

HEALTH AND HUMAN RIGHTS RESOURCE GUIDE



FXBCENTER
FOR HEALTH & HUMAN RIGHTS

HARVARD SCHOOL OF PUBLIC HEALTH | HARVARD UNIVERSITY

HEALTH AND HUMAN RIGHTS RESOURCE GUIDE

Table of Contents

Introduction

Chapter 1: Patient Care and Human Rights

Chapter 2: HIV, AIDS, and Human Rights

Chapter 3: TB and Human Rights

Chapter 4: Harm Reduction and Human Rights

Chapter 5: Palliative Care and Human Rights

Chapter 6: Children's Health and Human Rights

Chapter 7: Minority Health and Human Rights

Chapter 8: LGBTI, Health and Human Rights

Chapter 9: Disability, Health, Community Living and Human Rights

Health and Human Rights Resource Guide

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Cover photograph courtesy of Sven Torfinn - Panos for the Open Society Foundations, "A paralegal nurse named Mercy and a lawyer named Johnson, both with Nyeri Hospice in Nyeri, Kenya talk with Elizabeth (center) about her health and property. She has cancer and is cared for by her granddaughter Caroline (to her left). She wants to ensure her granddaughters can inherit her property even though other relatives are trying to claim it."

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CHAPTER I



PATIENT CARE AND HUMAN RIGHTS

“ If further progress is to be made towards the operationalization of the right to health, many more health professionals must begin to appreciate the human rights dimensions of their work. ”

— Paul Hunt, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/HRC/4/28 - January 17, 2007

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Cover photograph courtesy of Marilyn Keegan, COHSASA (Council for Health Service Accreditation of Southern Africa), “COHSASA staff work with hospital staff to bring about quality improvements in both the public and private sectors”

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Table of Contents

1. Introduction	1.1
How is patient care a human rights issue?.....	1.2
What is patient care?	1.2
What are the issues and how are they human rights issues?	1.2
What are the current practices in the area of patient care?.....	1.7
Table: Codifications of patients' rights	1.9
2. Which are the most relevant international and regional human rights standards related to patient care?	1.13
How to read the tables.....	1.13
Abbreviations	1.14
Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms.....	1.15
Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms.....	1.15
Table 1: Patient Care and the Right to Liberty and Security of the Person	1.16
Table 2: Patient Care and the Right to Privacy	1.17
Table 3: Patient Care and the Right to Information.....	1.19
Table 4: Patient Care and the Right to Bodily Integrity.....	1.21
Table 5: Patient Care and the Right to Life	1.23
Table 6: Patient Care and the Right to the Highest Attainable Standard of Physical and Mental Health	1.24
Table 7: Patient Care and Freedom from Torture and Cruel, Inhuman, and Degrading Treatment.....	1.26
Table 8: Patient Care and the Right to Participate in Public Policy	1.27
Table 9: Patient Care and the Right to Non-Discrimination and Equality.....	1.28
3. What is a human rights-based approach to advocacy, litigation, and programming?	1.30
4. What are some examples of effective human rights-based work in the area of patient care?	1.33
Example 1: Litigating to protect private patient medical records in Ukraine.....	1.33
Example 2: Monitoring and advocacy on patient rights at the European level	1.36
Example 3: Training and litigation guides: The Practitioner Guide Project	1.38
Example 4: Human rights in patient care courses initiative	1.40
Example 5: Uganda National Health Consumers' Organisation: Developing a patients' charter.....	1.42
5. Where can I find additional resources on patient care and human rights?	1.45
A. International Instruments	1.45
B. Regional Instruments	1.46
C. General Resources.....	1.46
D. Health Workers and Human Rights	1.47
E. Right to Life.....	1.47
F. Right to Information	1.47
G. Right to Participate in Public Policy.....	1.48
H. Right to Non-Discrimination and Equality.....	1.48
I. Cross-Border Health in Europe	1.48
J. Journals	1.49
K. Websites	1.49

INTRODUCTION

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

While other chapters in this Resource Guide focus on specific populations—such as people living with and affected by HIV, people who use drugs, LGBTI communities, and minority and indigenous communities—this chapter addresses human rights issues affecting patients as a whole.

The chapter is organized into six sections that answer the following questions:

1. How is patient care a human rights issue?
2. What are the most relevant international and regional human rights standards related to patient care?
3. What is a human rights-based approach to advocacy, litigation, and programming?
4. What are some examples of effective human rights-based work in the area of patient care?
5. Where can I find additional resources on human rights in patient care?
6. What are key terms related to human rights in patient care?

I. 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 health professionals.¹ Patient care consists of services rendered by health professionals (or non-professionals under their supervision) for the benefit of patients.² A patient is a user of health care services whether he or she is healthy or sick.³

What are the issues and how are they human rights issues?

Patients are entitled to the full range of human rights. Health care providers must respect each patient's dignity and autonomy, right to participate in making health care decisions, right to informed consent, right to refuse medical treatment, and right to confidentiality and privacy. The attention, treatment, and care that each health care provider gives to a patient must respect the human rights of every one of his or her patients.

The human rights-based approach to patient care draws from 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. Human rights standards apply to all stakeholders in the delivery of health care—including both patients and care providers.

A human rights-based approach seeks, above all, to uphold the inherent human dignity of all actors in the care provider-patient relationship. This relationship can be a complex one, especially when coupled with health care delivery. For example, as medicine becomes ever more advanced, providers and patients must work together to make diagnostic and therapeutic decisions.⁴ Financial and quality issues are always present in health care delivery and can lead to inequality and discrimination.⁵ Greater understanding is needed of the social determinants of health that straddle the lines between traditional medicine and a broader concept of health, as well as of the interdependence of the right to health and the realization of all human rights.⁶ A human rights-based approach uses the human rights framework to analyze these elements of patient care, among others.

Below are some common human rights issues that arise in patient care settings. This list is not comprehensive. The list alternates between highlighting issue areas and highlighting marginalized groups whose human rights are frequently violated in the health care setting.

¹ Dorland's Illustrated Medical Dictionary, 28th ed., p. 269.

² This definition, and other similar definitions, are often provided for the term "health care."

