



Human Rights in Patient Care: *A Resource Guide*

“There is no difference between men, in intelligence or race, so profound as the difference between the sick and the well.”

F. Scott Fitzgerald

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Open Society Institute

400 West 59th Street, New York, NY 10019 USA

Website: www.soros.org

Equitas – International Centre for Human Rights Education

1425, René-Lévesque Blvd. West, Suite 407

Montréal, Québec, Canada H3G 1T7

Website: www.equitas.org

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Acknowledgements

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The following people drafted, contributed, or commented on materials for this excerpt:

Magda Adamowicz, Volha Baraulia, Iain Byrne, Dmytro Groysman, Sarah Kalloch, Karyn Kaplan, Jane Li, Emma Lozman, Emily Martinez, Judith W. Overall, Yervand Shirinyan, Anthony So.

The Guide's translation project was managed by Volha Baraulia, and the Guide was formatted by Emma Lozman and other production assistance was provided by Paola Deles and Anna Vinnik. In addition, staff of the Open Society Institute Public Health Program and Human Rights and Governance Grants Program provided valuable comments on the Guide.

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INTRODUCTION

About this Guide

Now we have the responsibility to move forward by recognizing that true interdependence and real interconnectedness requires that we – from health and from human rights – advance together: equal partners in the belief that the world can change.

Jonathan Mann (1947-1998)

Purpose and organization

This Guide was prepared as a user-friendly, multi-purpose resource that can be used on a regular basis on the job. To ensure easy and widespread access to the Guide, a web-friendly version is available at www.equalpartners.info. On this website, you will also find translations of the guide into several other languages. It is divided into two parts: an introduction to **health and human rights in general** and a section specifically focused on **human rights in patient care**.

How to use and modify the Guide

The Guide is a practical **reference tool** for you to use in your day-to-day work. You can also **add** new materials as you see fit, **take notes** in the margins, and **print** specific sections for use in training.

Putting the Guide into action

This Guide is a **starting point** for a wide range of health and human rights programming. The Guide will provide you with ideas, information, and resources to develop programs.

You can use the Guide to:	How
Collaborate with colleagues on strategy development	There are many opportunities for Law Program and Public Health Coordinators to collaborate on health and human rights work. The Guide provides examples of projects that can be adapted at the country or regional level, as well as extensive information on developing claims before regional and international bodies. The annual strategy process is a good time to consult the Guide for ideas on how law and health staff can collaborate.
Develop regional or thematic courses and trainings	The Guide contains the information and resources needed to develop a course or training seminar. While it does not contain actual curricula or training materials, an experienced educator can use the information in the Guide to develop a course or seminar.

Continued

You can use the Guide to:	How
Identify human rights claims	The Guide contains real-life examples of human rights abuses, as well as legal standards and precedents that can be used to seek redress for these abuses. The introduction to health and human rights briefly describes the main regional and international human rights mechanisms with which you can lodge complaints. There is great potential for using regional and international mechanisms to advance health-related claims, and this is an excellent area of collaboration for law program and public health staff.
Adapt the project examples in your country	The Guide contains examples of effective health and human rights projects from around the world. Each project example summarizes the work accomplished and includes contact information for the implementing organization. You can adapt these project examples to any country or region. You can also share the project examples with your NGO partners to encourage them to take on more work on health and human rights.
Conduct further research	If you are conducting research on health and human rights—for example, writing an article or news item, preparing a conference presentation, or developing a Request for Proposals (RFP)—you can consult the Guide for a list of articles, books, websites, and other resources. While not comprehensive, the resource list was prepared by experts in the field and contains their recommendations of the most useful resources.
Educate other funders	While this Guide is initially directed at OSI (Open Society Institute) and the SFN (Soros Foundations Network), it can also be used by other funders who are interested in health and human rights. The Guide (or sections of it) can be translated into local languages and adapted to local contexts. Parts of it can be expanded, abbreviated, or modified depending on the purpose and audience.

PART I: HEALTH AND HUMAN RIGHTS

Using human rights mechanisms

Treaties and enforcement mechanisms

One of the main ways to advocate for health and human rights is to lodge complaints or file reports with regional or international human rights mechanisms. These mechanisms were established to enforce governments' compliance with the regional and international human rights treaties they have ratified. These treaties make up the so-called "hard law" of international human rights, while the interpretations of the treaty mechanisms make up "soft law" that is not directly binding on governments. There are two main types of enforcement mechanisms:

- ▶ **Courts**, which act in a judicial capacity and issue rulings that are binding on governments in the traditional sense;
- ▶ **Committees**, which examine reports submitted by governments on their compliance with human rights treaties, and in some cases examine individual complaints of human rights violations.

The main treaties and corresponding enforcement mechanisms discussed in this Guide are shown on the following page.

Using the mechanisms

One of the greatest advantages of regional and international human rights mechanisms is that they allow individuals and NGOs to lodge complaints or file reports of human rights abuses.

The best way to learn about how to use a particular mechanism is to visit its website or contact its Secretariat. The contact information for each enforcement mechanism discussed in the Guide, as well as some introductory information about its mandate and procedures is provided on the next pages.

Advocacy using these regional and international mechanisms go hand-in-hand with country advocacy as regional and international recommendations mean little without enforcement at the national level. Additionally, domestic remedies generally have to be exhausted (including the raising of regional and international claims) before complaints can be taken to regional or international bodies.

Treaties and corresponding enforcement mechanisms

Treaty	Enforcement Mechanism
International Covenant on Civil and Political Rights (ICCPR)	Human Rights Committee (HRC)
International Covenant on Economic, Social, and Cultural Rights (ICESCR)	Committee on Economic, Social and Cultural Rights (CESCR)
International Convention on the Elimination of all forms of Racial Discrimination (ICERD)	Committee on the Elimination of Racial Discrimination (CERD)
Convention concerning Indigenous and Tribal Peoples in Independent Countries (ILO Convention)	International Labour Organization (ILO)
Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)	Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW Committee)
Convention on the Rights of the Child (CRC)	Committee on the Rights of the Child (CRC Committee)
African Charter on Human and People's Rights (ACHPR) & Protocols	African Commission on Human and People's Rights (ACHPR Commission)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)	European Court of Human Rights (ECtHR) (with Committee of Ministers)
European Social Charter (ESC)	European Committee of Social Rights (ECSR) (with Governmental Committee and Committee of Ministers)
Framework Convention for the Protection of National Minorities (FCNM)	Committee of Ministers of the Council of Europe & Advisory Committee (AC)

Note: The above is only a fraction of the treaties and enforcement mechanisms that can be used to advocate for health and human rights. Some of the resources listed at the end of this Introduction contain more detailed information about the regional and international human rights systems.

Human Rights Committee

▶ Mandate

The Human Rights Committee (HRC) oversees government compliance with the International Covenant on Civil and Political Rights (ICCPR). The HRC has two mandates: to monitor country progress on the ICCPR by examining periodic reports submitted by governments; and to examine individual complaints of human rights violations under the Optional Protocol to the ICCPR.

▶ Civil society participation

NGOs can submit “shadow reports” to the HRC on any aspect of a government’s compliance with the ICCPR. Shadow reports should be submitted through the HRC Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the Committee. The HRC meets three times a year. Individuals and NGOs can also submit complaints to the HRC under the Optional Protocol.

Contact

Patrice Gillibert
HRC Secretary, UNOG-OHCHR, CH 1211 Geneva 10, Switzerland
Tel: +41 22 917 9249
Fax: +41 22 917 9006
Email: pgillibert@ohchr.org
Web: www.unhchr.ch/html/menu2/6/hrc.htm

Committee on Economic, Social, and Cultural Rights

▶ Mandate

The Committee on Economic, Social, and Cultural Rights (CESCR) oversees government compliance with the International Covenant on Economic, Social, and Cultural Rights (ICESCR). The CESCR monitors country progress on the ICESCR by examining periodic reports submitted by governments.

▶ Civil society participation

NGOs can submit “shadow reports” to the CESCR on any aspect of a government’s compliance with the ICESCR. Shadow reports should be submitted through the CESCR Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the Committee. The CESCR meets twice a year.

Contact

Wan-Hea Lee
CESCR Secretary, Office 1-025, Palais Wilson, Palais des Nations, 8-14 Avenue de la Paix, 1211 Geneva 10
Tel: +41 22 917 9321
Fax: +41 22 917 9046
Email: wlee@ohchr.org
Web: www.unhchr.ch/html/menu2/6/cescr.htm

Committee on the Elimination of Racial Discrimination

▶ Mandate

The Committee on the Elimination of Racial Discrimination (CERD) is the body of independent experts that monitors implementation of the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) by states. It monitors country progress on ICERD by examining periodic reports submitted by governments. The Committee then addresses its concerns and recommendations to the country in the form of “concluding observations.” Besides commenting on country reports, CERD monitors state compliance through an early-warning procedure and the examination of inter-state complaints and individual complaints.

▶ Civil society participation

NGOs can submit “shadow reports” to the CERD on any aspect of a government’s compliance with the ICERD. Shadow reports should be submitted through the CERD Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the committee. CERD meets twice a year.

Contact

Nathalie Prouvez
Secretary of the Committee on the Elimination of Racial Discrimination
Treaties and Commission Branch
Office of the High Commissioner for Human Rights
Palais Wilson - 52, rue des Pâquis, CH-1201
Geneva, Switzerland
Mailing address: UNOG-OHCHR, CH-1211 Geneva
10, Switzerland
Tel: +41.22.917.93.09,
Fax: +41.22.917.90.22
Email: nprouvez@ohchr.org
Web: www2.ohchr.org/english/bodies/cerd/index.htm

International Labour Organization

▶ Mandate

The International Labour Organization (ILO), located within the United Nations, is primarily concerned with respect for human rights in the field of labour. In 1989, they adopted the Convention concerning Indigenous and Tribal Peoples in Independent Countries. States must provide periodic reports on their compliance with the Convention to the ILO and to national employers and workers associations. National employers and workers associations may submit comments on these reports to the ILO. The ILO Committee of Experts (CE) evaluates the reports and may send “Direct Requests” to governments for additional information. The CE then publishes its “Observations” in a report, presented at the International Labour Conference. On the basis of this report, the Conference Committee on the Application of Standards may decide to more carefully analyze certain individual cases and publishes its conclusions. Additionally, an association of workers or employers may submit a representation to the ILO alleging that a member state has failed to comply with the Convention and a member state may file a complaint against another.

▶ **Civil society participation**

The Convention encourages governments to consult indigenous peoples in preparing their reports. Indigenous peoples may also affiliate with a worker association or form their own worker association in order to more directly communicate with ILO. The CE meets in November and December of each year, and the International Labour Conference is in June.

Contact

Office Relations Branch
4, rue des Morillons
CH-1211, Geneva 22, Switzerland
Tel. +41.22.799.7732
Fax: +41.22.799.8944
Email: RELOFF@ilo.org
Web: www.ilo.org/public/english/index.htm

Committee on the Elimination of All Forms of Discrimination Against Women

▶ **Mandate**

The Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW Committee) oversees government compliance with the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). The CEDAW Committee has three mandates: to monitor country progress on CEDAW by examining periodic reports submitted by governments; to examine individual complaints of violations of women's rights under the Optional Protocol to CEDAW; and to conduct missions to state parties in the context of concerns about systematic or grave violations of treaty rights.

▶ **Civil society participation**

NGOs can submit “shadow reports” to the CEDAW Committee on any aspect of a government's compliance with CEDAW. Shadow reports should be submitted through the Division for the Advancement of Women in New York, which also keeps a calendar of when governments come before the Committee. The CEDAW Committee meets twice a year. Individuals and NGOs can also submit complaints to the Committee under the Optional Protocol, or encourage the Committee to undertake country missions as part of its inquiry procedure.

Contact

Tsu-Wei Chang, Coordination and Outreach Unit, Division for the Advancement of Women, Department of Economic and Social Affairs, Two UN Plaza, Room DC2 12th Floor, New York, NY, 10017
Tel: +1 (212) 963-8070, Fax: +1 (212) 963-3463
Email: changt@un.org
Web: <http://www.un.org/womenwatch/daw/cedaw/cedaw38/NGOnote.pdf>

Committee on the Rights of the Child

▶ Mandate

The Committee on the Rights of the Child (CRC Committee) oversees government compliance with the Convention on the Rights of the Child (CRC). It monitors country progress on the CRC by examining periodic reports submitted by governments.

▶ Civil society participation

NGOs can submit “shadow reports” to the CRC Committee on any aspect of a government’s compliance with the Convention. Shadow reports should be submitted through the CRC Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the CRC Committee. It meets three times a year.

