed medicines too expensive

Essential medicines often out of stock

Medicine pricing and distribution system

Poverty in general

People cannot afford to pay the user fee

Current health policies requires payment of user fees

1 doctor for a population of 100.000

Low incentives for health workers to work in rural areas

Inadequate budget allocation for the health sector

This example was provided by Dr Igboekwu Chukwumuanya. See page 19 for a description of the case.

STEP 4 WHO IS INVOLVED? – THE ACTORS

Now that a combination of factors which cause the human rights issue have been mapped out the next step is to identify all the relevant actors. These are the people that are directly affected and the actors that are related to the different causes of the issue. During this step the map created during Step 3 will be completed by adding actors to the Spheres of Influence Diagram.

Start with a concrete relationship that best represents the issue; in many cases this is a health worker and a patient. These represent the person(s) directly affected and the actors that are immediately involved in the issue. Next, draw in all the relevant actors that are connected to the different causes written into the Spheres of Influence Diagram. The completed map should include all actors that influence or have an interest in the central issue.
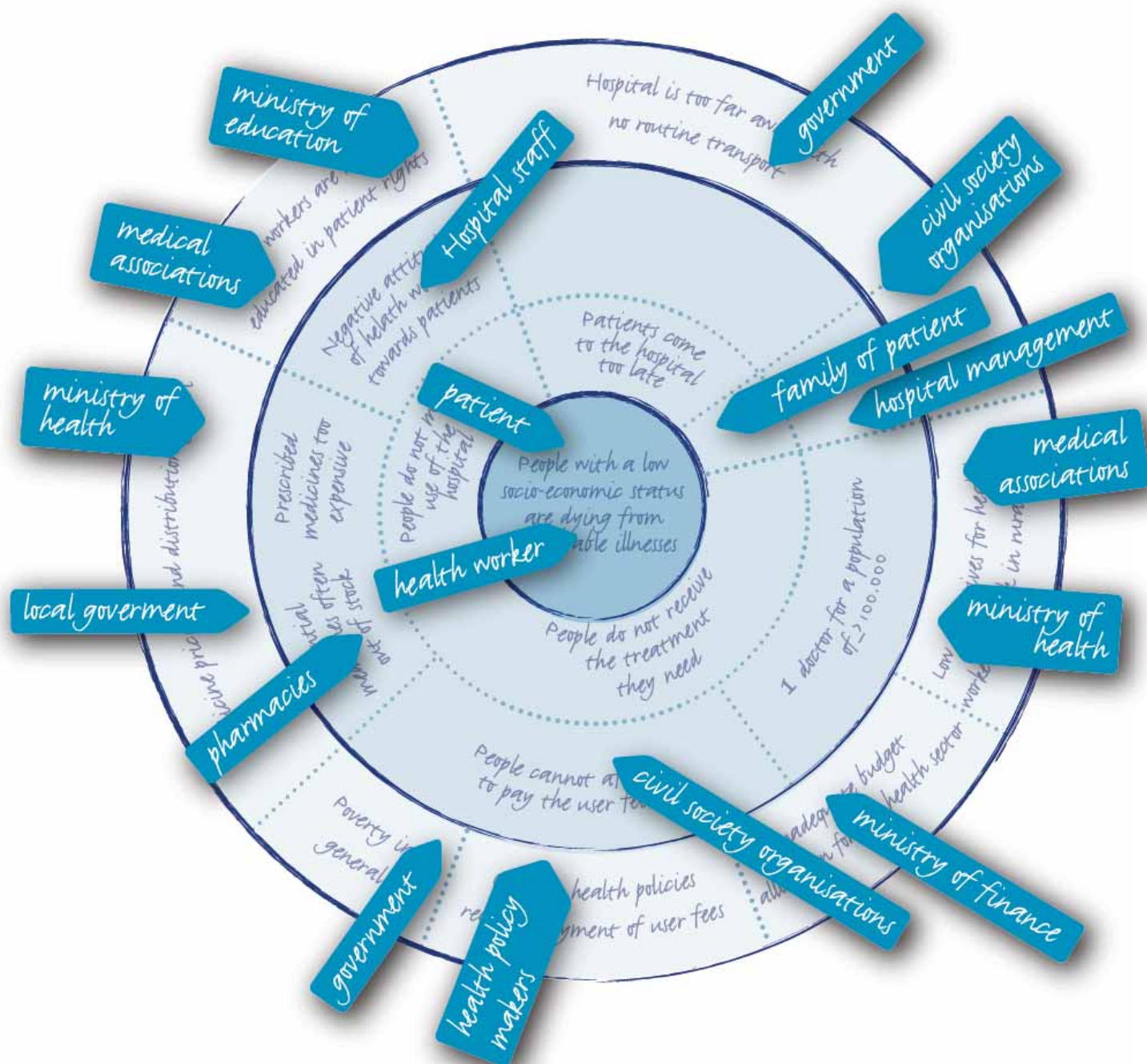