³ World Health Organization (WHO), *Declaration on the Promotion of Patients' Rights in Europe, European Consultation on the Rights of Patients*, (1994).

⁴ Leaning J, "Human rights and medical education," *Boston Medical Journal* 315 (1997): 1390. <http://dx.doi.org/10.1136/bmj.315.7120.1390>.

⁵ Ibid.

⁶ Ibid.

Right to information

Patients are often unaware of their rights, including the right to information on their condition and the right to access their medical records. In a study conducted at four hospitals in Lithuania, 85% of the staff and 56% of the patients surveyed had heard of or read about patients' rights laws.⁷ Moreover, only 50% of professionals and 69% of patients thought it was necessary for patients to have information about diagnosis, treatment results, and alternative modes of treatment.⁸ Another study in Macedonia found that 82% of respondents stated that there are patient rights, but 56% did not know what their rights were.⁹

Patients have the right to information about their health status, treatment options and reasonable alternatives, and the likely benefits and risks of proposed treatment and non-treatment. Patients also have the right to access their medical chart and medical history.

Right to privacy and confidentiality

Patients have the right to have their health information and data kept confidential. According to Gostin et al., "Health data may include not only a patient's sensitive health status, but also those facts or circumstances that the patient reveals to [health care workers] as part of seeking medical treatment."¹⁰ The "right to privacy and confidentiality must be applied sensitively, with respect for different cultural, social, and religious traditions."¹¹

For certain vulnerable groups, the right to privacy and confidentiality is an essential aspect of obtaining health care. For example, privacy and confidentiality are crucial to realizing sexual and reproductive rights for women and adolescents.¹² In General Comment 14 on the right to health, the Committee on Economic, Social and Cultural Rights states that "[t]he realization of the right to health of adolescents is dependent on the development of youth-friendly health care, which respects confidentiality and privacy and includes appropriate sexual and reproductive health services."¹³

Privacy and confidentiality are also crucial for patients seeking diagnosis and treatment of illnesses with which stigma is attached, such as HIV/AIDS and mental illness. Depending on the type of care an individual is seeking, some health care centers may only allow specific providers to access the patient's health information. For example, a nurse who is vaccinating a patient may not access that individual's private mental health records because the information is not relevant to the treatment being provided at that current moment.

The right to confidentiality of health information should not interfere with the right to access of private health information. While a holder of private health information should be prohibited from sharing that information with anyone who is not essential to providing health care to the individual, the holder must provide the individual access to their private health information upon the individual's request. Patients have the right to access their own health information, to be able to control how the information is shared with them (for example, being able to indicate to where mail or phone calls are directed), and to be able to authorize the disclosure of information when desired. The right to confidentiality of private health informa-

7 Ducinskiene D et al, "Awareness and practice of patient's rights law in Lithuania," *BMC International Health and Human Rights* 6 (2006):10. www.biomedcentral.com/1472-698X/6/10.

8 Ibid.

9 Velik-Stefanovska V et al, "Rights of Patients in Macedonia According to European Standards" (2005).

10 Gostin L et al, *The Domains of Health Responsiveness – A Human Rights Analysis* (World Health Organization Health and Human Rights Working Paper Series No 2, 2003). www.who.int/hhr/information/en/Series_2%20Domains%20of%20health%20responsiveness.pdf.

11 Ibid.

12 Inter-American Commission on Human Rights (IACHR), *Access to Information on Reproductive Health from a Human Rights Perspective* (Nov. 11, 2011). www.oas.org/en/iachr/women/docs/pdf/womenaccessinformationreproductivehealth.pdf.

13 UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000).

tion, as well as the right to accessibility of private health information, should be upheld and not compromised in respecting the rights of the patient.

Right to informed consent to treatment

The UN Special Rapporteur on the right to health, Anand Grover, defines informed consent as the following:

*Informed consent is not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers. Its ethical and legal normative justifications stem from its promotion of patient autonomy, self-determination, bodily integrity and well-being.*¹⁴

The right to informed consent is central to the right to health. Issues that arise concern the competency or legal capacity of the patient to consent, respect for personal autonomy, the sufficiency and completeness of information, and circumstances compelling limits on the need for informed consent.

The complexity of informed consent is mirrored by patients' lack of understanding of its meaning and importance. For example, in a 2006 study of 732 European surgical patients in obstetrics and gynecology during a six-month period, about 46% believed that the primary function of the written consent form was to protect the hospital, and 68% thought that the form allowed doctors to take control, while only 41% believed consent forms expressed their own wishes for treatment.¹⁵

Derogations, or departures, from the right to informed consent are necessary at times, but the question of when derogations may be permitted is a complicated one. When a patient is unconscious, medical providers must seek consent from a legally entitled representative. However, if there is an emergency situation where the patient's life is in danger, medical providers may presume that consent is given. Issues of informed consent also arise from public health policies that require compulsory testing, compulsory vaccinations, or mandated quarantine during epidemics. Procedural safeguards are crucial to derogations from informed consent, to ensure that proper circumstances are met and to provide a means to challenge the departure from the law. Some groups are particularly vulnerable to violations of the right to informed consent. The UN Special Rapporteur on the right to health brought attention to children, elderly persons, women, ethnic minorities, indigenous peoples, persons with disabilities, persons living with HIV/AIDS, persons deprived of liberty, sex workers, and persons who use drugs.¹⁶

The Inter-American Court points out the issues surrounding free and voluntary consent when it comes to women's sexual and reproductive rights.¹⁷ Access to information on sexual and reproductive health is crucial for women to make free and informed decisions. According to the Inter-American system, access to information on sexual and reproductive health "involves a series of rights such as the right to freedom of expression, to personal integrity, to the protection of the family, to privacy, and to be free from violence and discrimination."¹⁸

¹⁴ UN General Assembly, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/64/272 (Aug. 10, 2009).

¹⁵ Akkad A et al, "Patients' perceptions of written consent: questionnaire study," *Boston Medical Journal* 333(2006):528. www.bmj.com/content/333/7567/528.

¹⁶ UN General Assembly, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/64/272 (Aug. 10, 2009).