Contact

Maja Andrijasevic-Boko
CRC Secretary
8-14 Avenue de la Paix, CH 1211 Geneva 10,
Switzerland,
Tel: +41 22 917 9000
Fax: +41 22 917 9022
Email: mandrijasevic@ohchr.org
Web: www2.ohchr.org/english/bodies/crc/index.htm

African Commission on Human and People’s Rights

▶ Mandate

The African Commission on Human and People’s Rights, a body of the Organization of African Unity (OAU), has a broad mandate to protect and promote human rights in Africa, as well as to interpret the provisions of the African [Banjul] Charter on Human and People’s Rights. The Commission monitors country progress on the Convention by: examining periodic reports submitted by governments; examining complaints of violations of the Convention’s provisions brought by individuals, NGOs, and governments; and undertaking a range of promotional activities related to human rights in Africa.

▶ Civil society participation

Individuals or organizations may submit complaints to the Commission, provided all local remedies have been exhausted and other admissibility criteria have been met. (The requirement of exhausting domestic remedies may be waived if it is obvious to the Commission that this procedure has been unduly prolonged.) Individual or organizational complaints are only considered by the Commission at the request of a majority of its members. Detailed information about the submission procedure can be found on the Commissions website: www.achpr.org/english/information_sheets/ACHPR%20inf.%20sheet%20no.3.doc.

NGOs with observer status with the Commission may attend the Commission’s public sittings.

Additional treaties: Additional important treaties overseen by the African Commission on Human and People's Rights include the African Charter on the Rights and Welfare of the Child, OAU Doc. CAB/LEG/24.9/49 (1990) and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, Adopted by the 2nd Ordinary Session of the Assembly of the Union, Maputo, CAB/LEG/66.6 (Sept. 13, 2000), reprinted in 1 Afr. Hum. Rts. L.J. 40.

Note on the African Human Rights Court: To complement the mandate of the African Commission, the African Charter on Human and People's Rights contains a Protocol calling for the establishment of an African Court on Human and People's Rights. As of April 2007, judges for the African Court had been sworn in, however the Court was not yet operational. Once operational, the Court will have jurisdiction over the African Charter and its Protocols and any other "relevant human rights instrument" ratified by the concerned parties. The Court will accept complaints from the Commission, States Parties, and African Intergovernmental Organizations.

Contact

African Commission on Human and People's Rights,
48 Kairaba Avenue, P.O. Box 673 Banjul, The Gambia
Tel: +220 4392 962, 4372 070, 4377 721-23
Fax: +220 4390 764
Email: achpr@achpr.org
Web: www.achpr.org

European Court of Human Rights

► Mandate

The European Court of Human Rights (ECtHR), a body of the Council of Europe (COE), enforces the provisions of the [European] Convention for the Protection of Human Rights and Fundamental Freedoms. The ECtHR adjudicates both disputes between states and complaints of individual human rights violations. The Committee of Ministers of the Council of Europe is responsible for monitoring the implementation of judgments made by the ECtHR. (See note on Committee of Ministers below.)

► Civil society participation

Any individual or government can lodge a complaint directly with the ECtHR alleging a violation of one of the rights guaranteed under the Convention, provided they have exercised all other options available to them domestically. An application form may be obtained from the ECtHR website (www.echr.coe.int/echr/).

The Council of Europe has established a legal aid scheme for complainants who cannot afford legal representation. NGOs can file briefs on particular cases either at the invitation of the President of the Court, or as "Amici Curia" (Friends of the Court) if they can show that they have an interest in the case or special knowledge of the subject matter, and that their intervention would serve the administration of justice. Hearings of the ECtHR are generally public.

Contact

European Court of Human Rights,
Council of Europe, 67075 Strasbourg-Cedex, France,
Tel: +33 3 88 41 20 18
Fax: + 33 3 88 41 27 30
Web: www.echr.coe.int

European Committee of Social Rights

▶ Mandate

The European Committee of Social Rights (ECSR), also a body of the Council of Europe (COE), conducts regular legal assessments of government compliance with provisions of the European Social Charter. These assessments are based on reports submitted by governments at regular two-to-four-year intervals known as “supervision cycles.” The Governmental Committee and the Committee of Ministers of the Council of Europe also evaluate government reports under the ECSR. (See note on Committee of Ministers below.)

▶ Civil society participation

Reports submitted by governments under the European Social Charter are public and may be commented upon by individuals or NGOs. International NGOs with consultative status with the COE, as well as national NGOs authorized by their government, may also submit “collective complaints” to the COE alleging violations of the Charter.

Contact

Web: www.humanrights.coe.int/cseweb/GB/index.htm

Advisory Committee

▶ Mandate

The Advisory Committee (AC) assists the Committee of Ministers in monitoring compliance with the Framework Convention for the Protection of National Minorities (FCNM). It monitors country progress on the FCNM by examining periodic reports submitted by governments. Besides examining these reports, the AC may hold meetings with governments and request additional information from other sources. The AC then prepares an opinion, which is submitted to the Committee of Ministers. Based on this opinion, the Committee of Ministers issues conclusions concerning the adequacy of measures taken by each state party. The AC may be involved by the Committee of Ministers in the monitoring of the follow-up to the conclusions and recommendations.

▶ Civil society participation

NGOs can submit “shadow reports” to the AC on any aspect of a government’s compliance with the FCNM. Shadow reports should be submitted through the FCNM Secretariat.

Contact

Directorate General of Human Rights (DGII)
Secretariat of the Framework Convention for the
Protection of National Minorities
F – 67075 STRASBOURG CEDEX
France
Tel: +33/(0)3.90.21.44.33
Fax: +33/(0)3.90.21.49.18
Email: minorities.fcnm@coe.int
Web: www.coe.int/minorities

UN Charter bodies

In addition to the treaty bodies listed above, there are a number of bodies created under the Charter of the United Nations for the protection and promotion of human rights.

The principal charter body is the Human Rights Council (HRC), which replaced the Commission on Human Rights (CHR) in 2006. The HRC is a subsidiary organ of the UN General Assembly with a mandate “to address situations of violations of human rights, including gross and systematic violations.”

The responsibilities of the Human Rights Council include: the Universal Periodic Review (UPR); the Special Procedures; the Human Rights Council Advisory Committee (formerly the Sub-Commission on the Promotion and Protection of Human Rights); and the Complaints Procedure. These responsibilities are summarized at:

http://www.ohchr.org/english/bodies/hrcouncil/docs/FACTSHEET_OUTCOMES_FINAL.pdf

▶ Universal Periodic Review (UPR)

Beginning in 2008, the HRC will periodically review the human rights obligations and commitments of all countries. All UN Member States will be reviewed for the first time within four years. A working group will meet three times per year for two weeks to carry out the review. The review will take into account a report from the State concerned, as well as recommendations from the Special Procedures (see below) and Treaty Bodies (see above) and information from non-governmental organizations and national human rights institutions.

▶ Special Procedures

“Special Procedures” is the general term given to individuals (known as “Special Rapporteurs,” “Special Representatives,” or “Independent Experts”) or groups (known as “Working Groups”) mandated by the HRC to address specific country situations or thematic issues throughout the world. The HRC currently includes twenty-eight thematic and ten country Special Procedures.

Activities undertaken by the Special Procedures include responding to individual complaints, conducting studies, providing advice on technical cooperation at the country level, and engaging in general promotional activities. The Special Procedures are considered “the most effective, flexible, and responsive mechanisms within the UN system.”¹

Special Procedures cited in this Resource Guide include:

- Working Group on Arbitrary Detention
- Special Rapporteur on Extrajudicial, Summary or Arbitrary Executions

¹ FACTSHEET: Work and Structure of the Human Rights Council, July 2007.

- Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health
- Special Rapporteur on Violence against Women, its Causes and Consequences

For more information about the Special Procedures, see:

<http://www.ohchr.org/english/bodies/chr/special/index.htm>

▶ **Human Rights Council Advisory Committee**

The HRC Advisory Committee functions like a “think tank,” providing expertise and advice and conducting substantive research and studies on issues of thematic interest to the HRC at its request. The Committee is made up of eighteen experts serving in their personal capacity for a period of three years.

▶ **Complaints Procedure**

This confidential complaints procedure allows individuals or organizations to bring complaints about “gross and reliably attested violations of human rights” to the attention of the HRC. The procedure is intended to be “victims-oriented” and to conduct investigations in a timely manner. Complaints are reviewed by two working groups that meet at least twice a year for five days during each period.

Other committees and groups

▶ **Committee of Ministers**

The Committee of Ministers (www.coe.int/cm) is the decision-making body of the Council of Europe, and is comprised of the foreign ministers (or their permanent representatives) of all COE member states.

In addition to supervising judgments of the ECtHR and evaluating reports under the ECSR (see above), the Committee of Ministers also makes separate Recommendations to member states on matters for which the Committee has agreed to a “common policy”—including matters related to health and human rights.

Some of these Recommendations are provided by the **Parliamentary Assembly** of the Council of Europe (assembly.coe.int), which is a consultative body composed of representatives of the Parliaments of member states.

▶ **European Union**

The European Union (www.europa.eu/europa.ed.int/eur-lex/) has twenty-seven member states and is a separate system from the Council of Europe (www.coe.int), which has forty-seven member states. Mechanisms for advocating for health and human rights within the European Union (such as

EU Directives and the European Court of Justice) are not discussed in this Guide. It should be noted, however, that all member states of the European Union are bound by the institutions and instruments under the Council of Europe.

▶ **Economic and Social Council (ECOSOC)**

The UN Economic and Social Council (ECOSOC) coordinates the work of fourteen UN specialized agencies, functional commissions, and regional commissions working on various international economic, social, cultural, educational, and health matters. ECOSOC holds several short sessions per year as well as an annual substantive session for four weeks every July.

ECOSOC consults regularly with civil society, with close to 3,000 non-governmental organizations enjoying consultative status. ECOSOC-accredited NGOs are permitted to participate, present written contributions, and make statements to the Council and its subsidiary bodies. Information about NGOs with consultative status can be found at: <http://www.un.org/esa/coordination/ngo/>.

ECOSOC agencies and commissions that may be cited in or relevant to this Resource Guide include:

- Commission on the Status of Women
- Commission on Narcotic Drugs
- Commission on Crime Prevention and Criminal Justice
- Committee on Economic, Social and Cultural Rights
- International Narcotics Control Board

The Right to the Highest Attainable Standard of Health

What is the legal basis for the “right to health”?

- ▶ The best and most complete statement of the “right to health” can be found in the International Covenant on Economic, Social and Cultural Rights (ICESCR), Article 12. It sets out “the right of everyone to the enjoyment of the **highest attainable standard of physical and mental health.**”
- ▶ *See also* International Convention on the Elimination of All Forms of Racial Discrimination, article 5(e) (iv); Convention on the Elimination of All Forms of Discrimination, Articles 11(f) and 12; Convention on the Rights of the Child, Article 24.
- ▶ The Committee on Economic, Social and Cultural Rights, the UN body monitoring compliance with the ICESCR, has provided detailed guidance on implementing the right to health (General Comment 14).

What does the right to health mean?

- ▶ A right to **health care** that is **available, accessible, acceptable, and quality** and
- ▶ A right to the **underlying determinants of health**, including civil and political rights

What are the components of the right to health care?

- ▶ **Availability** of health facilities, goods, and services
- ▶ **Accessibility** of health facilities, goods and services; this includes:
 - Non-discrimination
 - Physical accessibility
 - Economic accessibility/affordability
 - Information accessibility
- ▶ **Acceptability** of health facilities, goods, and services; they must be:
 - Respectful of medical ethics
 - Culturally appropriate
 - Sensitive to gender and life-cycle requirements

- ▶ **Quality** health facilities, goods, and services that are scientifically and medically appropriate

How can this right be meaningfully protected if it is dependent on resources?

- ▶ This right contains a **minimum core**, priority obligations, and aspects for **progressive realization to the maximum of available resources**.
- ▶ The minimum core includes:
 - Non-discriminatory access to health care.
 - Equitable distribution of health facilities, goods, and services
 - Essential medicines, as defined by the WHO; this encompasses access to palliative care and harm reduction medications.
 - Minimum essential food, potable water, basic shelter, and sanitation.
 - National public health strategies and plans of actions adopted and implemented through a participatory process. National strategies and plans must give particular attention to vulnerable and marginalized groups in both their process and content.
- ▶ Priority obligations include:
 - Ensuring reproductive, maternal, and child health care.
 - Providing immunization against major infectious diseases.
 - Taking measures to prevent, treat, and control epidemics.
 - Providing education and information on major health problems.
 - Appropriately training health personnel, including education on health and human rights.
- ▶ National public health strategies and plans need to include **benchmarks** to measure progressive realization. There is thus an important **monitoring** role for civil society.
- ▶ Courts, tribunals, and health ombuspersons can also play a critical role in ensuring government accountability for the right to health.