Spheres of Influence Diagram with Actors
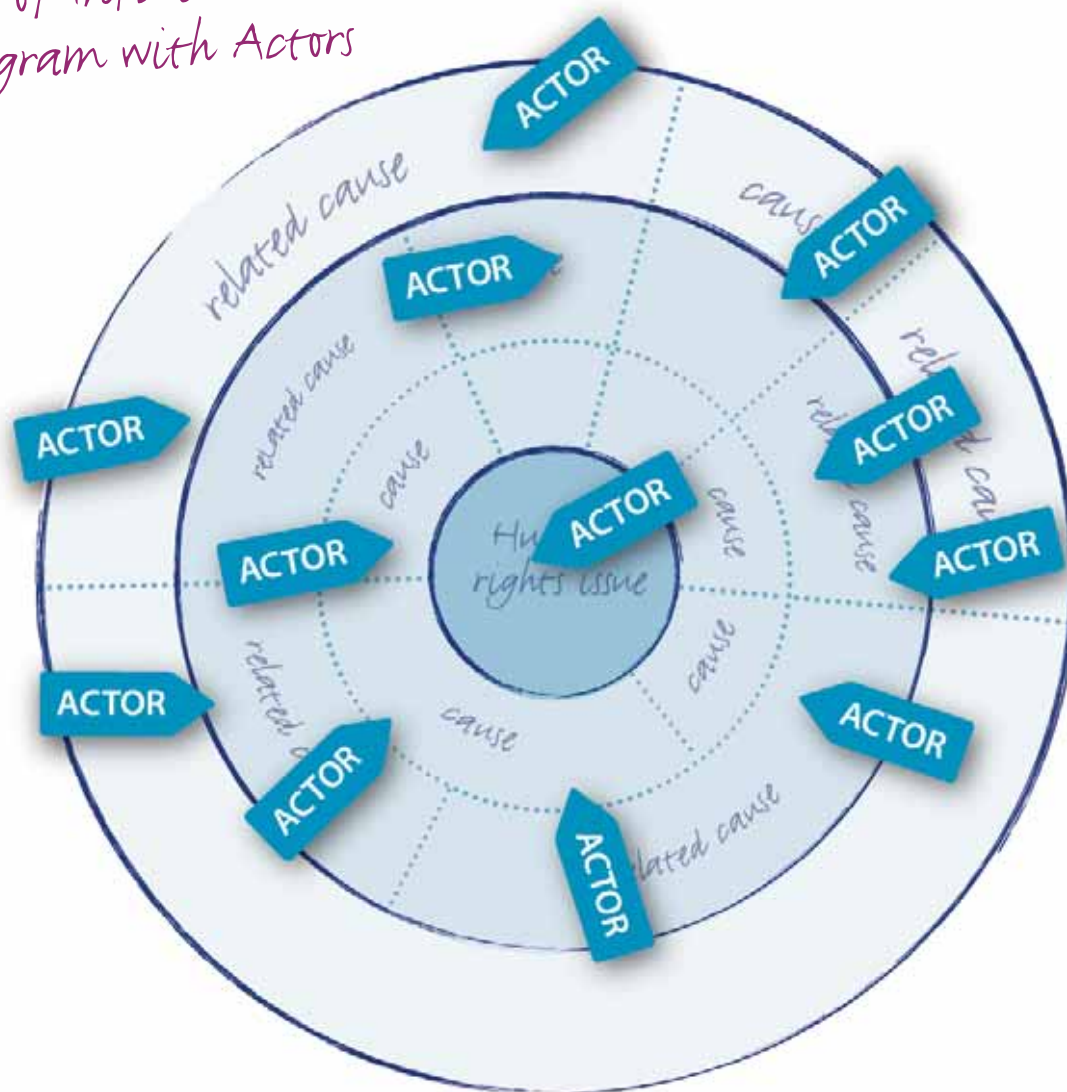
Steps for change by a health worker from Nigeria
COMPLETED STEP 4 - WHO IS INVOLVED?