¹⁷ Inter-American Commission on Human Rights, *Access to Information on Reproductive Health from a Human Rights Perspective* (Nov. 11, 2011). www.oas.org/en/iachr/women/docs/pdf/womenaccessinformationreproductivehealth.pdf.

¹⁸ *Ibid.*

There is also particular concern and confusion regarding the right to informed consent for persons with disabilities or mental health illness, two groups whose rights are frequently violated. Treatment decisions are often based on inappropriate factors such as ignorance or stigma surrounding disabilities, and indifference or expediency from staff. The Special Rapporteur on the right to health writes, “[These inappropriate considerations are] inherently incompatible with the right to health, [and] the prohibition of discrimination on the ground of disability ... In these circumstances, it is especially important that the procedural safeguards protecting the right to informed consent are both watertight and strictly applied.”¹⁹ For more detailed information on disability and health, please see Chapter 9.

Persons unable to provide informed consent

Patients may be deemed legally incompetent to make decisions on their own behalf, including providing informed consent to treatment. Patients who are declared legally incompetent can include unconscious patients; minors; patients experiencing confusion or other altered mental states (this includes the elderly); those under the influence of sedatives or other drugs that affect alertness and cognition; and on occasion, persons with disabilities, depending upon their perceived impairment.²⁰

Many countries have a system in which a guardian or representative is authorized to make decisions on behalf of the legally incompetent individual. Depending on the jurisdiction and circumstances, health providers might also have the authority to commit a person involuntarily to a health care facility. Involuntary commitment is generally reserved for severe cases where the person is in immediate danger of harming him/herself or others.

There are frequent issues with guardianship and involuntary commitment because these processes involve denying an individual their autonomy to make decisions. It is crucial that the system be as formal and transparent as possible and to establish procedural safeguards to ensure that the dignity and rights of the individual are upheld. An example of a procedural safeguard for involuntary commitment is to allow courts or tribunals access to challenge the admission.²¹ For more information, please see Chapter 9 on Disability.

Prisoners

Prisoners who are ill often face violations of their rights as patients. Prisoners have the same rights as other patients, including the right to refuse treatment, the right to informed consent, the right to privacy and confidentiality, and the right to information. For example, they have the right to refuse treatment, including abortions and medical testing.²² Conducting these procedures without informed consent would be coerced or forced and in violation of the prisoner’s right to refuse treatment. Derogations from the right to refuse treatment in prison include the prevention and control of communicable diseases and the treatment of mental illness, but both are subject to specific conditions and should be implemented in line with international standards.²³ The prison population includes especially vulnerable groups with special needs, including prisoners with mental health care needs, elderly prisoners, and prisoners with terminal illness.²⁴ These vulnerable sub-populations may require special attention to ensure that their rights to health and life with dignity are realized.

19 UN Commission on Human Rights, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, E/CN.4/2005/51 (Feb. 11, 2005).

20 World Medical Assembly (WMA), Declaration of Lisbon on the Rights of the Patient, (1981). www.wma.net/en/30publications/10policies/14/.

21 UN Commission on Human Rights, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, E/CN.4/2005/51 (Feb. 11, 2005).

22 Lines R, “The right to health of prisoners in international human rights law,” *International Journal of Prisoner Health*, 4, no. 1 (March 2008): 3-53. www.ahrn.net/library_upload/uploadfile/file3102.pdf.

23 Ibid.

24 United Nations Office of Drugs and Crime, *Handbook on Prisoners with special needs* (2009). www.unodc.org/documents/justice-and-prison-reform/Prisoners-with-special-needs.pdf.

Women

Women are particularly vulnerable to violations of their rights while seeking health care, especially for sexual and reproductive health care services. For example, Human Rights Watch documented abuse of pregnant women during health care visits in South Africa:

[Forms of abuse] include ridiculing or ignoring women's needs when in pain, especially during labour, unnecessary delays in providing treatment, leaving women to deliver their babies without help, accusing women who appear not to be following nurses' orders of wanting to harm their babies, verbal insults and degrading treatment, such as asking women to clean up their own blood, or intimidation and threats of harm. Physical abuse involves slapping, pinching, rough treatment and a deliberate refusal to give pain-relieving medication.²⁵

Other issues include independent and autonomous access to sexual and reproductive services, forced sterilization and forced contraception, and physical and sexual abuse by the care giver.²⁶ Violence and assault against women in sexual and reproductive health care settings perpetuates stigma and discrimination against women that denies them human dignity.

The Special Rapporteur to health notes, “Stigma and discrimination against women from marginalized communities, including indigenous women, women with disabilities and women living with HIV/AIDS, have made women from these communities particularly vulnerable to such abuses.”²⁷ The Special Rapporteur on water explains, “Stigma is, by its demeaning and degrading nature, antithetical to the very idea of human dignity. Stigma as a process of devaluation, of making some people “lesser” and others “greater”, is inconsistent with human dignity, which is premised on notions of the inherent equality and worthiness of the human person. It undermines human dignity, thereby laying the groundwork for violations of human rights.”²⁸ Female patients from marginalized populations have the right to seek health care in a manner that is non-discriminatory and respects their dignity.

Access to essential medicines

Access to essential medicines is lacking in many developing countries. An estimated 1.3 to 2.1 billion people worldwide have no access to essential medicines. According to a 2011 study, about one third of the world population lacks regular access to essential medicines.²⁹ Only 10% of pharmaceutical research and development 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.³⁰ However, “Inequity in access to essential medicines is part of inequity in health care.”³¹ An expert consultation on access to medicines recommended in 2011 that “From the right to health perspective, access to medicines must be equitable. Additionally, more research and development is needed to promote the availability of new drugs for those diseases causing a heavy burden on developing countries.”³²

25 Human Rights Watch, *Healthcare is Failing Women* (Dec. 20, 2011). www.hrw.org/news/2011/12/20/healthcare-failing-women.

26 Inter-American Commission on Human Rights, *Access to Information on Reproductive Health from a Human Rights Perspective* (Nov. 11, 2011). www.oas.org/en/iachr/women/docs/pdf/womenaccessinformationreproductivehealth.pdf; UN General Assembly, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/64/272 (Aug. 10, 2009).