Essential reading

General resources in health and human rights

Part II of this Guide contains topic-specific resources. The following are general resources on health and human rights, divided into the following categories:

- ▶ Conventions: UN
- ▶ Conventions: Regional
- ▶ Guidelines and interpretations
- ▶ Books
- ▶ Key articles, reports, and other documents
- ▶ Periodicals
- ▶ Websites
- ▶ Search engines
- ▶ Training materials

Conventions: UN

- ▶ International Covenant on Civil and Political Rights.
Source: www.unhchr.ch/html/menu3/b/a_ccpr.htm
- ▶ International Covenant on Economic, Social and Cultural Rights.
Source: www.unhchr.ch/html/menu3/b/a_cescr.htm
- ▶ International Convention on the Elimination of all forms of Racial Discrimination.
Source: www.ohchr.org/english/law/cerd.htm
- ▶ Convention concerning Indigenous and Tribal Peoples in Independent Countries.
Source: www.unhchr.ch/html/menu3/b/62.htm
- ▶ Convention on the Elimination of all Forms of Discrimination Against Women.
Source: www.ohchr.org/english/law/cedaw.htm

- ▶ Convention on the Rights of the Child.
Source: www.ohchr.org/english/law/crc.htm
- ▶ Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.
Source: www.ohchr.org/english/law/cat.htm

Conventions: Regional

- ▶ African Charter on Human and People's Rights.
Source: www.achpr.org/english/info/charter_en.html
- ▶ Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa.
Source: www.achpr.org/english/info/women_en.html
- ▶ African Charter on the Rights and Welfare of the Child.
Source: www.achpr.org/english/info/child_en.html
- ▶ [European] Convention on the Protection of Human Rights and Fundamental Freedoms.
Source: conventions.coe.int/Treaty/en/Treaties/Html/005.htm
- ▶ European Social Charter.
Source: conventions.coe.int/Treaty/EN/Treaties/Html/035.htm
- ▶ Framework Convention for the Protection of National Minorities.
Source: conventions.coe.int/treaty/en/Treaties/Html/157.htm

Guidelines and interpretations

- ▶ The Siracusa Principles on the Limitation and Derogation Principles in the ICCPR, especially Article 25.
Source: www1.umn.edu/humanrts/instree/siracusaprinciples.html
- ▶ The Maastricht Guidelines on Violations of Economic, Social, and Cultural Rights.
Source: www1.umn.edu/humanrts/instree/Maastrichtguidelines_.html
- ▶ Committee on Economic, Social and Cultural Rights, General Comment 14, The Right to the Highest Attainable Standard of Health.
Source: [www.unhcr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En](http://www.unhcr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En)

- ▶ Committee on the Elimination of Discrimination against Women, General Recommendation 24, Women and Health.
Source:
www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm#recom24

Books

General Human Rights

- ▶ Buergenthal, Thomas and Dinah Shelton and David Stewart. *International Human Rights in a Nut Shell*. West Publishing Company, 1995.
- ▶ Cranston M. *What are Human Rights?* New York: Basic Books, 1973.
- ▶ Nussbaum M. Capabilities, Human Rights and the Universal Declaration. In: *Weston and Marks. The Future of International Human Rights*, Transnational Publishers, 1999.
- ▶ Orend B. *Human rights—Concept and Context*. Broadview Press, 2000.
- ▶ Steiner HJ and Alston P. *International Human Rights in Context – Law, Politics, Morals*. 2nd ed. Oxford University Press, 2000. Chapters 1, 4 and 11.
- ▶ Sen, Amartya, *Development as Freedom*. Pp.87-100. New York: Anchor Books, 1998.

Health and Human Rights

- ▶ Alfredsson, G. and K. Tomasevski. *A Thematic Guide to Documents on Health and Human Rights: Global and Regional Standards adopted by Intergovernmental Organizations, International Non-Governmental Organizations and Professional Associations*. Martinus Nijhoff, 1998.
- ▶ Asher, Judith. *Right to Health: A Resource Manual for NGOs.*, 2004
[www.shr.aas.org/Right to Health Manual/index.shtml](http://www.shr.aas.org/Right_to_Health_Manual/index.shtml)
- ▶ Beyrer, Christopher and Hank Pizer, eds. *Public Health and Human Rights: Evidence-Based Approaches*. (forthcoming).
- ▶ Chapman, Audrey and Sage Russell, eds. *Core Obligations: Building a Framework for Economic, Social and Cultural Rights*. Intersentia, 2002.
- ▶ Cook, Rebecca J, Bernard Dickens, and Mahmoud Fathalla. *Reproductive Health and Human Rights: Integrating Medicine, Ethics, and Law*. Oxford: Oxford University Press, 2003.

- ▶ Farmer, Paul. *Infections and Inequalities: The Modern Plagues*. California: University of California Press, 2001.
- ▶ Farmer, Paul. *Pathologies of Power: Health, Human Rights and the New War on the Poor*. California: University of California Press, 2003.
- ▶ Gostin, Lawrence O. *Public Health Law: Power, Duty, Restraint*. California: University of California Press, 2003.
- ▶ Gruskin, Sofia and Michael A. Grodin, George J. Annas, and Stephen P. Marks, eds. *Perspectives on Health and Human Rights*. Routledge, 2005.
- ▶ Mann, Jonathan M. and Sofia Gruskin, Michael A. Grodin, and George J. Annas, eds. *Health and Human Rights: A Reader*. Routledge, 1999.
- ▶ Marks, Stephen. *Health and Human Rights: Basic International Documents*. Boston: Harvard University Press, 2006.

Key articles, reports, and other documents

- ▶ Annas, George J. Human Rights and Health—The Universal Declaration of Human Rights, 339 *New Eng. J. Med.* 1778 (1998).
- ▶ Beyrer, Chris. Public Health, Human Rights, and the Beneficence of States, *Human Rights Review* 2004, 5(1) 28-33.
- ▶ Burris Scott. “Law as a Structural Factor in the Spread of Communicable Disease.” *Houston Law Review* 36 (1999): 1756-1786.
- ▶ Burris, Scott and Zita Lazzarini and Lawrence O Gostin. “Taking Rights Seriously.” *Journal of Law, Medicine & Ethics*, 30(2002):490-491.
- ▶ Farmer P, Gastineau N. Rethinking Health and Human Rights: Time for a Paradigm Shift. *J Law, Med and Ethics* (2002) 30:4:655-666.
- ▶ Farmer, Paul. *Never Again? Reflections on Human Values and Human Rights*. Tanner lectures on Human Values. University of Utah: 2005.
- ▶ Goodman T. Is There A Right To Health? *J. of Medicine and Philosophy*, 30:643-662, 2005.
- ▶ Gruskin, Sofia and Trantola, Daniel. “Health and Human Rights, paper, to appear as chapter in *The Oxford Textbook of Public Health*, 4th edition, Detels, McEwan, Beaglehole and Tanaka, eds, (Oxford University Press).

- ▶ *Human Rights and Health in Prisons: a review of strategy and practice*, Penal Reform International and Royal Netherlands Tuberculosis Foundation (2006).
- ▶ *Human Right to Health Information Sheet 1: Human Right to Health*, National Economic and Social Rights Initiative.
- ▶ *Human Right to Health Information Sheet 2: Human Right to Health Care*, National Economic and Social Rights Initiative.
- ▶ Leary, V. “The Right to Health in International Human Rights Law,” *Health and Human Rights: An International Journal*, 1994, 1(1):24-56.
- ▶ London, Leslie. “Human Rights and Public Health: Dichotomies or Synergies in Developing Countries? Examining the Case of HIV in South Africa.” *Journal of Law, Medicine and Ethics* 30 (2002): 677-691
- ▶ London, Leslie. “Issues of equity are also issues of rights: Lessons from Experiences in Southern Africa,” *BMC Public Health* 2007, 7:14.
- ▶ Mann, Jonathan. *Medicine and Public Health, Ethics and Human Rights*, Hastings Center Rep., May-June 1997.
- ▶ Ngwena, Charles. “The Recognition of Access to Health Care as a Human Right in South Africa: Is It Enough?” *Health and Human Rights: An International Journal* 5 (1): 26-44 (2000).
- ▶ Odinkalu, Chidi Anselm. “Analysis of Paralysis or Paralysis by Analysis? Implementing Economic, Social and Cultural Rights under the African Charter on Human and Peoples’ Rights.” *Human Rights Quarterly* 23.2 (2001) 327-369.
- ▶ Office of the High Commissioner for Human Rights, Fact Sheet on the Right to Health.
- ▶ Potts, Helen. Human Rights Centre. University of Essex. *Accountability and the Right to the Highest Attainable Standard of Health*. 2008.
www2.essex.ac.uk/human_rights_centre/rth/docs/HRC_Accountability_Mar08.pdf
- ▶ Right to Health Unit, Human Rights Centre, University of Essex, UK, Right to the Highest Attainable Standard of Health, Inter-Regional Conference on Human Rights and Judiciary Systems.
- ▶ Human Rights Centre, University of Essex, International Federation of Health and Human Rights Organizations. *Our Right to the Highest Attainable Standard of Health*.

http://www2.essex.ac.uk/human_rights_centre/rth/docs/REVISED_MAY_07_RtH_8pager_v2.pdf

- ▶ United Nations Special Rapporteur on the Right to the Highest Attainable Standard of Health, Initial Report on Sources and Content of the Right to Health, E/CN.4/2003/58.
- ▶ United Nations Special Rapporteur on the Right to the Highest Attainable Standard of Health, Report on Mission to Uganda, E/CN.4/2006/48/Add.2.
- ▶ United Nations Special Rapporteur on the Right to the Highest Attainable Standard of Health, Report on Progress and Obstacles to the Health and Human Rights Movement, in addition to Cases on the Right to Health and other Health- Related Rights, A/HRC/4/28.
- ▶ World Health Organization. 25 Questions and Answers on Health and Human Rights, Health and Human Rights Publications Series 1 (2002).
- ▶ World Health Organization. Fact Sheet on the Right to Health.
- ▶ Zuckerman, Barry and Ellen Lawton and Samatra Morton. *From Principles to Practice: Moving from Human Rights to Legal Rights to Ensure Child Health*.

Periodicals

- ▶ Health and Human Rights: An International Journal.
- ▶ The Lancet (contains a regular health and human rights section).
- ▶ BMC International Health and Human Rights.

Websites

- ▶ Amnesty International Health Professional Network
web.amnesty.org/pages/health-index-eng
- ▶ BMC International Health and Human Rights
www.biomedcentral.com/bmcinthealthhumrights/
- ▶ François Xavier Bagnoud Centre for Health and Human Rights, Harvard School of Public Health
www.hsph.harvard.edu/fxbcenter/

- ▶ Global Lawyers and Physicians
www.glphr.org
- ▶ The International Center for the Legal Protection of Human Rights (monthly report of significant human rights decisions from common law jurisdictions)
www.interights.org
- ▶ International Federation of Health and Human Rights Organizations
www.ifhhro.org
- ▶ International Society for Health and Human Rights
www.ishhr.org
- ▶ International Helsinki Federation for Human Rights (IHF)
The IHF is a community of 46 human rights NGOs in the OSCE area that co-operate on promoting implementation of human rights and compliance with international human rights standards.
www.ihf-hr.org/index.php
- ▶ Johns Hopkins School of Public Health Center for Public Health and Human Rights
www.jhsph.edu/humanrights/index.html
- ▶ National Economic and Social Rights Initiative
www.nesri.org
- ▶ Physicians for Human Rights
physiciansforhumanrights.org/
- ▶ Science and Human Rights Program of the American Association for the Advancement of Science
shr.aaas.org
- ▶ Special Rapporteur on the Right to the Highest Attainable Standard of Health
www2.essex.ac.uk/human_rights_centre/rth/rapporteur.shtml or
www.ohchr.org/english/issues/health/right/
- ▶ University of Minnesota Human Rights Library contains a lengthy list of health and human rights websites, though many of these are out of date
www1.umn.edu/humanrts/links/health.html
- ▶ World Health Organization's Health and Human Rights page
WHO's 25 Questions and Answers on Health and Human Rights is a useful introductory document
www.who.int/hhr/en/

Search engines

- ▶ The UN Treaty Body Database includes all general comments, concluding observations, reports, and other documents of the UN human rights system, organized by treaty monitoring body and special procedure.
www.unhchr.ch/tbs/doc.nsf
- ▶ The International Human Rights Index also includes the above documents but is searchable by key word, country, and right.
www.universalhumanrightsindex.org
- ▶ The University of Minnesota has an excellent database of international human rights documents and information. It is organized simply and clearly and is generally the easiest way to find documents.
www1.umn.edu/humanrts/
- ▶ Professor Anne Bayefsky's website (York University, Toronto, Canada) includes international human rights documents and jurisprudence that are searchable by country, category of document, and theme or subject matter.
www.bayefsky.com
- ▶ The Global Justice Center maintains a database of domestic and international court decisions that cite to CEDAW or the CEDAW Optional Protocol.
www.globaljusticecenter.net/casebank
- ▶ The European Court of Human Rights maintains a database of decisions.
cmiskp.echr.coe.int/tkp197/search.asp?skin=hudoc-en
- ▶ Health and Human Rights Info, a project of the International Society for Health and Human Rights, is a searchable database of organizations, manuals, training materials, projects and reports, and articles related to several areas of health and human rights.
www.hhri.org
- ▶ The Harvard School of Public Health has produced a searchable database of syllabi from health and human rights courses around the world.
www.hsph.harvard.edu/pihhr/syllabidatabase.html

Training materials

- ▶ The Human Rights Resource Center, part of the University of Minnesota human rights library, contains a range of interactive training packages on human rights.

www1.umn.edu/humanrts/edumat/

- ▶ The website of Equitas contains a collection of education manuals and resources as well as extensive information and links to Equitas projects and partners.
www.equitas.org

What are key terms related to health and human rights?