In the following diagram actors have been added to the causes identified during the previous
step. A number of relevant actors that are not linked to one specific cause are also included.

This example was provided by Dr Igboekwu Chukwumuanya.
See page 19 for a description of the case.

STEP 5 WHAT CAN I DO? – TAKING ACTION

After having identified the issue (Step 1) and the relevant human rights (Step 2) and having created a structural overview of the known causes (Step 3) and the actors involved (Step 4) the next step is to find out where to start taking action.

It is important that the action decided is feasible and realistic. A small and personal action to generate change is often an easier and better place to start. There is no need to immediately think in terms of projects or programmes. Action leads to reaction, this means that an action can expand; it can start in the individual patient care sphere and extend to the work sphere or even outside the work sphere. How actions develop will be different for each individual depending on different factors including situation, position, abilities, time, financial resources and information.

Complete the questions below to plan for your concrete action and think about what is needed to make it happen.

PLAN

Which cause can **you** address?	▶	Look at the map created during Step 3 and select a cause where you can make a difference.
What should change?	▶	Define what should change to improve the situation.
How can you contribute?	▶	What action do you need to take to start working on improving the situation? Think small: start with something feasible with a clear outcome. Consult the overview on the following pages for possible actions in the different spheres.

NEEDS

Which actor(s) are involved? ▶ Look at the actor(s) that were identified during Step 4.

- Do you need them for your action? If so, explore your direct and indirect connections with them.
- How can you establish contacts when there is no connection?

What is your position? ▶ Take your professional position into account.
Look at the possibilities or constraints your position entails.

- Are you in a position to accomplish changes by yourself?
- Are you in a position that you need help from others?
- Would your position be in danger if you undertake action?
- Do you need any kind of protection?

What information do you need? ▶ Make a list of the information you need and how or where to collect it.

- Can you collect the information yourself or do you need help?
- Which sources are available and accessible?
- Are there people or organisations who you can ask for help or advice?

Do you have the capacity? ▶ Make an inventory of specific capacities you need for the planned action.

- Do you have the right skills?
- Are you willing and in the position to learn new skills?
- Do you have sufficient time to undertake the action yourself?
- Do you need human resources?
- Do you need financial resources?
- Are you able to arrange this or do you need help?

The answers to these questions indicate what needs to be taken into account when planning action. Concrete examples of different types of action can be found in the overview on the following pages. There are countless ways to make a difference as a health worker, just remember that it is a matter of taking time to find out what steps for change fit best.
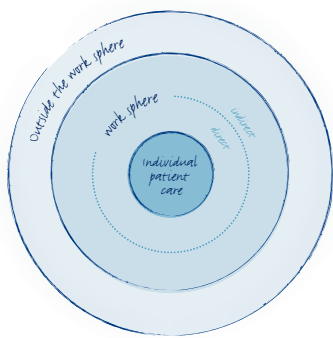
POSSIBILITIES FOR ACTION

This overview contains examples of different types of action within the three spheres of influence. The examples have been divided over the five categories of human rights action described in Section I (see pages 14-15). The overview is meant as a source of inspiration on what steps for change to take.