27 Ibid.

28 UN Human Rights Council, *Special Rapporteur on the human right to safe drinking water and sanitation*, A/HRC/21/42 (July 2, 2012).

29 Hogerzeil H and Mirza Z, *The World Medicines Situation in 2011: Access to Essential Medicines as Part of the Right to Health* (WHO, 2011). <http://apps.who.int/medicinedocs/documents/s18772en/s18772en.pdf>.

30 World Health Organization (WHO), *The World Medicines Situation* (2004). <http://apps.who.int/medicinedocs/en/d/Js6160e/9.html>. The 2011 edition is being released chapter by chapter and will be available at: www.who.int/medicines/areas/policy/world_medicines_situation/en/index.html.

31 Hogerzeil H and Mirza Z, *The World Medicines Situation in 2011: Access to Essential Medicines as Part of the Right to Health* (WHO, 2011). <http://apps.who.int/medicinedocs/documents/s18772en/s18772en.pdf>.

32 UN Human Rights Council, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/HRC/17/43 (Mar. 16, 2011).

High pricing is another factor that hinders access to medicines. Companies that develop new medicines are often granted a patent, which permits that company to be the sole manufacturer of that medicine for a designated period of time. The expert consultation on access to medicines explains:

While intellectual property rights have the important function of providing incentives for innovation, they can, in some cases, obstruct access by pushing up the price of medicines. The right to health requires a company that holds a patent on a lifesaving medicine to make use of all the arrangements at its disposal to render the medicine accessible to all.³³

Access to essential medicines is considered an integral part of the right to health. However, 60 countries do not recognize the right to health in their national constitutions and more than 30 countries have not yet ratified the International Convention on Economic, Social, and Cultural Rights. General Comment 14 says that States must make public health and health care facilities available, including “essential drugs, as defined by the WHO Action Programme on Essential Drugs.”³⁴

What are the current practices in the area of patient care?

Methods for applying human rights to patient care are diverse and occur on multiple levels of government and through engagement with private actors. A common approach to incorporating human rights norms into patient care is through the development of a code or declaration of patient rights. It is important to keep in mind that this approach does not cover the full range of rights and duties that should be applied to all stakeholders in health care provision. However, developing patient rights that are based upon human rights standards and principles is an important step in delineating the rights and obligations of patients in relation to their health care providers.

Bioethics is another avenue to incorporating human rights into patient care. The definition of “bioethics” remains controversial, but generally the field covers ethical issues arising in the life sciences, medicine, and technology. Bioethics often deals with moral and ethical issues of medical and scientific research as well as approaches to dealing with epidemics. Subsumed under bioethics, too, are ethical issues arising from the relationship between patient and doctor.

When evaluating codifications of patients’ rights or bioethics, it is important to understand that they may contain some human rights principles and elements, but may not necessarily contain the full range of rights granted under human rights law.

In the table below, we provide four different codifications of patients’ rights. We provide these four to offer a picture of the different approaches that can be taken to this subject. It is interesting to note the extent to which each codification incorporates human rights principles and how each codification focuses on certain sets of rights.

³³ Ibid.

³⁴ UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000). [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).

1. **Universal Declaration on Bioethics and Human Rights (UDBHR).**³⁵ The UDBHR was adopted by UNESCO's General Conference on October 19, 2005. The declaration was developed by the International Bioethics Committee under UNESCO, which "follows progress in the life sciences and its applications in order to ensure respect for human dignity and freedom."³⁶
2. **Declaration of Lisbon.**³⁷ The World Medical Association's Declaration of Lisbon on the Rights of the Patient was created in 1981. This declaration was not created using the human rights framework. The preamble states:

*While a physician should always act according to his/her conscience, and always in the best interests of the patient, equal effort must be made to guarantee patient autonomy and justice. The following Declaration represents some of the principal rights of the patient that the medical profession endorses and promotes.*³⁸

This statement expressly recognizes the rights of physicians to act according to their best medical knowledge. To this end, it is the only declaration in the table below that incorporates a provision on procedures against the patient's will.

3. **European Convention on Human Rights and Biomedicine.**³⁹ 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 was adopted by the Council of Europe in 1997. This convention sets out certain basic patient rights principles, such as equitable access to health care and protection of consent, private life, and right to information.
4. **European Charter of Patients' Rights (ECPR).**⁴⁰ The ECPR was compiled in 2002 by Active Citizenship Network, a European network of civic, consumer, and patient organizations. This charter 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.⁴¹ Although this charter is not legally binding, a strong network of patient rights groups across Europe has successfully lobbied their national governments for recognition and adoption of rights in the charter.⁴² 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.

35 United Nations Educational, Scientific and Cultural Organization (UNESCO), Universal Declaration of Bioethics and Human Rights, 2005. www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/.

36 United Nations Educational, Scientific and Cultural Organization (UNESCO), "International Bioethics Committee," www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/international-bioethics-committee/.

37 World Medical Assembly, Declaration of Lisbon on the Rights of the Patient [Declaration of Lisbon], 1981. www.wma.net/en/30publications/10policies/14/.

38 Ibid.

39 Council of Europe, 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], 1997. <http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm>.

40 Active Citizenship Network, European Charter of Patients' Rights [ECPR], 2002. www.eesc.europa.eu/self-and-coregulation/documents/codes/private/o85-private-act.pdf.

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

42 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.