Glossary

The following terms relate both to health and human rights and to human rights in general.

A

Acceptability

One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Acceptability: means that all health facilities, goods and services must be respectful of medical ethics, culturally appropriate, sensitive to gender and life-cycle requirements, as well as designed to respect confidentiality and improve the health status of those concerned (General Comment 14). *See also* “Adequacy,” “Availability,” and “Quality.”

Accessibility

One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Accessibility: means that health facilities, goods and services have to be accessible to everyone without discrimination. Accessibility has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility (affordability), and information accessibility (General Comment 14). *See also* “Acceptability,” “Adequacy,” and “Quality.”

Accession

Acceptance by a state of the opportunity to become a party to a treaty and be legally bound by it. Unlike *ratification*, this is a one-step process.

Actio popularis (public action)

A legal action brought by any member of a community in vindication of a public interest.

Adoption

Process by which the parties drafting a treaty agree to its text and open the treaty for *accession* or *ratification* by potential state parties.

Adoption theory

Theory maintaining that international law becomes an automatic part of domestic law following treaty *accession* or *ratification*, without further *domestication*.

Amicus curiae (friend of the court)

A legal document filed with the court by a party not involved in a lawsuit, generally advocating a particular legal position or interpretation.

Availability

One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Availability: means that functioning public health and health care facilities, goods, and services, as well as programmes, have to be available in sufficient quantity. This should include the underlying determinants of health, such as safe drinking water, adequate sanitation facilities, clinics and health-related buildings, trained medical personnel, and essential drugs (General Comment 14). *See also* “Acceptability,” “Accessibility,” and “Quality.”

B

Basic needs

Used largely in the development community to refer to basic health services, education, housing, and other goods necessary for a person to live.

C

Concluding observations

Recommendations by a treaty’s enforcement mechanism on the actions a state should take in ensuring compliance with the treaty’s obligations. This generally follows both submission of a state’s *country report* and a constructive dialogue with state representatives.

Country report

A state’s report to the enforcement mechanism of a particular treaty on the progress it has made in implementing it.

Customary international law

A source of international law consisting of rules derived from the consistent conduct of states acting out of the belief of a legal obligation. A particular category of customary international law, *jus cogens*, refers to a principle of international law so fundamental that no state may opt out by treaty or otherwise.

D

De facto (in fact, in reality)

Existing in fact.

De jure (by right, lawful)

A situation or conclusion based on law.

Dignity

The quality of being worthy, honored, or esteemed. Human rights are based on inherent human dignity and aim to protect and promote it.

Discrimination

Distinction between persons in similar cases on the basis of race, sex, religion, political opinions, national or social origins, association with a national minority, or personal antipathy (WHO).

Domestication

Process by which an international treaty is incorporated into domestic legislation.

E**Entry into force**

Point at which a treaty becomes a legally binding document on all state parties.

Essential medicines

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

Exhaustion of domestic remedies

Requirement to seek all available avenues for national redress before submitting a complaint on behalf of a victim to any regional or international tribunal. There are limited exceptions to this requirement if national remedies are unavailable, ineffective (sham proceedings), or unreasonably delayed.

G**General comments/recommendations**

Interpretive texts issued by a treaty's enforcement mechanism on the content of particular rights. Although these are not legally binding, they are widely regarded as authoritative and have significant legal weight.

H**Health**

A state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity (WHO).

Human rights

Universal legal guarantees for all human beings, set out in international standards, protecting human dignity and fundamental freedoms and privileges. Human rights cannot be waived or taken away.

Human rights covenants/conventions

Treaties which are legally binding on states which ratify them.

Human rights declarations

Statements of non-binding human rights norms and principles (though they may reflect binding customary international law).

Human rights indicators

Criteria used to measure compliance with international human rights standards.

I

Interdependent/ indivisible

Term used to describe the relationship between civil and political rights and economic and social rights. Interdependence and indivisibility mean that one set of rights does not take precedence over the other, and that guaranteeing each set of rights is contingent upon guaranteeing the other.

International law

The set of rules and legal instruments regarded and accepted as binding agreements between nations. Sources are: treaties, custom, general principles of law, and judicial decisions and juristic writings (Statute of the International Court of Justice, art. 38(1)(d)).

Interpretive declaration

Declaration by a state as to its understanding of some matter covered by a treaty. Unlike *reservations* (see below), declarations merely clarify a state's position and do not purport to exclude or modify the legal effect of a treaty.

M

Maximum available resources

Key provision of ICESCR, Article 2 obliging governments to devote the maximum of available government resources to realizing economic, social and cultural rights.

Monitoring/ fact finding/ investigation

Terms often used interchangeably, generally intended to mean the tracking and/or gathering of information about government practices and actions related to human rights.

N

Negative rights

State obligations to refrain from interfering with a person's attempt to do something.

Neglected diseases

Diseases affecting almost exclusively poor and powerless people in rural parts of low-income countries that receive less attention and resources.

P

Positive rights

State obligations to do something for someone.

Progressive realization

Requirement that governments move as expeditiously and effectively as possible toward the goal of realizing economic, social and cultural rights, and to ensure there are no regressive developments.

Protocol

Addition to a treaty that clarifies terms, amends text, or establishes new obligations.

Public health

What we as a society do collectively to ensure the conditions in which people can be healthy (Institute of Medicine).

Q

Quality

One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Quality: means that health facilities, goods, and services must be scientifically and medically appropriate and of good quality. This requires skilled medical personnel, scientifically approved and unexpired drugs, and hospital equipment (General Comment 14). *See also* “Acceptability,” “Accessibility,” and “Availability.”

R

Ratification

Follows *signature* and indicates a state’s acceptance of a treaty and agreement to be bound by it.

Reservation

A unilateral statement by a state when signing, ratifying, or acceding to a treaty which purports to exclude or modify the effect of certain treaty provisions. Under the Vienna Convention on the Law of Treaties, a state cannot enter a reservation that is “incompatible with the object and purpose of the treaty.”

Respect, protect, and fulfill

Governments’ obligations with respect to rights. **Respect:** government must not act directly counter to the human rights standard. **Protect:** government must act to stop others from violating the human rights standard. **Fulfill:** government has an affirmative duty to take appropriate measures to ensure that the human rights standard is attained.

Right to health

Right to the enjoyment of a variety of facilities, goods, services, and conditions necessary for the realization of the highest attainable standard of health.

S

Self executing treaty

A treaty that does not require implementing legislation for its provisions to have effect in domestic law.

Shadow report

Independent NGO submission to a treaty enforcement mechanism to help it assess a state's compliance with that treaty.

Signature

Expression of a state's willingness to continue the treaty-making process and proceed to ratification. Although the provisions of the treaty are not yet legally binding on the states, signature creates an obligation to refrain in good faith from acts that would defeat the object and purpose of the treaty.

Special procedures

Mechanisms with the Human Rights Council, including special rapporteurs, clarifying communications with countries, and country missions, to address country-specific human rights violations or thematic issues.

Special rapporteurs

Individuals appointed by the Human Rights Council to investigate human rights violations and present an annual report with recommendations for action. There are both country-specific and thematic special rapporteurs, including one on the right to the highest attainable standard of health.

T

Transformation theory

Theory maintaining that international law only becomes part of domestic law after *domestication* and the incorporation of treaty provisions into domestic legislation.

Treaty

A formal agreement entered by two or more nations which is binding upon them.

U

Underlying determinants of health

Conditions necessary for good health, including safe and potable water, adequate food, housing, healthy occupational and environmental conditions, health-related education, non-discrimination, etc. This includes both social and economic and civil and political rights.

W

Working groups

Small committees appointed by the Human Rights Council on a particular human rights issue. Working groups write governments about urgent cases and help prevent future violations by developing clarifying criteria on what constitutes a violation.

PART II: HUMAN RIGHTS IN PATIENT CARE

Overview

This section will introduce you to key issues and resources related to human rights in **patient care**, with a particular focus on issues such as **consent**, **confidentiality**, **access to information** and **care**.

This section is organized into six segments that answer the following questions:

- ▶ **How** is patient care a human rights issue?
- ▶ **What** is OSI's work in the area of human rights in patient care?
- ▶ **Which** are the most relevant international and regional human rights standards related to patient care?
- ▶ **What** are some examples of effective human rights programming in the area of patient care?
- ▶ **Where** can I find additional resources on human rights in patient care?
- ▶ **What** are key terms related to human rights in patient care?

As you read through this section, consult the **glossary of terms** found in the back, *What are key terms related to patient care and human rights?*

How is patient care a human rights issue?

What is patient care?

Patient care refers to the prevention, treatment and management of illness and the preservation of physical and mental well-being through services offered by medical and allied health professions this, and similar definitions, often are provided for the term “*health care*” as well. Patient care consists of services rendered by members of the health professions or non-professionals under their supervision for the benefit of the patient.² A **Patient** is a user of health care services, whether healthy or sick.³

What are human rights in patient care?

The concept of “**human rights in patient care**” brings together the rights of both patients and health care providers. It refers to the application of general human rights principles to all stakeholders in the delivery of health care. It encompasses all rights recognized under international law that are relevant to the provision of health services. This includes basic empowerment rights (such as information, consent, free choice, privacy and confidentiality), rights to a remedy for abuses, and rights of access to services.

Human rights in patient care is complementary to bioethics but provides a set of universally accepted norms and procedures for making conclusions about abuses within health care settings and providing remedies. It uses standards contained in the international human rights framework, which are often mirrored in regional treaties and national constitutions. It differs from patients’ rights, which codify particular rights that are relevant only to patients rather than applying general human rights standards to all stakeholders in health care service delivery, including providers. It draws on concepts such as dual loyalty, which attributes much human rights abuse in health settings to health care providers’ simultaneous and often conflicting obligations to their patients and to the State.

What are patient rights?

“**Patient rights**” refers to a “set of rights, responsibilities and duties under which individuals seek and receive health care services.”⁴

The call for patients’ rights is a movement that is growing globally to make governments and health care providers more accountable for providing access to quality health services. In 1997, the Council of Europe adopted the **Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine** (European Convention on Human Rights and Biomedicine). This convention sets out certain basic patient rights principles,

² Dorland’s Illustrated Medical Dictionary, 28th ed., p.269

³ Declaration on the Promotion of Patients’ Rights in Europe, European Consultation on the Rights of Patients, WHO, Amsterdam 1994.

⁴ European Observatory on Health Systems and Policies Glossary (citing USAID, 1999).

such as equitable access to health care and protection of consent, private life, and right to information, binding on ratifying states.

The **European Charter of Patients' Rights**, compiled in 2002 by Active Citizenship Network, a European network of civic, consumer, and patient organizations, provides a clear, comprehensive statement of patient rights. This statement was part of a grassroots movement across Europe for patients to play a more active role in shaping the delivery of health services and an attempt to translate regional documents on the right to health care into specific provisions.⁵ Although this Charter is not legally binding, a strong network of patient rights groups across Europe have successfully lobbied their national government for recognition and adoption of rights in the Charter.⁶ The Charter has also been used as a reference point to monitor and evaluate health care systems across Europe. In September 2007, the European Economic and Social Committee (EESC) approved its own initiative opinion on patients' rights, declaring that it "welcomes and acknowledges" the European Charter of Patients' Rights.

European Charter of Patients' Rights

Source: Active Citizenship Network, 2002

The 14 'immutable' rights	Description
1. Right to preventive measures	Every individual has the right to a proper service, in order to prevent illness.
2. Right of access	Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness, or time of access to services.
3. Right to information	Every individual has the right of access to all kinds of information regarding their state of health, the health services (and how to use them), and all that scientific research and technological innovation makes available.
4. Right to consent	Every individual has the right of access to all information that might enable him or her to actively participate in the decisions regarding his or her health. This information is prerequisite for any procedure and treatment, including participation in scientific research.