PROTECTION

Stop, prevent or remedy human rights violations

DOCUMENTATION
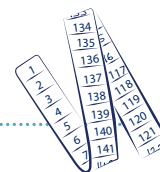
Record, monitor and assess

Individual patient care

PROTECTION
- Upholding human rights while treating your patient: see page 12 of the guide for more information

DOCUMENTATION
- Look further into outside circumstances that affect the health status of the patient
- Identify individuals or groups that do not have adequate access to your health institution
- Recognize patterns and connect these to human rights
- Keep a register of patients whose rights are at risk

Worksphere

direct

PROTECTION
- Discuss with colleagues: practices or regulations that are not in line with human rights
- Challenge colleagues if their own conduct does not comply with human rights

DOCUMENTATION
- Keep a record of human rights concerns within your health institution
- Keep a record of action taken to address human rights concerns
- Collect data necessary to measure compliance with human rights from your own health institution

indirect

PROTECTION
- Inform superiors about practices or regulations that are not in line with human rights
- File complaints about incidents that have put human rights of patients at risk
- Ask for support from professional associations when protecting patients

DOCUMENTATION
- Make an inventory of existing policies and guidelines of professional associations
- Compare existing policies and guidelines with daily practice
- Assess whether policies/guidelines and their effects are in line with human rights

Outside worksphere

PROTECTION
- Act as a witness in court
- Support strategic litigation
- Challenge regulations that do not comply with human rights in court

DOCUMENTATION
- Collect additional information from outside sources on human rights issues in your health institution
- Make an inventory of national health policies
- Check correct implementation of national health policies with daily practice
- Assess whether national health policies and their effects are in line with human rights
- Collect good practices from other countries

DISSEMINATION

Advocate, report and raise awareness

MOBILISATION

Participate, stimulate and connect

CREATION

Develop new ideas and alternatives

| DISSEMINATION	MOBILISATION	CREATION
• Raise awareness about available health services • Refer patients to outside organisations that can help • Inform patients about their rights where necessary	• Stimulate patients to join forces with others who encounter similar obstacles • Stimulate patients to claim their rights	• Set up a complaint mechanism for patients • Provide space for a support group of patients facing wsimilar obstacles
• Discuss your human rights findings with colleagues • Discuss your human rights findings with family of patients / patient groups • Distribute materials on human rights within your health institution	• Mobilise colleagues to take up human rights issues • Motivate families of patients to stand-up against human rights issues • Form an action group with colleagues	• Create patient-friendly surroundings • Introduce a periodical meeting to discuss human rights issues that arise • Develop information material for patients and colleagues
• Write to professional associations • Inform influential health workers • Train other health workers on human rights • Disseminate materials on human rights within the health sector • Contribute to the inclusion of human rights in medical curricula	• Organise round table discussions with health workers and patients • Motivate influential health workers to support change • Propose the establishment of a human rights committee within professional associations • Petition among health workers • Negotiate for necessary medicines, supplies and staff	• Develop procedures and guidelines • Set up a hotline • Set up a complaint mechanism for colleagues • Create specific education materials for health workers on health and human rights
• Share your human rights findings with government, human rights institutions, NGOs, the media • Personally meet with influential actors to share your experience as a health worker • Invite the media for an interview • Write an article • Sensitise policy makers and lawyers on health and human rights • Organise activities for public awareness	• Join existing action groups • Petition • Demonstrate • Motivate schools to pay attention to the issue • Build relations with policy makers • Lobby for policy change and law reform • Organise round table discussions with policy makers, health workers and patients	• Participate in formulation of health policies • Set up a complaint mechanism within a community, region or at the national level • Create a newsletter or website about human rights and healthcare

Steps for Change by a Health Worker from Nigeria
COMPLETED STEP 5 - WHAT CAN I DO?

The table below describes the actions undertaken in the example from Nigeria during a period of 7 years. The actions are matched to the relevant categories identified in Section I, pages 14-15.