Table: Codifications of patients' rights

	UHBHR (2005)	Declaration of Lisbon (1981)	Convention on Human Rights and Biomedicine (1997)	ECPR (2002)
Protection of Human Dignity	<p>Article 3 – Human dignity and human rights</p> <p>1. Human dignity, human rights and fundamental freedoms are to be fully respected.</p> <p>Article 10 – Equality, justice and equity</p> <p>The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably.</p>	<p>10. Right to dignity</p> <p>a. The patient's dignity and right to privacy shall be respected at all times in medical care and teaching, as shall his/her culture and values.</p>	<p>Article 1 – Purpose and object</p> <p>Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.</p>	
Non-Discrimination	<p>Article 11 – Non-discrimination and non-stigmatization</p> <p>No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.</p>	<p>1. Right to medical care of good quality</p> <p>a. Every person is entitled without discrimination to appropriate medical care.</p>	<p>Article 11 – Non-discrimination</p> <p>Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.</p>	<p>2 - Right of access</p> <p>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.</p>
Primacy of the Patient	<p>Article 3 – Human dignity and human rights</p> <p>2. The interests and welfare of the individual should have priority over the sole interest of science or society.</p>	<p>1. Right to medical care of good quality</p> <p>c. The patient shall always be treated in accordance with his/her best interests.</p>	<p>Article 2 – Primacy of the human being</p> <p>The interests and welfare of the human being shall prevail over the sole interest of society or science.</p>	
Access to Health Care	<p>Article 14 – Social responsibility and health</p> <p>2. ... progress in science and technology should advance:</p> <p>(a) access to quality health care and essential medicines, especially for the health of women and children, because health is essential to life itself and must be considered to be a social and human good.</p>		<p>Article 3 – Equitable access to health care</p> <p>Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.</p>	<p>2 - Right of access</p> <p>Every individual has the right of access to the health services that his or her health needs require. ...</p>

Table: Codifications of patients' rights (cont.)

	UHBHR (2005)	Declaration of Lisbon (1981)	Convention on Human Rights and Biomedicine (1997)	ECPR (2002)
Quality of Care		<p>1. Right to medical care of good quality</p> <p>c. ... The treatment applied shall be in accordance with generally approved medical principles.</p> <p>d. Quality assurance should always be a part of health care. Physicians, in particular, should accept responsibility for being guardians of the quality of medical services.</p>	<p>Article 4 – Professional standards</p> <p>Any intervention in the health field, including research, must be carried out in accordance with relevant professional obligations and standards.</p>	<p>8 - Right to the Observance of quality standards</p> <p>Each individual has the right of access to high quality health services on the basis of the specification and observance of precise standards. The right to quality health services requires that health care institutions and professionals provide satisfactory levels of technical performance, comfort and human relations ...</p>
Individual Autonomy	<p>Article 5 – Autonomy and individual responsibility</p> <p>The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests.</p>	<p>3. Right to self-determination</p> <p>a. The patient has the right to self-determination, to make free decisions regarding himself/herself. The physician will inform the patient of the consequences of his/her decisions.</p>		<p>5 - Right to free choice</p> <p>Each individual has the right to freely choose from among different treatment procedures and providers on the basis of adequate information. The patient has the right to decide which diagnostic exams and therapies to undergo, and which primary care doctor, specialist or hospital to use ...</p>
Information		<p>7. Right to information</p> <p>a. The patient has the right to receive information about himself/herself recorded in any of his/her medical records, and to be fully informed about his/her health status including the medical facts about his/her condition. ...</p>	<p>Article 10 – Private life and right to information</p> <p>2. Everyone is entitled to know any information collected about his or her health. ...</p>	<p>3 - Right to information</p> <p>Every individual has the right to access to all kind 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. ...</p>

Table: Codifications of patients' rights (cont.)

	UHBHR (2005)	Declaration of Lisbon (1981)	Convention on Human Rights and Biomedicine (1997)	ECPR (2002)
Informed Consent	<p>Article 6 – Consent</p> <p>1. Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information ...</p>	<p>3. Right to self-determination</p> <p>b. A mentally competent adult patient has the right to give or withhold consent to any diagnostic procedure or therapy. The patient has the right to the information necessary to make his/her decisions...</p>	<p>Article 5 – General rule</p> <p>An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it ...</p>	<p>4 - Right to consent</p> <p>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 a prerequisite for any procedure and treatment ...</p>
Persons Who Lack Capacity to Provide Informed Consent	<p>Article 7 – Persons without the capacity to consent</p> <p>In accordance with domestic law, special protection is to be given to persons who do not have the capacity to consent:</p> <p>(a) authorization for research and medical practice should be obtained in accordance with the <u>best interest of the person concerned</u> and in accordance with domestic law. However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent; ...</p>	<p>4. The unconscious patient</p> <p>a. If the patient is unconscious or otherwise unable to express his/her will, informed consent must be obtained whenever possible, from a <u>legally entitled representative</u>. ...</p> <p>5. The legally incompetent patient</p> <p>a. If a patient is a minor or otherwise legally incompetent, the consent of a <u>legally entitled representative</u> is required in some jurisdictions. Nevertheless the patient must be involved in the decision-making to the fullest extent allowed by his/her capacity...</p>	<p>Article 6 – Protection of persons not able to consent</p> <p>1. ... an intervention may only be carried out on a person who does not have the capacity to consent, for his or her <u>direct benefit</u> ...</p> <p>Article 7 – Protection of persons who have a mental disorder</p> <p>... a person who has a mental disorder of a serious nature may be subjected, without his or her consent, to an intervention aimed at treating his or her mental disorder only where, without such treatment, serious harm is likely to result to his or her health.</p> <p>Article 8 – Emergency situation</p> <p>Article 9 – Previously expressed wishes</p>	<p>4 - Right to consent</p> <p>In all circumstances which provide for a <u>legal representative</u> to give the informed consent, the patient, whether a minor or an adult unable to understand or to will, must still be as involved as possible in the decisions regarding him or her. The informed consent of a patient must be procured on this basis.</p>

Table: Codifications of patients' rights (cont.)

	UHBHR (2005)	Declaration of Lisbon (1981)	Convention on Human Rights and Biomedicine (1997)	ECPR (2002)
Privacy and Confidentiality	<p>Article 9 – Privacy and confidentiality</p> <p>The privacy of the persons concerned and the confidentiality of their personal information should be respected. ...</p>	<p>8. Right to confidentiality</p> <p>a. All identifiable information about a patient's health status, medical condition, diagnosis, prognosis and treatment and all other information of a personal kind must be kept confidential, even after death. ...</p>	<p>Article 10 – Private life and right to information</p> <p>Everyone has the right to respect for private life in relation to information about his or her health.</p>	<p>6-Right to privacy and confidentiality</p> <p>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. ...</p>

The European Charter of Patients' Rights contains 14 provisions, of which only seven are featured within the table above. The full list of provisions is:

1. Right to Preventative Measures
2. Right of Access
3. Right to Information
4. Right to Consent
5. Right to Free Choice
6. Right to Privacy and Confidentiality
7. Right to Respect Patients' Time
8. Right to the Observance of Quality Standards
9. Right to Safety
10. Right to Innovation
11. Right to Avoid Unnecessary Suffering and Pain
12. Right to Personalized Treatment
13. Right to Complain
14. Right to Compensation

2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO PATIENT CARE?