⁵ It is important to note that the pharmaceutical company Merck & Co. also provided funding for this movement.

⁶ One of the activities of new EU member-states during the process of preparation for accession in the EU was adjustment of health care legislation towards European standards. Many countries, such as Bulgaria, adopted a new health law, whose structure and contents are strictly in line with the European Charter of Patients' Rights.

The 14 'immutable' rights	Description
5. Right to free choice	Each individual has the right to freely choose from among different treatment procedures and providers, on the basis of adequate information.
6. Right to privacy and confidentiality	Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general.
7. Right to respect for patients' time	Each individual has the right to receive necessary treatment within a swift and predetermined period of time. This right applies at each phase of the treatment.
8. Right to observance of quality standards	Each individual has the right of access to high-quality health services, on the basis of the specification and observance of precise standards.
9. Right to safety	Each individual has the right to be free from harm caused by the poor functioning of health services, medical malpractice and errors, and the right of access to health services and treatments that meet high safety standards.
10. Right to innovation	Each individual has the right of access to innovative procedures (including diagnostic procedures), according to international standards and independently of economic or financial considerations.
11. Right to avoid unnecessary suffering and pain	Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness.
12. Right to personalised treatment	Each individual has the right to diagnostic or therapeutic programmes tailored as much as possible to his or her personal needs.
13. Right to complain	Each individual has the right to complain whenever he or she has suffered harm, and the right to receive a response or other feedback.
14. Right to compensation	Each individual has the right to receive sufficient compensation within a reasonably short time whenever he or she has suffered physical (or moral and psychological) harm caused by a health service treatment

Did you know?

- ▶ Worldwide, information about patient rights is severely lacking.
 - In **Macedonia**, while 82% of respondents stated that there are patient rights, 56% do not know what their rights are.⁷
 - In **Lithuania**,
 - 85% of medical staff (out of 255) and 56% of patients (out of 451) had heard of or read about patients' rights laws;
 - 50% of professionals and 69% of patients thought information about diagnosis, treatment results, and alternatives necessary for patients.⁸
- ▶ There are widespread misconceptions about the meaning of forms providing for patient consent to invasive surgery.
 - In a recent survey among 732 European surgical patients,
 - 46% believed that the primary function of the written consent form was to protect the hospital,
 - 68% thought that the form allowed doctors to take control, and
 - 41% believed consent forms made their wishes known.⁹
- ▶ Access to essential medicines is lacking in developing countries.
 - The total number of people without access to essential medicines is estimated at between 1.3 and 2.1 billion people.
 - According to a 1999 study, about 30% of the world population lacked access to essential medicines.
 - Only 10% of R&D spending is directed to health problems that account for 90% of the global disease burden.
 - A small number of companies dominate global production, trade, and sale of medicines. Ten companies account for almost half of all sales.¹⁰
- ▶ Worldwide, medicines are often inappropriately taken.
 - Half of all medicines are inappropriately prescribed, dispensed, or sold.
 - Half of all patients fail to take their medicines properly.
 - An estimated 2/3 of global antibiotic sales occur without any prescription.
 - In **Pakistan** and **India**, 70% of patients were prescribed antibiotics, and up to 90% of injections are estimated to be unnecessary.

⁷ Rights of Patients in Macedonia According to European Standards 2005.

⁸ BMC International Health and Human Rights 2006, 6:10.

⁹ BMJ September 2006.

¹⁰ World Health Organization, The World Medicines Situation (2004).

- In the **United States**, adverse drug events rank among the top 10 causes of death and cost between \$30-130 billion each year.¹¹

¹¹ World Health Organization, *The World Medicines Situation* (2004).

What is OSI's work in the area of human rights in patient care?

Although OSI does not have a program on human rights in patient care, patient care issues arise in the work of the International Harm Reduction Development Program, International Palliative Care Initiative, Sexual Health and Rights Project, and Roma Health Project. Moreover, the OSI **Mental Health Initiative (MHI)** focuses on ensuring the human rights of people with mental disabilities to participate in society and live as equal citizens, working to end their unjustified and inappropriate institutionalization (www.soros.org/initiatives/mhi).

The **Human Rights and Governance Grants Program (HRGGP)** supports the leading mental disability rights NGOs working in Central and Eastern Europe and the former Soviet Union as well as other projects on patients' rights through human rights monitoring, documentation, and litigation.

The **Law and Health Initiative (LAHI)** has a specific objective to promote human rights in patient care (www.soros.org/initiatives/health/focus/law). It supports the establishment of human rights guidelines for the delivery of medical services and the training of health workers, as well as legal action to remedy abuses in the health care system. In February 2007, LAHI sponsored a one-week seminar, which brought together experts from legal, public health, and medical perspectives and patient advocates to think creatively about human rights in patient care and how to structure a course dealing with this concern. Topics explored included:

- ▶ International Framework for Health and Human Rights
- ▶ Regional and Constitutional Protection of Health
- ▶ Institutionalization and the Health Care System
- ▶ Criminalized Populations and Disease Vulnerability
- ▶ Patient Privacy, Consent, and Confidentiality
- ▶ Providers' Rights and Their Relationship to Patients' Rights
- ▶ Legal Remedies for Health Care Abuses
- ▶ Human Rights in Health Care Reform

Delegations came from six former Soviet Union countries: Armenia, Georgia, Kazakhstan, Kyrgyzstan, Russia, and Ukraine.

Which are the most relevant international and regional human rights standards related to patient care?

Overview

A wide variety of human rights standards at the international, regional, and national levels applies to patient care. These standards can be used for many purposes:

- ▶ **To document** violations of patient rights
- ▶ **To advocate** for the cessation of these violations
- ▶ **To sue** governments for violations of national human rights laws
- ▶ **To complain** to regional and international human rights bodies about breaches of human rights agreements.

In the tables on the following pages, **examples** of human rights violations related to patient care are provided. Relevant human rights **standards** are then cited, along with examples of legal **precedents** and **provisions** from patient right charters and declarations, **interpreting** each standard.

How to read the tables

As you read through each table, ask yourself the following questions about the **violations**, **standards**, and **precedents and interpretations** that are cited:

EXAMPLES OF HUMAN RIGHTS VIOLATIONS

Do any of these violations occur in your country? Are there other violations of this human right that exist in your country?

HUMAN RIGHTS STANDARDS

Are these violations prohibited by the “human rights standards”? Can the standards be interpreted to apply to this violation?

PRECEDENTS AND INTERPRETATIONS

Do any of the “examples of precedents and interpretations” apply to this issue? Can they be interpreted to apply to this issue?

Remember that human rights law is an evolving field, and that many human rights violations are not directly addressed by existing legal standards and precedents. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on patient care and human rights.

Abbreviations

In the tables, the seven treaties and their corresponding enforcement mechanisms are referred to with the following abbreviations:

Treaty	Enforcement Mechanism
International Covenant on Civil and Political Rights (ICCPR)	Human Rights Committee (HRC)
International Covenant on Economic, Social, and Cultural Rights (ICESCR)	Committee on Economic, Social and Cultural Rights (CESCR)
Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)	Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW Committee)
Convention on the Rights of the Child (CRC)	Committee on the Rights of the Child (CRC Committee)
African Charter on Human and People's Rights (ACHPR) & Protocols	African Commission on Human and People's Rights (ACHPR Commission)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)	European Court of Human Rights (ECtHR) (with Committee of Ministers)
European Social Charter (ESC)	European Committee of Social Rights (ECSR)

Table 1: Patient care and the right to liberty and security of the person

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • A hospital employs excessive restraints on patients, such as tying them to a bed or wheelchair for hours each day. • Mentally ill patients are confined without a set procedure or standard. • There are unjustified delays in reviewing whether mentally ill patients must continue to be institutionalized. • Patients are detained in hospitals for their inability to pay bills. 	
Human Rights Standards	Precedents and Interpretations
<p>ICCPR 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.</p> <p>ACHPR 6 Every individual shall have the right to liberty and to the security of his person. No one may be deprived of his freedom except for reasons and conditions previously laid down by law. In particular, no one may be arbitrarily arrested or detained.</p> <p>ECHR 5(1) Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law.</p>	<p>HRC: considering a period of 14 days of detention for mental health reasons without review by a court in Estonia incompatible with ICCPR 9. [CCPR/CO/77/EST (HRC, 2003), para. 10].</p> <p>ECtHR: establishing that civil commitment must follow a procedure prescribed by law and cannot be arbitrary; the person must have a recognized mental illness and require confinement for the purposes of treatment. [Winterwerp v. The Netherlands, 33 Eur. Ct. H.R. (ser. A) (1979)].</p> <p>ECtHR: mandating speedy periodic legal review of civil commitment with the essential elements of due process. [X v. United Kingdom, 46 Eur. Ct. H.R. (ser. A) (1981)].</p> <p>ECtHR: awarding damages for violation of liberty interests to a patient detained in a Hungarian psychiatric hospital for 3 years where the commitment procedure was superficial and insufficient to show dangerous conduct. [Gajcsi v. Hungary (Application No. 34503/03), Oct. 3, 2006].</p>

Table 2: Patient care and the right to privacy

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • Patient medical information is open to all hospital staff, including those not involved in patient care. • Patients are forced to disclose their medical diagnosis to their employer in order to obtain sick leave from work. • Medical examinations take place under public conditions. • Terminally-ill patients are forced to remain in public wards. • Staff of medical/ psychiatric institutions routinely open patient mail and review their correspondence. 	
Human Rights Standards	Precedents and Interpretations
<p>ICCPR 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.</p> <p>CRC 16(1) No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation.</p> <p>ECHR 8(1) Everyone has the right to respect for his private and family life, his home and his correspondence.</p> <p><i>See also:</i></p> <ul style="list-style-type: none"> • European Convention on Human Rights and Biomedicine, art 10(1): “Everyone has the right to respect for private life in relation to information about his or her health.” 	<p>CESCR: referring to “the right to have personal health data treated with confidentiality.” [CESCR GC 14, para 12].</p> <p>CRC Committee: highlighting the need for confidentiality for adolescents with respect to sexual and reproductive health in Djibouti [CRC/C/97(2000)96, para. 555].</p> <p>ECtHR: holding that “the protection of personal data, not least medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life. Respecting the confidentiality of health data is a vital principle It is crucial not only to respect the sense of privacy of the patient but also to preserve his or her confidence in the medical profession and in the health services in general.” [M.S. v. Sweden (27/08/1997)].</p> <p>ECtHR: noting that disclosure of health data “may dramatically affect a person’s private and family life, as well as social and employment situation, by exposing him or her to opprobrium and the risk of ostracism.” [Z. v. Finland, 25/02/1997].</p> <p><i>See also:</i></p> <ul style="list-style-type: none"> • The European Charter of Patients’ Rights sets out: “Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general.” [art. 6].

Table 2: Patient care and the right to privacy continued

Human Rights Standards	Precedents and Interpretations
	<ul style="list-style-type: none">• Under the Declaration on the Promotion of Patients' Rights in Europe, "All information about a patient's health status . . . must be kept confidential, even after death." "Patients admitted to health care establishments have the right to expect physical facilities which ensure privacy." [art. 4.1, 4.8].

Table 3: Patient care and the right to information

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • A state fails to provide information on various health care services. For instance, rape victims are entitled to obtain post-exposure prophylaxis to prevent HIV infection, but very few are aware of this option. • Hospitals fail to provide information on patient satisfaction, clinical performance, and waiting lists. • Physicians fail to comprehensibly explain to patients the facts related to their condition. • Physicians fail to provide patients with information about treatment options and the potential risks and benefits of each procedure. • Patients are denied access to their medical files. • Information services are unavailable for people who speak certain languages or who are deaf or blind. 	
Human Rights Standards	Precedents and Interpretations
<p>ICCPR 19(2) Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.</p> <p>ACHPR 9 (1) Every individual shall have the right to receive information.</p> <p>(2) Every individual shall have the right to express and disseminate his opinions within the law.</p> <p>ECHR 10 (1) Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises.</p> <p>See also:</p> <ul style="list-style-type: none"> • European Convention on Human Rights and Biomedicine, art 10(2): “Everyone has the right to know any information collected about his or her health.” 	<p>CESCR: health care accessibility “includes the right to seek, receive and impart information and ideas concerning health issues.” [CESCR GC 14, para 12].</p> <p>See also:</p> <ul style="list-style-type: none"> • Under the European Charter of Patients’ Rights, “Every individual has the right of access to all kinds of information regarding their state of health and health services and how to use them, and all that scientific research and technological innovation makes available.” [art. 3]. • The Declaration on the Promotion of Patients’ Rights in Europe emphasizes, “Patients have the right to be fully informed about their health status, including the medical facts about their conditions; about the proposed medical procedures, together with potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis, and progress of treatment.” Moreover, “[p]atients have the right to choose who, if any one, should be informed on their behalf.” [art. 2.2, 2.6].