These steps for change are a clear example of action leading to reaction. What started small and relatively simple with the organisation of community dialogue sessions to find out the reasons why people were not making use of the rural hospital, expanded over time to structured and successful activities over a longer period which still continues today.
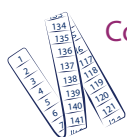
Collection ▶
- Conducted community dialogue sessions to find causes for underutilization of health services
- Collected collated and analysed data on current human costs of user fee policies on the rural poor

Dissemination ▶
- Held patient's rights education sessions for clinic staff
- Educated poor rural people about their right to health entitlements
- Wrote an article to raise awareness about the underutilization of the clinic
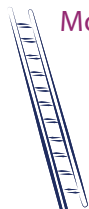
Mobilisation ▶
- Organised community members and health workers to form a Community Mutual Health Association as a platform for advocacy to the local government for essential drugs and medical supplies
- Influenced colleagues to speak up or do something about the user fee policy

Creation ▶
- Renovated the clinic
- Started a mobile health clinic to reach people in remote areas
- Co-founded an NGO (Physicians for Social Justice) to advocate for health rights of marginalized rural communities

> "When I became more aware of the human rights dimension of my work in 2005 I was motivated to continue to serve beyond the one year specified by the national Youth Service Scheme. 2011 marks 7 years since I stepped foot in rural Mashegu, it is difficult for me to leave. My knowledge of human rights changed my life and the way I see and care for my patients. Now I am not just a clinician, I am also a human rights advocate, working at the intersection of health and human rights."
>
> **Dr Chukwumuanya Igboekwu, Nigeria**

Additional Resources

PUBLICATIONS

Health and Human Rights
- 25 Questions & Answers on Health & Human Rights, WHO, 2002
- Health and Human Rights: A Resource Guide, OSF, 2007
- The Right to Health: A Resource Manual for NGOs, J. Asher, 2004
- The Right to Health: A Toolkit for Health Professionals, BMA, IFHHRO, Commat, 2007
- Dual Loyalty & Human Rights in Health Professional Practice, PHR, University of Cape Town, 2002
- The UN Special Rapporteur on the Right to Health: A Guide for Civil Society, IFHHRO, 2009

Health Advocacy
- Promoting Health: Advocacy Guide for Health Professionals, ICN 2008
- Public Health Advocacy Toolkit, PHA, 2007
- Advocacy Guide for Sexual and Reproductive Health & Rights, IPPF, 2001
- Providers as Advocates for Safe Abortion Care: A Training Manual, Ipas, 2009

The publications can be found online in the Information Centre at: www.ifhhro.org

TRAINING MATERIALS

Training materials on human rights specifically designed for health workers are available from the IFHHRO Training Manual: Human Rights for Health Workers at www.ifhhro-training-manual.org
The manual contains training session plans which can be used to introduce this guide.

ORGANISATIONS

Intergovernmental Organisations
Office of the UN High Commissioner for Human Rights
www.ohchr.org

World Health Organisation
www.who.int

International Professional Associations
World Medical Association
www.wma.net

International Council of Nurses
www.icn.ch

For information on relevant _non-governmental organizations_ please consult www.ifhhro.org for a list of members and observers of the International Federation of Health and Human Rights Organisations.

WEBSITES

ESCR-Net Caselaw Database – Includes right to health cases from around the world
www.escr-net.org/caselaw/

Website of the current UN Special Rapporteur on the Right to Health
unsrhealth.org

Right to Health Unit Archives, Essex University, Human Rights Centre
www.essex.ac.uk/human_rights_centre/research/rth/

The Human Rights Key: for teaching and learning about health and human rights, Veronica Mitchell, University of Cape Town, 2011

Glossary

Accountability mechanism
Committee, commission, court, institution or other procedure which monitors whether and to what extent a government complies with its human rights obligations.

Advocacy
Evidence based strategic action to influence laws, policies, practices, public opinion and attitudes.

Complaint mechanism
A clear, accessible, acceptable, confidential and structured procedure to file complaints within the healthcare system.