How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to patient care. The tables are organized as follows:

Human right or fundamental freedom	
Examples of Human Rights Violations	
Human rights standards	<p>UN treaty body interpretation</p> <p>This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.</p>
Human rights standards	<p>Case law</p> <p>This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.</p>
<p>Other interpretations: This section references other relevant interpretations of the issue. It includes interpretations by:</p> <ul style="list-style-type: none"> • UN Special Rapporteurs • UN working groups • International and regional organizations • International and regional declarations 	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights in patient care.

Abbreviations

In the tables, we use the following abbreviations to refer to the eleven treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights (UDHR)	None
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 Discrimination Against Women (CEDAW Committee)
International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)	Committee on the Elimination of Racial Discrimination (CERD)
Convention on the Rights of the Child (CRC)	Committee on the Rights of the Child (CRC Committee)
African Charter on Human and Peoples' Rights and Protocols (ACHPR)	African Commission on Human and Peoples' Rights (ACHPR Commission)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)	European Court of Human Rights (ECtHR)
1996 Revised European Social Charter (ESC)	European Committee of Social Rights (ECSR)
American Convention on Human Rights (ACHR)	Inter-American Court of Human Rights (IACHR)
American Declaration of the Rights and Duties of Man (ADRDM)	Inter-American Court of Human Rights (IACHR)

Also cited are the former Commission on Human Rights (CHR) and various UN Special Rapporteurs (SR) and Working Groups (WG).

Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
Liberty and Security of Person	Art. 3	Art. 9(1)			Art. 5(b)	
Privacy	Art. 12	Art. 17				Art. 16
Expression and Information	Art. 19	Art. 19(2)				Art. 13, Art. 17
Bodily Integrity						
Life	Art. 3	Art. 6(1)				Art. 6(1)
Health	Art. 25		Art. 12	Art. 12	Art. 5(e)(iv)	Art. 24
Torture or Cruel, Inhuman or Degrading Treatment*	Art. 5	Art. 7				Art. 37(a)
Participate in Public Policy	Art. 21	Art. 25		Art. 7	Art. 5(c)	
Non-discrimination and Equality	Art. 1, 2	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2

*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADRDM	Americas: ACHR
Liberty and Security of Person	Art. 6	Art. 5(1)		Art. I	Art. 7
Privacy		Art. 8		Art. V	Art. 11
Expression and Information	Art. 9	Art. 10		Art. IV	Art. 13
Bodily Integrity					
Life	Art. 4	Art. 2		Art. I	Art. 4
Health	Art. 16		Art. 11 Art. 13	Art. XI	
Torture or Cruel, Inhuman or Degrading Treatment*	Art. 5	Art. 3			Art. 5(2)
Participate in Public Policy	Art. 13			Art. XX	Art. 23
Non-discrimination and Equality	Art. 2 Art. 19	Art. 14	Art. E	Art. II	Art. I (I)

Table I: 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. • Patients are quarantined unnecessarily.

Human Rights Standards	Treaty Body Interpretation
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.	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)

Human Rights Standards	Case Law
ECHR 5(1) Everyone has the right to liberty and security of person. No one shall be deprived of their liberty except in accordance with a procedure prescribed by law [due process] and except in those instances specifically enumerated by this Convention (paraphrase).	<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. <i>Winterwerp v. The Netherlands</i>, 6301/73 (November 27, 1979)</p> <p>ECtHR: Mandating speedy periodic legal review of civil commitment with the essential elements of due process. <i>X v. United Kingdom</i>, 7215/75 (November 5, 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 judicial decision of the national court was superficial and insufficient to show dangerous conduct. <i>Gajcsi v. Hungary</i>, 34503/03 (October 3, 2003).</p> <p>ECtHR: The applicant, who had been diagnosed with autism, was admitted to the hospital as an “informal patient” between 22 July and 29 October 1997, which he maintained amounted to a deprivation of liberty under Art. 5(1). The Court noted that there were no formalised admission procedures, and that because of the lack of procedural safeguards the hospital staff “assumed full control of the liberty and treatment of a vulnerable incapacitated individual solely on the basis of their own clinical assessments completed as and when they considered fit.” The Court held that “this absence of procedural safeguards fails to protect against arbitrary deprivations of liberty on grounds of necessity and, consequently, to comply with the essential purpose of Article 5 § 1” and therefore found a violation of Art. 5(1). <i>H.L. v. United Kingdom</i>, 45508/99 (October 5, 2004).</p> <p>ECtHR: The applicant was admitted to a clinic for an extended stay where she attempted to escape several times. The Court stated that in order to determine whether there was a deprivation of her liberty, the starting-point had to be the specific situation of the individual concerned with account taken of a wide range of factors, such as the type, duration, effects and manner of implementation of the measure in question. Because the applicant never consented and attempted to escape several times, the Court found that there was a violation of Art. 5(1). <i>Storck v. Germany</i>, no. 61603/00 (June 16, 2005).</p> <p>ECtHR: The applicant, a mental health patient subject to internment, was detained in a prison where he subsequently committed suicide. The Court held there was a violation of Art. 5(1) because the detention was contrary to national law, which required the internment take place in a specialised institution, or at worst the psychiatric wing of a prison. The Court also recalled its finding in <i>Aerts v. Belgium</i>, 25357/94 (July 30, 1998) in which it held that the detention of a mentally ill person under Art. 5(1)(e) is only lawful if it is carried out in a hospital, clinic or other appropriate institution. <i>De-Donder and De Clippel v. Belgium</i>, 8595/06 (December 6, 2011).</p>

Table 1: (Cont.)