Table 4: Patient care and the right to bodily integrity

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • Physicians either fail to obtain consent from patients before performing medical procedures, or do not provide patients with adequate information so that they can make an informed decision. • In the case of a very young patient or a patient lacking capacity, the hospital does not allow for a substitute decision-maker. • A hospital lacks standardized procedures for obtaining patients' consent to participate in scientific research. • Physicians ignore patient wishes regarding treatment. • Patients are not allowed to switch physicians or healthcare providers. 	
Human Rights Standards	Precedents and Interpretations
<p>ACHPR 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.</p> <p><i>Note:</i> The right to bodily integrity is not specifically recognized under the ICCPR, ICESCR, or European conventions, but has been interpreted to be part of the right to security of the person (ICCPR 9, ECHR 5), the right to freedom from torture and cruel, inhuman, and degrading treatment (ICCPR 7, ECHR 3), the right to privacy (ICCPR 17, ECHR 8), and the right to the highest attainable standard of health (ICESCR 12, ESC 11).</p> <p>See also:</p> <ul style="list-style-type: none"> • CRC 19(1) (protecting the child from all forms of physical or mental violence) • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 4(1): "Every woman shall be entitled to respect for her life and the integrity and security of her person." • European Convention on Human Rights and Biomedicine, art 5: "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it." 	<p>CESCR: explaining that the right to health includes "the right to be free from non-consensual medical treatment and experimentation." [CESCR GC 14, para. 8].</p> <p>ECtHR: "[The imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person's physical integrity in a manner capable of engaging the rights protected under Article 8 § 1 of the Convention" [Pretty v. United Kingdom, 2002].</p> <p>ECtHR: finding a breach of physical and moral integrity when dimorphine was administered to a son against his mother's wishes and a DNR (Do Not Resuscitate) order was placed in his records without his mother's knowledge [Glass v. United Kingdom (Application no. 61827/00, 2004)].</p> <p>See also:</p> <ul style="list-style-type: none"> • The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, ("CPT 2001") : "[E]very competent patient...should be given the opportunity to refuse treatment or any other medical intervention. Any derogation from this fundamental principle should be based upon law and only relate to clearly and strictly defined exceptional circumstances." • The European Charter of Patients' Rights sets out the right to "informed consent." "A patient has the right to refuse a treatment or a medical intervention and to change his or her mind during the treatment, refusing its continuation." [art. 4]. Moreover, a patient has "the right to freely choose from different treatment procedures and providers on the basis of adequate information." [art. 5]. • Under the Declaration on the Promotion of Patients' Rights in Europe, "[t]he informed consent of the patient is a prerequisite for any medical intervention," and "[a] patient has the right to refuse or halt a medical intervention." [art. 3.1, 3.2].

Table 5: Patient care and the right to life

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • Due to inadequate reproductive health and prenatal care, complications from pregnancy and childbirth are a leading cause of death for young women. • Ambulances fail to arrive at certain communities in a timely manner. • Patients are unable to obtain low cost medications due to bureaucratic hurdles and an overly restrictive patent regime. As a result, their life is in danger. • Health services do not include preventive screening for many types of cancer. As a result, patients learn they have cancer when it is already too late for effective treatment. 	
Human Rights Standards	Precedents and Interpretations
<p>ICCPR 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.</p> <p>ACHPR 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.</p> <p>ECHR 2(1) Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.</p>	<p>HRC: explaining that the right to life “should not be interpreted narrowly” or “in a restrictive manner,” and its protection “requires that States adopt positive measures . . . to increase life expectancy.” [HRC GC 6, paras 1, 5].</p> <p>ECtHR: holding that a violation of the right to life occurs “whre it is shown that the authorities . . . put an individual’s life at risk through the denial of health care which they have undertaken to make available to the population generally.” [Cyprus v. Turkey, 35 EHRR 721, para. 219 (2002)]</p>

Table 6: Patient care and the right to the highest attainable standard of health

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • Hospitals do not take adequate measures to prevent hospital-borne infections, oversee health risks following transfusions, and ensure their tests and treatment remain of high quality. • Hospitals fail to meet the needs of patients who require religious or psychological support or provide treatment appropriate for the terminally ill. • Hospitals fail to provide care suited to the needs of small children. • Long, unjustified delays in the provision of health services regularly lead to a worsening in patients' health. • A state lacks adequate compensation procedures for patients harmed by health care providers. 	
Human Rights Standards	Precedents and Interpretations
<p>ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p> <p>12(2) The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . . (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.</p> <p>CRC 24(1) States Parties recognize 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.</p> <p>ACHPR 16(1) Every individual shall have the right to enjoy the best attainable state of physical and mental health. 16(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.</p> <p>ESC 11 – The right to protection of health</p> <p>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 . . . (2) to provide advisory and educational facilities for the promotion of health . . .</p> <p>See also:</p> <ul style="list-style-type: none"> • African Charter on the Rights and Welfare of the Child, art. 14 (child's right to the highest attainable standard of health) 	<p>CESCR: “As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality.” They must also be “sensitive to gender and life-cycle requirements.” [CESCR GC 14, para 12].</p> <p>CESCR: pointing to a need for federal legislation on the patient rights in Russia, including redress for medical errors. [E/C.12/1/ADD.94 (CESCR, 2003), para. 32].</p> <p>ECtHR: holding that states have a duty to protect the health of detainees and lack of treatment may amount to a violation of the right to freedom from torture or to inhuman or degrading treatment [Hutardo v. Switzerland (Series A No. 280-A, 28/01/94); Ilhan v. Turkey, 34 EHRR 36 (2002)].</p> <p>See also:</p> <ul style="list-style-type: none"> • CPT 2001: The provision of basic necessities of life must always be guaranteed in institutions where the State has persons under its care and/or custody. These include adequate food, heating and clothing as well as, in health establishments – appropriate medication. [Para 33]. • The European Charter of Patients' Rights refers to the right to “the observance of quality standards,” “safety,” “innovation.” [arts 8-10]. • The Declaration on the Promotion of Patients' Rights in Europe, promulgated by a WHO European Consultation, “Patients have the right to a quality of care which is marked both by high technical standards and by a humane relationship between the patient and health care provider.” [art. 5.3].

Table 7: Patient care and freedom from torture and cruel, inhuman, and degrading treatment

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • Victims of state torture are denied needed medical care. • Prisoners lack basic health services and are forced to subsist on very little food and with inadequate clothes and no heat during the winter. • Mentally ill prisoners are punished for symptoms of their illness, including self-mutilation and attempted suicide. • National laws restricting opioid availability and access cause cancer and AIDS patients to suffer unnecessary pain. 	
Human Rights Standards	Precedents and Interpretations
<p>ICCPR 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.</p> <p>ACHPR 5 Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited.</p> <p>ECHR 3 No one shall be subjected to torture or to inhuman or degrading treatment or punishment.</p> <p><i>See also:</i></p> <ul style="list-style-type: none"> • Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment • Code of Conduct for Law Enforcement Officials • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 4(1) "All forms of exploitation, cruel, inhuman or degrading punishment and treatment shall be prohibited." • European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment 	<p>HRC: calling for the improvement of hygienic conditions, regular exercise, and adequate treatment of the mentally ill in detention facilities in Bosnia and Herzegovina (both in prisons and mental health institutions). [CCPR/C/BIH/CO/1 (HRC, 2006), para. 19].</p> <p>ECtHR: upholding prisoners' right to confinement under conditions compatible with human dignity. Prisoners' health and wellbeing must be adequately secured by the provision of requisite medical assistance. [Kudla v. Pologna, Oct. 26, 2000].</p> <p><i>See also:</i></p> <ul style="list-style-type: none"> • Committee Against Torture: pointing to overcrowding, inadequate living conditions, and lengthy confinement in Russian psychiatric hospitals as "tantamount to inhuman or degrading treatment." [CAT/C/RUS/CO/4 (CAT, 2007), para. 18]. • The European Charter of Patients' Rights sets out: "Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative care treatment and simplifying patients' access to them." [art. 11]. • Under the Declaration on the Promotion of Patients' Rights in Europe, "Patients have the right to relief of their suffering according to the current state of knowledge. . . . Patients have the right to humane terminal care and to die in dignity." [art. 5.10, 5.11].

Table 8: Patient care and the right to participate in public policy

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • A country fails to adopt a national health plan or to make it publicly available to its citizens. • Citizens lack an opportunity to comment on and participate in the setting of public health priorities. • The government will not accept or respond to information and proposals on health care delivery submitted by citizens. 	
Human Rights Standards	Precedents and Interpretations
<p>ICCPR 25 Every citizen shall have the right and the opportunity, without . . . distinctions . . . (a) To take part in the conduct of public affairs, directly or through freely chosen representatives.</p> <p>CEDAW 7 State Parties shall take all appropriate measures to eliminate discrimination against women in the political and public life of the country and, in particular, shall ensure to women, on equal terms with men, the right: . . . (b) [t]o participate in the formulation of government policy and the implementation thereof.</p> <p>See also:</p> <ul style="list-style-type: none"> • CEDAW 14(2)(a) (right of rural women to participate in development planning) • Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa, art. 9(1): “States Parties shall take specific positive action to promote participative governance and the equal participation of women in the political life of their countries.” • The Ljubljana Charter on Reforming Health Care 	<p>CESCR: calling for countries to adopt “a national public health strategy and plan of action” to be “periodically reviewed, on the basis of a participatory and transparent process.” [CESCR GC 14, para. 43].</p> <p>CESCR: “Promoting health must involve effective community action in setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health. Effective provision of health services can only be assured if people’s participation is secured by States.” [CESCR GC 14, para. 54].</p> <p>See also:</p> <ul style="list-style-type: none"> • The European Charter of Patients’ Rights has a whole section on the “Rights of Active Citizenship”--- citizens’ “right to participate in the definition, implementation and evaluation of public policies relating to the protection of health care rights.” [Part III].

Table 9: Patient care and the right to non-discrimination and equality

Examples of Human Rights Violations	
<ul style="list-style-type: none"> Members of certain communities are treated in separate wards with a lower standard of care. Health workers refuse to treat sex workers, drug workers, or LGBT persons. Maternal and reproductive health services for women are lacking. A country fails to provide health services to the poor or non-citizens. 	
Human Rights Standards	Precedents and Interpretations
<p>ICCPR 26 All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.</p> <p>ICESCR 2(2) The States Parties to the present Covenant undertake to guarantee the rights enunciated in the present Covenant shall be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, birth or other status.</p> <p>ACHPR 2 Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, color, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status.</p> <p>See also:</p> <ul style="list-style-type: none"> International Convention on the Elimination of All Forms of Racial Discrimination, art. 5(e)(iv) Convention relating to the Status of Refugees European Convention on Human Rights and Biomedicine, art 3 (equitable access to health care) European Convention on Citizenship and the Convention Relating to the Status of Stateless Persons 	<p>CESCR: explaining that health facilities, goods, and services have to be accessible to everyone without discrimination “and especially to the most vulnerable and marginalized sections of the population.” The Committee further urged particular attention to the needs of “ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities and persons with HIV/AIDS.” [CESCR GC 14, para 12].</p> <p>CESCR: explaining that health facilities, goods, and services “must be affordable for all,” and “poorer households should not be disproportionately burdened with health expenses as compared to richer households.” [CESCR GC 14, para 12].</p> <p>CESCR: criticizing China for inadequate medical care provided to low-income patients. Many expensive drugs required by chronically ill and mentally ill patients are not subsidized and thus in practice denied them. [E/C.12/1/ADD.107 (CESCR, 2005), para. 87].</p> <p>CESCR: admonishing Russia where hospitals and clinics in poor regions often do not stock all essential drugs. [E/C.12/1/ADD.94 (CESCR, 2003), para. 31].</p> <p>ESCR: declaring that the health care system must be accessible to everyone, including the disadvantaged. [Conclusions XVII-2 and 2005, Statement of Interpretation on Article 11].</p>

What are some examples of effective human rights programming in the area of patient care?