Dual loyalty
A conflict between a health worker's professional duties to the patient and obligations to a third party such as an employer or the state. These obligations can be express or implied, real or perceived. When health workers give priority to the interest of a third party this can have the effect of violating individual patient's human rights.

Essential medicines
Medicines that satisfy the priority health care needs of the population. Essential medicines are intended to be available within the context of functioning health systems at all times in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information and at a price the individual and the community can afford. (WHO)

Healthcare system
All institutions, organisations, facilities, services and individuals providing care to promote, restore or maintain health.

Health policy
A health related strategy, plan or programme agreed upon by a (local) government, institute or organisation.

Health worker
All those developing, managing, delivering, monitoring and evaluating preventive, curative and rehabilitative health in the private and public health sectors, including traditional healers. (UN Special Rapporteur on the Right to Health)

Human Rights Court
Supra-national court where individuals can file complaints about government violations of the corresponding human rights treaty. The rulings of the court are legally binding. There exist three regional human rights courts: the African Court on Human and People's Rights, the Inter-American Court of Human Rights and the European Court of Human Rights.

Human rights treaty
A binding agreement between two or more nations in which human rights are legally protected.

Lobby
To persuade an official, most often legislators or members of regulatory agencies, with the purpose to change a particular law or guideline.

Monitoring
The process of observing, checking closely or continuously to collect information necessary to measure and report compliance with human rights.

National Human Rights Institute
An institution with a constitutional and/or legislative mandate to protect and promote human rights. National Human Rights Institutes are independent, autonomous institutions that operate at the national level. (Office of the UN High Commissioner for Human Rights)

Patient autonomy
The right of patients to make their own decisions about their medical care. Health workers can inform and educate the patient but cannot make the decision for the patient.

Patient confidentiality
The rule that all information about the patient will be kept secret unless the patient gives permission to share information. This is to allow patients to make full and frank disclosure to their physician, enabling appropriate treatment and diagnosis.

Professional association
An organisation formed to unite and represent people with the same profession. Usually the organisation provides guidelines to maintain a certain standard within the profession.

Respect, protect, fulfil
Government's obligations related to human rights. **Respect**: government must refrain from violating human rights. **Protect**: government must prevent others from violating human rights. **Fulfil**: government has to take measures necessary for the realisation of human rights.

Underlying determinants of health
Conditions that are necessary for health and people's health, this includes safe and potable water, adequate sanitation, adequate supply of safe food, housing, healthy occupational and environmental conditions and access to health-related education and information.

UN Special Rapporteur
An individual appointed by the United Nations Human Rights Council to investigate, monitor, advise and report on human rights concerns.

UN Treaty Body
Committee of independent experts which examines government reports to assess compliance with the corresponding international human rights treaty. Several committees also accept individual complaints of human rights violations.

Vulnerable groups
Groups of people that need special protection because they are at a higher risk of human rights abuse due to marginalization, socially exclusion, prejudice, discrimination, or limited opportunities and income. Examples of vulnerable groups are minorities, people with disabilities, older persons, children, refugees, people with HIV, detainees.

ENDNOTES

[1] Based on: BMA, The Right to Health: A toolkit for health professionals, June 2007, p.14

[2] UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights), May 2000

[3] UN Committee on Economic, Social and Cultural Rights, General Comment No. 20, Non-discrimination in economic, social and cultural rights (art. 2, para. 2, of the International Covenant on Economic, Social and Cultural Rights), May 2009