Other Interpretations

UN Working Group on Arbitrary Detention: “The Working Group has also been informed by several sources that, in some countries, the disabled, drug addicts and people suffering from AIDS are detained in places that are incompatible with their state of health, sometimes without treatment and without it having been established that their detention is justified on medical or public health grounds. The Group is concerned because it is vulnerable persons that are involved, people who are often stigmatized by social stereotypes; but it is concerned above all because often such administrative detention is not subject to judicial supervision.” E/CN.4/2004/3 (December 15, 2003), ¶ 74. (See also, E/CN.4/2005/6 (December 1, 2004), ¶¶ 47-58 on psychiatric detention).

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	Treaty Body Interpretation
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.	CESCR General Comment No. 14 (12): While highlighting the importance of information accessibility in health care, CESCR says that State Parties “should not impair the right to have personal health data treated with confidentiality.”
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.	CRC General Comment No. 4: Encouraging state parties to strictly protect adolescent health privacy and describing health care provider obligations to maintain privacy of adolescent patients; suggesting state parties enact legislation to protect adolescent patient privacy; and drawing attention to patient confidentiality and privacy component living in CESCR’s commitment to the highest attainable standard of health. CRC/GC/2003/4 (2003), ¶ 11, 33, 40. CRC: Highlighting the need for confidentiality for adolescents with respect to sexual and reproductive health in Djibouti . CRC/C/97 (2000), para 555.
CEDAW 12 (1). States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning. CEDAW 12(2). Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.	CEDAW: Recommending that Paraguay “adopt a policy for patient privacy, to safeguard doctor-patient confidentiality specifically when treating women for abortion complications.” CEDAW/C/PRY/CO/6 (2011), para. 31.

Table 2: (cont.)

Human Rights Standards	Case Law
<p>ECHR 8(1). Everyone has the right to respect for his private and family life, his home and his correspondence.</p> <p>ECHR 8(2). There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.</p>	<p>ECtHR: The applicant’s medical records were sent from her clinic to the Social Insurance Office without her knowledge or consent. The Court held that “the protection of personal data, particularly 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.” <i>M.S. v. Sweden</i>, 20837/92 (August 27, 1997).</p> <p>ECtHR: The applicant’s medical records, including her HIV diagnosis, were included in her husband’s trial against her will, and the trial record was subsequently made public. The Court noted 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.” <i>Z. v. Finland</i>, 22009/93 (February 25, 1997).</p> <p>ECtHR: The applicant’s correspondence sent to him during at his stay at a psychiatric hospital was first sent to a curator who selected which correspondence to pass on to the applicant. Although Art. 8(2) permits violations of Art. 8(1) for the protection of health, the Court found that the hospital violated Art. 8, stating that there were no measures to ensure that the law permitting correspondence screening was not arbitrarily applied or to protect against arbitrary interference of Art. 8(1). <i>Herczegfalvy v. Austria</i>, 10533/83 (September 24, 1992).</p>

Other Interpretations

Declaration of Lisbon on the Rights of the Patient, Principle 8: Right to Confidentiality.

- All identifiable information about a patient’s health status, medical condition, diagnosis, prognosis and treatment and all other information of a personal kind must be kept confidential, even after death. Exceptionally, descendants may have a right of access to information that would inform them of their health risks.
- Confidential information can only be disclosed if the patient gives explicit consent or if expressly provided for in the law. Information can be disclosed to other health care providers only on a strictly “need to know” basis unless the patient has given explicit consent.
- All identifiable patient data must be protected. The protection of the data must be appropriate to the manner of its storage. Human substances from which identifiable data can be derived must be likewise protected.

Declaration on the Promotion of Patients’ Rights in Europe:

Art. 4.1: All information about a patient’s health status . . . must be kept confidential, even after death.

Art. 4.8: Patients admitted to health care establishments have the right to expect physical facilities which ensure privacy.

Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data.

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.”

Explanatory Report, Para.63: The first paragraph establishes the right to privacy of information in the health field, thereby reaffirming the principle introduced in Article 8 of the European Convention on Human Rights and reiterated in the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data. It should be pointed out that, under Article 6 of the latter Convention, personal data concerning health constitute a special category of data and are as such subject to special rules.

European Charter of Patients’ Rights, Art. 6: 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.

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 comprehensively 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	Treaty Body Interpretation
<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>CESCR General Comment No. 14 (12): Health care accessibility “includes the right to seek, receive and impart information and ideas concerning health issues.”</p>
<p>CEDAW 10 States Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure to them equal rights with men in the field of education and in particular to ensure, on a basis of equality of men and women:</p> <p>(h) Access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning.</p> <p>CEDAW 16(1) States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women:</p> <p>(e) The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.</p>	<p>CEDAW [Jurisprudence]: The petitioner was sterilized during a Caesarean section to remove a dead fetus. She signed the consent form while on the surgical table, in shock and without understanding of what sterilization meant. She argued that Hungary violated CEDAW 10(h) and 16(1) (e) because she had not received “specific information about the sterilization, the effects of the operation on her ability to reproduce, or advice on family planning and contraceptive measures — either immediately before the operation or in the months/years before the operation was carried out. She claims that she was not given information about the nature of the operation, the risks and consequences, in a way that was comprehensible to her before she was asked to sign the consent form.” The Committee reasoned that “the author has a right protected by article 10(h) of the Convention to specific information on sterilization and alternative procedures for family planning in order to guard against such an intervention being carried out without her having made a fully informed choice. Furthermore, the Committee notes the description given of the author’s state of health on arrival at the hospital and observes that any counselling that she received must have been given under stressful and most inappropriate conditions. Considering all these factors, the Committee finds a failure of the State party, through the hospital personnel, to provide appropriate information and advice on family planning, which constitutes a violation of the author’s right under article 10 (h) of the Convention.” <i>A.S. v. Hungary</i>, Communication No. 4/2004, CEDAW/C/36/D/4/2004.</p>

Table 3: (cont.)