Introduction

In this section, you are presented with four **examples** of effective activities in the area of patient care and human rights. These are:

1. Litigation to protect the confidentiality of medical information in the Ukraine
2. Litigation to ensure patient treatment with dignity in the United Kingdom
3. Monitoring of patient rights in Europe
4. Engaging health workers in health rights education and action in Uganda

Rights-based programming

As you review each activity, ask yourself whether it incorporates the **five elements** of “rights-based” programming:

- ▶ **Participation**
Does the activity include participation by affected communities, civil society, marginalized groups, and others? Is it situated in close proximity to its intended beneficiaries?
- ▶ **Accountability**
Does the activity identify both the *entitlements of claim-holders* and the *obligations of duty-holders*? Does it create mechanisms of accountability for violations of rights?
- ▶ **Non-discrimination**
Does the activity identify who is most vulnerable, and how? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, and prisoners?
- ▶ **Empowerment**
Does the activity give its beneficiaries the power, capability, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- ▶ **Linkage to rights**
Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?

Finally, ask yourself whether the activity might be replicated in your country:

- ▶ Does such a project **already exist** in your country?
- ▶ If not, should it be **created**? If so, does it need to be **expanded**?
- ▶ What **steps** need to be taken to replicate this project?
- ▶ What **barriers** need to be overcome to ensure its successful replication?

Example 1: **Litigation to protect the confidentiality of medical information in Ukraine**

In 2006, on a patient's behalf, Vinnystya Human Rights Group challenged a Ukrainian regulation requiring the inclusion of a person's medical diagnosis in forms submitted to employers to permit absence from work due to sickness and the collection of benefits.

Project type

Litigation

Health and human rights issue

A government decree in Ukraine stipulated that a medical certificate, which included a person's diagnosis and ICD (International Classification of Diseases and Causes of Death) disease code, had to be submitted to employers to excuse absence from work due to sickness and allow for the collection of benefits.

Actions taken

- ▶ Vinnystya Human Rights Group filed a challenge to this regulation on behalf of Svitlana Yuriyivna Poberezhets at the Pecherskyi District Court in Kyiv.
- ▶ Ms. Poberezhets claimed that this regulation violated her rights to privacy and confidentiality under the Ukrainian Constitution and Basic Law on Health Care. She was forced to submit a medical certificate with information about her acute respiratory infection to her place of work, which was then disclosed to her co-workers.
- ▶ Vinnystya Human Rights Group and Ms. Poberezhets were opposed by the Ministry of Health, Ministry of Labour and Social Policy, the Social Insurance Fund for Temporary Disability, the Social Insurance Fund for Industrial Accidents and Occupational Diseases, and the Ministry of Justice.

Results

- ▶ On July 2006, the court agreed with Vinnystya Human Rights Group and Ms. Poberezhets that requiring the submission of diagnosis information to a person's place of work infringed on basic constitutional rights. The court specifically held that it violated (1) privacy protections under the Ukrainian Constitution and [European] Convention for the Protection of Human Rights and Fundamental Freedoms and (2) confidentiality protections under the Ukraine Basic Law on Health Care, Civil Code, and "On Information" Law.
- ▶ The court pointed out that regulatory bodies must act within the scope of their authority under the Constitution and legislation.
- ▶ It thus ordered the regulation's registration as unlawful and contradictory and its cancellation.
- ▶ The government later amended the decree, excluding confidential information from medical certificates.

Contact

Vinnystya Human Rights Group, Ukraine
Email: vpg@ukr.net

Example 2: *Litigation to ensure patient treatment with dignity in the United Kingdom*

A psychiatric patient in the UK sued a hospital which overmedicated her and treated her lice infection by shaving off her hair.

Project type

Litigation

Health and human rights issue

A psychiatric patient based at an NHS (National Health Service) hospital was making good progress. She was moved without notice to a private hospital with an NHS contract. She developed an infection of head lice. Initially, she was treated with anti-lice shampoo, but this was quickly discontinued. After a 20-minute talk with a doctor and nurse, she was persuaded to sign a consent form to have her hair completely shaved off. The patient was a woman in her 20's who was very careful about her appearance and had sported shoulder length blond hair for many years. At this time, she was receiving 7000 mg of anti-psychotics daily, compared with a maximum dose of 1000 mg recommended by the Royal College of Psychiatrists.

Actions taken

- ▶ The patient sued the hospital for assault and breach of human rights and lodged a claim against the doctor for overmedication.

Results

- ▶ The hospital made various offers for compensation and issued an apology. The patient and her family accepted an offer of just over £10,000. The court approved the compensation award.
- ▶ The doctor denied wrongdoing, but the court awarded £1000 in damages for the period of overmedication.
- ▶ Positive media coverage during this case drew public attention to the importance of patient rights protection and ensuring the humane treatment of psychiatric patients.

Contact

Christian Khan Solicitors, 42 Museum Street, Bloomsbury
London WC1A 1LY
Tel: +44-207-831-1750
Web: www.christiankhan.co.uk

Example 3: **Monitoring of patient rights in Europe**

In 2003, the Active Citizenship Network partnered with local NGOS to monitor the compliance of 13 European Union countries with the European Charter of Patients' Rights.

Project type

Human rights monitoring and documentation

Health and human rights issue

Governments across Europe have been slow to establish health care systems in line with WHO standards. With growing medical expenses, governments have been rationing health services. Patients, in turn, are pressing for greater access to medical information in order to play a more active role in managing their treatment and shaping the delivery of health services. With increasing freedom of movement across European Union states, there is also a need for greater harmonization of health systems and the assurance of basic standards.

Actions taken

- ▶ In 2003, the Active Citizens Network (ACN), a European network of civic, consumer, and patient organizations, undertook a two-year study of 13 European Union countries to see how they measure up to the European Charter of Patients' Rights.
- ▶ Working with public health experts, ACN translated the Charter into 160 measurable indicators that could be assessed across various countries.
- ▶ ACN partnered with local NGOs to carry out the monitoring project. Partner organizations interviewed 70 key stakeholders—including medical professionals, journalists, insurance carriers, and government ministry representatives—and visited 39 main hospitals in each of the European capital cities. NGOs further answered a questionnaire on their country's patient rights legislation. This methodology was piloted in Italy and then rolled out to the rest of the countries.

Results

- ▶ The results of the study were available in 2005 and publicly disseminated.
- ▶ The study concluded that Europeans do not have sufficient access to high-quality health care, medical innovation, or information about health care choices and documented the degree to which access to care is lacking.
- ▶ The monitoring project helped initiate a dialogue between civil society and governments on health care delivery. The hope is that this will lead to greater governmental accountability.
- ▶ Citizens can also use the results of the study as a basis for advocacy for better care and for health policy changes.

Contact

Active Citizenship Network (ACN)
Via Flaminia, 53-00196 Rome, Italy;
Tel.: (+39)06367181
Fax: (+39)0636718333
E-mail: info@activecitizenship.net
Web: www.activecitizenship.net

Example 4: *Engaging health workers in health rights education and action in Uganda*

In 2003, Ugandan health workers united to urge their colleagues and government to recognize and protect the right to health through anti stigma, health rights leadership, and health budget campaigns.

Project Type

Movement-building and advocacy

Health and human rights issue

Uganda faces major health and human rights challenges including AIDS-related stigma and discrimination, a lack of human rights awareness amongst health workers, and severe under-funding of the health sector.

Action taken

To address these and other health rights, seven health worker leaders founded the Action Group for Health, Human Rights and HIV/AIDS (AGHA) in 2003. AGHA brings together over 600 Ugandan doctors, nurses, other health professionals, NGOs and other institutions interested in promoting the right to health. AGHA spearheads three major campaigns to improve Uganda's AIDS and health response:

- ▶ Anti-Stigma Campaign: a Stigma Task Force of over 50 health workers to combat stigma in health settings through education of health workers and community members.
- ▶ The Health Rights Leadership Campaign: outreach and training to health workers, the general public, and the media on health and human rights in order to integrate human rights into the medical paradigm.
- ▶ Health Funding Campaign: Government advocacy on budget gaps for health services through the media, public forums, and research.
- ▶ Health Workforce Campaign: Advocacy for improved and increased health workforce.

Results

- ▶ The medical paradigm is changing to embrace human rights:
 - The AGHA Stigma Task Force has trained over 250 health workers in four districts on preventing stigma and discrimination and promoting patient rights, and AGHA's curriculum is now included in their official continuing medical education program.
 - The Uganda Medical Association has started a human rights committee.
 - AGHA's health student leadership program has over 300 members and chapters at all public medical schools in Uganda.
- ▶ Health rights are becoming entrenched in key Ugandan institutions:
 - The Ministry of Health and the Uganda Human Rights Commission have both created right to health desks.
 - AGHA has helped WHO train Parliamentarians in health, human rights, and policy.
- ▶ The health budget in Uganda is increasing: In April 2007, the parliament announced an 8 billion Uganda shilling increase in the health budget.

Contact

Action Group for Health, Human Rights and HIV/AIDS (AGHA)
 PO Box 24667 Kampala Uganda
 Tel: +256 414 348 491
 Email: info@aghauganda.org; Web: www.aghauganda.org

Physicians for Human Rights (PHR)
 2 Arrow Street Suite 301
 Cambridge MA 02138
 Tel: 1-(617) 301 4235

Where can I find additional resources on human rights in patient care?

Resources

To further your understanding on the topic of human rights in patient care, a list of commonly used resources has been compiled and organized into the following categories:

- ▶ Declarations and resolutions UN
- ▶ Declarations and resolutions: non-UN
- ▶ Books
- ▶ Reports, key articles, and other documents
- ▶ Periodicals
- ▶ Websites
- ▶ Blogs

Declarations and resolutions: UN

- ▶ 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).
Source: www.unhchr.ch/html/menu3/b/h_comp40.htm

Declarations and resolutions: non-UN

- ▶ A Declaration on the Promotion of Patients' Rights in Europe: European Consultation on the Rights of Patients, Amsterdam (WHO, Regional Office for Europe 1994).
Source: www.who.int/genomics/public/eu_declaration1994.pdf
- ▶ Charter on the Right to Health (International Union of Lawyers 2005).
Source: www.uianet.org/documents/qquia/resolutions/Sante4GB.pdf
- ▶ Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Council of Europe 1997).
Source: conventions.coe.int/Treaty/EN/Treaties/Html/164.htm

- ▶ Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data.
Source: conventions.coe.int/Treaty/en/Treaties/Html/108.htm
- ▶ Declaration on Medical Care for Refugees (World Medical Association)
Source: www.wma.net/e/policy/m10.htm
- ▶ Declaration on the Rights of the Patients (World Medical Association).
Source: www.wma.net/e/policy/l4.htm
- ▶ European Charter of Patients Rights (Active Citizens Network, 2002).
Source: www.activecitizenship.net/health/european_charter.pdf
- ▶ International Alliance of Patients' Organizations: Declaration on Patient-Centered Health Care (March 30, 2007).
Source: www.patientsorganizations.org/
- ▶ Jakarta Declaration on Leading Health Promotion into the 21st Century (1997).
Source: www.who.int/hpr/NPH/docs/jakarta_declaration_en.pdf
- ▶ Ljubljana Charter on Reforming Health Care (WHO, Regional Office for Europe 1996).
Source: www.euro.who.int/AboutWHO/Policy/20010927_5
- ▶ Position Statement: Nurses and Human Rights (International Council of Nurses).
Source: www.icn.ch/abouticn.htm
- ▶ Principles on the Effective Documentation of Torture. Istanbul Protocol
Source: physiciansforhumanrights.org/library/istanbul-protocol.html
- ▶ Recommendation Rec (2000)5 and Explanatory Memorandum of Committee of Ministers to Member States on the Development of Structures for Citizen and Patient Participation in the Decision-Making Process Affecting Health Care (Council of Europe).
Source:
wcd.coe.int/ViewDoc.jsp?id=1062769&BackColorInternet=9999CC&BackColorIntranet=FFBB55&BackColorLogged=FFAC75

Books

- ▶ Angell, Marcia. *The Truth about Drug Companies: How They Deceive Us and What to Do about It*. New York: Random House, 2005.
- ▶ British Medical Association. *The Medical Profession and Human Rights*. Zed Books, 2001.

- ▶ Den Exeter, Andre. *Health Care Law-Making in Central and Eastern Europe: Review of a Legal-Theoretical Model*, Intersentia, 2002.
- ▶ Gevers, J.K.M., Hondius, E.H., and Hubben, J.H, eds. *Health Law, Human Rights and the Biomedical Convention: Essays in Honour of Henriette Roscam Abbing*, 2005.
- ▶ Lavik, JL. *Pain and Survival: Human Rights Violations and Mental Health*. Scandinavian University Press, 1994.
- ▶ Rosenmoller, McKee and Baeten, eds. *Patient Mobility in the European Union: Learning from Experience*. European Observatory on Health Systems and Policies, 2006.
- ▶ World Health Organization. *Enforcement of Public Health Legislation*. WHO Western Pacific Region, 2006.