[4] Dr. Helen Potts, Participation and the right to the highest attainable standard of health, Human Rights Centre, University of Essex, 2008
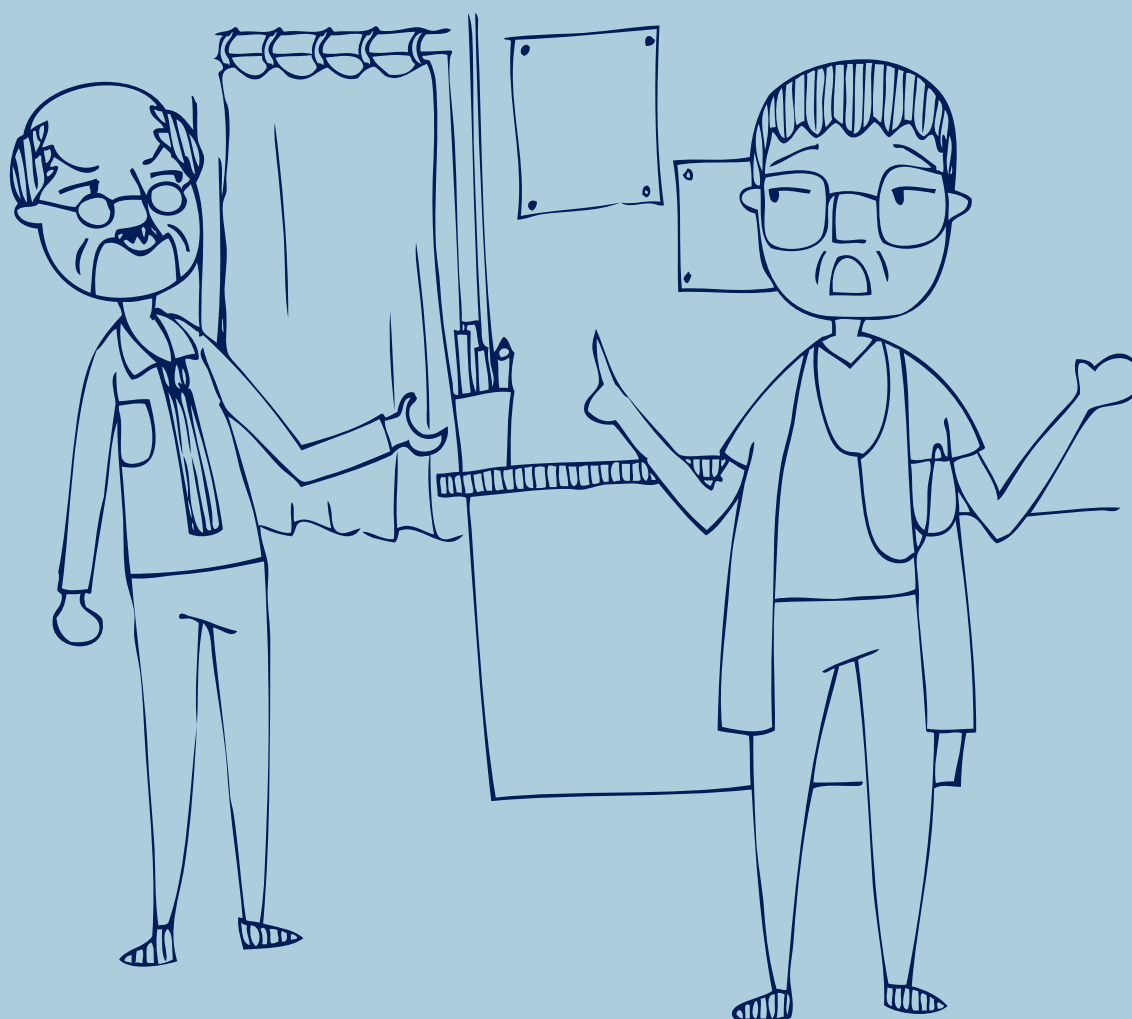
INTERNATIONAL FEDERATION OF HEALTH AND HUMAN RIGHTS ORGANISATIONS (IFHHRO)

IFHHRO forms a unique network of active organisations committed to the protection and promotion of health related human rights. The Federation currently consists of 31 member and observer organisations worldwide. These members and observers are human rights groups which address health-related rights violations, medical associations involved in human rights work and organisations that have been created specifically to mobilize health workers for human rights protection.

Vision: IFHHRO strives for the full enjoyment of health related human rights by everyone.

Mission: IFHHRO engages health workers in the realisation of health related human rights.

Copies of this guide can be found online at www.ifhhro.org
The guide is also available in Spanish, Portuguese, French, Russian, Georgian and Arabic