Reports, key articles, and other documents

- ▶ Amnesty International Ethical Code and Declarations Relevant to Health Professionals.
Source: web.amnesty.org/pages/health-ethicsindex-eng
- ▶ Aydin, E., *Rights of Patients in Developing Countries: the Case of Turkey*, Journal of Medical Ethics 2004; 30:555-557.
- ▶ Crofts, N., Louie, R., Loff, B. *The next plague: stigmatization and discrimination related to hepatitis C virus infection in Australia*. Health and Human Rights, 2(2), 86-97 (1997).
- ▶ “Cross-border Health Care in Europe”, Policy Brief, European Observatory on Health Systems and Policies (2005).
- ▶ Council of the European Union, General Secretariat: Conclusions of the Council on patient mobility and health care developments in the European Union, Brussels, 19 April 2004.
- ▶ EPHA Briefing on Human Rights, European Health Alliance (2005).
- ▶ Fallberg, Lars, “Patients’ Rights in Europe: Where do we stand and where do we go,” European Journal of Health Law 7: 1-3 (2000).
- ▶ Fridli, Judit, “New Challenges in the Domain of Health Care Decisions,” Policy Paper, International Policy Fellowship Program, Open Society Institute, Budapest (2006).

- ▶ Gilson, Lucy. “Trust and the Development of Health Care as a Social Institution,” *Social Science & Medicine* 56 1453-1468 (2003).
- ▶ Glinos, Irene A. and Baeten, *A Literature Review of Cross-Border Patient Mobility in the European Union*, Europe for Patients Project (September 2006).
- ▶ *Human Rights in Action---A Framework for Local Action* (designed by Department of Health, British Institute of Human Rights, and 5 NHS Trusts), Equality and Human Rights Group (2007).
- ▶ Hungarian Civil Liberties Union, Policy Paper on the Rights of Patients.
- ▶ Leenen, Henk, Givers, Sjef and Pinet, Genevieve (eds), “Promotion of the Rights of Patients in Europe, a Comparative Study,” Amsterdam: Academic Publishers (1993).
- ▶ Mackintosh, Maureen. “Do Health Care Systems Contribute to Inequalities?” *Poverty, Inequality and Health* 175-193.
- ▶ Milevska-Kosova, Neda, “Patients Rights as a Policy Issue in South Eastern Europe, Policy Paper, International Policy Fellowship Program, Open Society Institute, Budapest (2006)
- ▶ *National Activities on Patients’ Rights and Quality of Health Care (Asia and Pacific, Africa, Latin America, Countries in Transition, Developed Economies)*, Consumers International (2005).
- ▶ *Patients’ Rights in Europe: A Citizens’ Report*, Summary of Meeting Organized by Active Citizenship Network at the European Parliament, Brussels, February 28 to March 1, 2005, Health and Social Campaigners’ Network, Wales, Commissioned by Oxford Vision 2020 (March 2005).
- ▶ “Patients’ Rights in Europe Today,” Speech, European Ombudsman (2005).
- ▶ PHR and University of Cape Town. Dual Loyalty And Human Rights in Health professional Practice: Proposed Guidelines and Institutional Mechanisms. Online at physiciansforhumanrights.org/library/report-dualloyalty-2006.html Policy Paper on the Rights of Patients, Hungarian Civil Liberties Union.
- ▶ Rich, Robert F. and Merrick, Kelly R., *Cross Border Health Care in the European Union: Challenges and Opportunities*, University of Illinois Working Paper, October 2006.
- ▶ Scott, Penelope, *Undocumented Migrants in Germany and Britain: the Human “Rights” and “Wrongs” Regarding Access to Health Care*, *Electronic Journal of Sociology* (2004).

- ▶ *Social Challenge to Health: Equity and Patients' Rights in the Context of Health Reforms*, Council of Europe 5th Conference of European Health Ministers (1996).
- ▶ Stefanoska, Cavdar, Isajlovska, and Stefanovska, "Rights of the Patients in Macedonia According to the European Standards," Report, Skopje: MIA--- Association of Health Education and Promotion of Health (2005).
- ▶ *Survey of the UK Public: Patients' Rights* (Backgrounder to Main Report: Patients' Rights in Europe and the UK), The Patients' Association (2005).
- ▶ United States Department of Health and Human Services, Centers for Medicare and Medicaid Services: 42 CFR Part 482, Medicare and Medicaid Programs; Hospital Conditions of Participation; *Patients Rights; Final Rule*, Federal Register, Friday, December 8, 2006
- ▶ Written Contribution to Communication from the Commission-Consultation Regarding Community Action on Health Services, ILGA Europe (2007).

Periodicals

- ▶ British Medical Journal
- ▶ Conflict and Health
- ▶ European Journal of Health Law
- ▶ Journal of Law, Medicine and Ethics
- ▶ Journal of Medical Ethics
- ▶ The Lancet

Websites

- ▶ British Medical association Human Rights Publications.
www.bma.org.uk/ap.nsf/Content/HRpublications
- ▶ Europe for Patients Project
www.europe4patients.org
- ▶ European Court of Human Rights- Mental Disability Cases
www.mdac.info/resources/echr_cases.htm

- ▶ European Public Health Alliance
www.epha.org
- ▶ Health and Social Campaigners' Network International
www.patient-view.com/hscnetwork.htm
- ▶ Oxford Vision 2020
www.oxfordvision2020.org
- ▶ The Patients Association
www.patients-association.org.uk
- ▶ Penal Reform International
www.penalreform.org/health-in-prisons.html
- ▶ Physicians for Human Rights
physiciansforhumanrights.org/
- ▶ Sharing for Action, Patients Rights
www.sharingforaction.med.bg.ac.yu

Blogs

- ▶ The Health Consumer Blog @ Health Consumer Powerhouse
- ▶ Global Directory of Patients' Organizations @ International Alliance of Patients' Organizations
www.patientsorganizations.org

What are key terms related to human rights in patient care?

Glossary

A variety of terms is used in human rights and patient care work.

A

Ambulatory care

Medical care including diagnosis, observation, treatment, and rehabilitation provided on an outpatient basis.

D

Dual loyalty

Role conflict between professional duties to a patient and obligations—express or implied, real or perceived—to the interests of a third party such as an employer, insurer, or the state.

H

Health care or patient care (see also Patient care)

1. The prevention, treatment, and management of illness and the preservation of mental and physical well-being through the services offered by the medical, nursing, and allied health professions. This definition and similar ones sometimes are given for “*patient care*” as well. The World Health Organization states that this embraces all the goods and services designed to promote health, including preventive, curative, and palliative interventions, whether directed to individuals or populations.
2. “Any type of services provided by professionals or paraprofessionals with an impact on health status” (European Observatory on Health Systems and Policy online glossary).
3. “Medical, nursing or allied services dispensed by health care providers and health care establishments” (Declaration on Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

Health care establishment

Any health care facility such as a hospital, nursing home, or establishment for disabled persons (Declaration on Promotion of Rights of Patients in Europe, WHO, Amsterdam, 1994).

Health care providers

Physicians, nurses, dentists, or other health professionals (Declaration on Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

Health care system

The organized provision of health care services.

Human rights in patient care

Concept that brings together the rights of both patients and health care providers and refers to the application of general human rights principles to all stakeholders in the delivery of health care. It encompasses all rights recognized under international law that are relevant to the provision of health services.

I**Informed consent**

A legal condition in which a person can be said to agree to a course of action based upon an appreciation and understanding of the facts and implications. The individual needs to be in possession of relevant facts and the ability to reason.

Informed consent in the health care context

A process by which a patient participates in health care choices. A patient must be provided with adequate and understandable information on matters such as the treatment's purpose, alternative treatments, risks, and side-effects.

In-patient

A patient whose care requires a stay in hospital or hospice facility for at least one night.

M**Medical intervention**

Any examination, treatment, or other act having preventive, diagnostic therapeutic or rehabilitative aims and which is carried out by a physician or other health care provider (Declaration on the Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

N**Neglected diseases**

Diseases affecting almost exclusively poor and powerless people in rural parts of low-income countries that receive less attention and resources.

O**Out-patient**

Patient receiving treatment without spending any nights at a health care institution.

P

Patient

A user of health care services, whether healthy or sick (Declaration on the Promotion of Patients' Rights in Europe, WHO, Amsterdam 1994).

Patient autonomy

The right of patients to make decisions about their medical care. Providers can educate and inform patients, but cannot make decisions for them.

Patient care (see also Health care)

The services rendered by members of the health professions or non-professionals under their supervision for the benefit of the patient. Similar definitions often are provided for the term "health care."

Patient-centered care

Doctrine recognizing the provision of health services as a partnership among health care providers and patients and their families. Decisions about medical treatments must respect patients' wants, needs, preferences, and values.

Patient confidentiality

Doctrine that holds that the physician has the duty to maintain patient confidences. This is to allow patients to make full and frank disclosure to their physician, enabling appropriate treatment and diagnosis.

Patient mobility

Concept describing patient movement beyond their catchment area or area of residence to access health care; mobility can take place within the same country or between countries.

Patient responsibility

A doctrine recognizing the doctor/patient relationship as a partnership with each side assuming certain obligations. Patient responsibilities include communicating openly with the physician or provider, participating in decisions about diagnostic and treatment recommendations, and complying with the agreed-upon treatment program.

Patients' rights

1. Set of rights calling for government and health care provider accountability in the provision of quality health services. Associated with a movement empowering patients, particularly in countries where patients are assuming a greater share of health care costs and thus expect to have their rights as "consumers" respected.
2. A set of rights, responsibilities and duties under which individuals seek and receive health care services (European Observatory on Health Systems and Policy online glossary).

Patient safety

Freedom from accidental injury due to medical care or medical errors (Institute of Medicine).

Primary health care

General health services available in the community near places where people live and work; the first level of contact individuals and families have with the health system.

S**Secondary health care**

General health services available in hospitals.

T**Terminal care**

Care given to a patient when it is no longer possible to improve the fatal prognosis of his or her illness/condition with available treatment methods, as well as care at the approach of death (Declaration on the Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

Tertiary health care

Specialized health services available in hospitals.

APPENDIX

Links

Thirteen Health and Human Rights Documents

- ▶ International Covenant on Civil and Political Rights (ICCPR)
www.equalpartners.info/Appendix/App_01iccpr.html
- ▶ Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights (Siracusa Principles)
www.equalpartners.info/Appendix/App_02siracusa.html
- ▶ International Covenant on Economic, Social and Cultural Rights (ICESCR)
www.equalpartners.info/Appendix/App_03icescr.html
- ▶ Committee on Economic, Social and Cultural Rights, General Comment 14, The right to the highest attainable standard of health
www.equalpartners.info/Appendix/App_04EcSocCult.html
- ▶ The Maastricht Guidelines on Violations of Economic, Social and Cultural Rights (Maastricht Guidelines)
www.equalpartners.info/Appendix/App_05Maastricht.html
- ▶ International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)
www.equalpartners.info/Appendix/App_06icerd.html
- ▶ Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)
www.equalpartners.info/Appendix/App_07cedaw.html
- ▶ Committee on the Elimination of Discrimination against Women, General Recommendation 24, Women and Health
www.equalpartners.info/Appendix/App_08EIDisWo.html
- ▶ African [Banjul] Charter on Human and Peoples' Rights (ACHPR)
www.equalpartners.info/Appendix/App_09achpr.html
- ▶ Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Women's Protocol to the African Charter)
www.equalpartners.info/Appendix/App_10WoProtocol.html
- ▶ [European] Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)
www.equalpartners.info/Appendix/App_11echr.html
- ▶ European Social Charter (ESC)
www.equalpartners.info/Appendix/App_12esc.html

- ▶ Appendix to the European Social Charter
www.equalpartners.info/Appendix/App_13escapp.html
- ▶ European Charter of Patients' Rights
www.equalpartners.info/Appendix/App_14ecpr.html

Human Rights in Patient Care

A Resource Guide

A modified excerpt from *Health and Human Rights: A Resource Guide*

Edited by Jonathan Cohen, Tamar Ezer, Paul McAdams, and Minda Miloff

The field of health and human rights brings together two important movements. For public health advocates, human rights provide an essential tool for promoting accountability and addressing the non-medical roots of poor health. For human rights advocates, the protection of public health is a mark of democracy, good governance, and open society. As governments respond to urgent health threats in the 21st century, it is more important than ever for human rights groups to partner with health experts in advocating against abuses and generating pragmatic, rights-based solutions.

This Resource Guide provides a practical tool for all staff working at the intersection of health and human rights. It includes fact sheets, program descriptions, jurisprudence, case studies, and glossary definitions regarding human rights in patient care. It also contains links to thirteen foundational human rights documents containing health-related provisions.

Prepared by OSI and Equitas staff together with leading experts in the field, this guide is designed to support health and human rights advocacy, training, education, programming, and grantmaking worldwide.

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