Human Rights Standards	Case Law
<p>ECHR 8(2). There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.</p>	<p>ECtHR: The applicants, eight women of Roma origin, could not conceive any longer after being treated at gynaecological departments in two different hospitals. They suspected that it was because they had been sterilised during their stay in those hospitals. The hospitals refused to release their medical records to their authorised legal representative or to allow them to obtain a photocopy of the documents. The women then obtained judicial orders permitting them to consult the records under the Health Care Act 1994, but were not allowed to make photocopies. The Court found that this violated Art. 8. Since this case was filed, the Health Care Act 2004 now explicitly provides for patients or persons authorised by them to make copies of medical records. <i>K.H. and Others v. Slovakia</i>, 32881/04 (April 28, 2009)</p> <p>ECtHR: The applicant, a serviceman, complained about inadequate access to information about the tests performed on him at a defence establishment. The defence establishment conducted research into chemical weapons for the UK's armed forces, including tests of gases on humans and animals. The Court found that "the State has not fulfilled the positive obligation to provide an effective and accessible procedure enabling the applicant to have access to all relevant and appropriate information that would allow him to assess any risk to which he had been exposed during his participation in the tests." <i>Roche v. United Kingdom</i>, 32555/96 (October 19, 2005).</p>

Other Interpretations

Declaration of Lisbon on the Rights of the Patient, Principle 7: Right to Information.

- a. The patient has the right to receive information about himself/herself recorded in any of his/her medical records, and to be fully informed about his/her health status including the medical facts about his/her condition. However, confidential information in the patient's records about a third party should not be given to the patient without the consent of that third party.
- b. Exceptionally, information may be withheld from the patient when there is good reason to believe that this information would create a serious hazard to his/her life or health.
- c. Information should be given in a way appropriate to the patient's culture and in such a way that the patient can understand.
- d. The patient has the right not to be informed on his/her explicit request, unless required for the protection of another person's life.
- e. The patient has the right to choose who, if anyone, should be informed on his/her behalf.

Declaration on the Promotion of Patients' Rights in Europe:

Art. 2.2: 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.

Art. 2.6: Patients have the right to choose who, if any one, should be informed on their behalf.

European Convention on Human Rights and Biomedicine, Art. 10(2): Everyone is entitled to know any information collected about his or her health. See *also* Explanatory Report, paras. 65-70 (interpreting the right to private life and right to information).

European Charter of Patients' Rights, Art. 3: Every individual has the right to access to all kind 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.

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 enough information to 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 health care providers.

Note On Bodily Integrity in International and National Treaties: 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).

Human Rights Standards	Treaty Body Interpretation
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.	CESCR General Comment No. 14(8): Explaining that the right to health includes “the right to be free from torture, non-consensual medical treatment and experimentation.”

Human Rights Standards	Case Law
ECHR 8(1). Everyone has the right to respect for his private and family life, his home and his correspondence.	<p>ECtHR: Pregnant mother wanted access to genetic test to determine the health of her child within the time-limit for abortion to remain a lawful option. The Court stated that “[c]ompliance with the State’s positive obligation to secure to their citizens their right to effective respect for their physical and psychological integrity may necessitate, in turn, the adoption of regulations concerning access to information about an individual’s health.” The Court also reasoned that the “right of access to such information falling within the ambit of the notion of private life can be said to comprise, in the Court’s view, on the one hand, a right to obtain available information on one’s condition. The Court further consider[ed] that during pregnancy the fetus’ condition and health constitute[s] an element of the pregnant woman’s health.” The Court therefore found a violation of Art. 8. <i>R. R. v. Poland</i>, 27617/04 (May 26, 2011).</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.” <i>Pretty v. United Kingdom</i>, 2346/02 (Apr. 29, 2002), para. 83.</p> <p>ECtHR: “The applicants maintained that the decisions to administer diamorphine to the first applicant against the second applicant’s wishes and to place a DNR notice in his notes without the second applicant’s knowledge interfered with the first applicant’s right to physical and moral integrity as well as with the second applicant’s Article 8 rights. . . . The Court considers that, having regard to the circumstances of the case, the decision of the authorities to override the second applicant’s objection to the proposed treatment in the absence of authorisation by a court resulted in a breach of Article 8. . . .” <i>Glass v. United Kingdom</i>, 61827/00 (Mar. 9, 2004).</p> <p>ECtHR: “The applicant complained that her right to respect for her private and family life had been violated as a result of her sterilisation without her full and informed consent.” The Court found that there was a violation of Art. 8. <i>V.C. v. Slovakia</i>, 18968/07 (November 8, 2011).</p>

Table 4: (cont.)

Human Rights Standards	Case Law
<p>ECHR 8(1). Everyone has the right to respect for his private and family life, his home and his correspondence.</p>	<p>ECtHR: The applicant, NB, was sterilized while undergoing a Caesarean section at a public hospital. However, NB was only 17 years old at the time of the intervention, so she was also legally a minor. The hospital, in addition to having NB sign the consent form after the administration of tranquilizing pre-medication, never obtained the consent of her legal guardians. NB did not learn of her sterilization until several months after the fact because it was not noted in her release report from the hospital. The Court unanimously held that NB had been sterilized without informed consent and in contravention of Articles 8 and 13. <i>N.B. v. Slovakia</i>, 29518/10 (June 12, 2012).</p> <p>ECtHR: Between 1977 and 1979, the applicant was placed in a clinic against her will, where she was immobilized and received medical treatment against her will. The Court found that “[i]n so far as the applicant argued that she had been medically treated against her will while detained, the Court reiterates that even a minor interference with the physical integrity of an individual must be regarded as an interference with the right to respect for private life under Article 8 if it is carried out against the individual’s will.” The Court also found that she was administered medication against her will and that this too constituted an interference with her right to respect for her private life under Art. 8. <i>Storck v. Germany</i>, 61603/00 (June 16, 2005).</p> <p>ECtHR: Following police custody, the applicant alleged that the police forced a gynaecological examination of his wife by a doctor without her consent. The Court found that there was no consent and that “in the circumstances, the applicant’s wife could not have been expected to resist submitting to such an examination in view of her vulnerability at the hands of the authorities who exercised complete control over her throughout her detention.” The Court held that there was a violation of Art. 8. <i>Y.F. v. Turkey</i>, 24209/94 (July 22, 2003).</p>

Other Interpretations

World Medical Assembly, Declaration of Tokyo: Guidelines for Physicians Concerning Torture and other Cruel, Inhuman or Degrading Treatment or Punishment in Relation to Detention and Imprisonment (www.wma.net/en/2oactivities/1oethics/2otokyo/index.html)

European Charter of Patients’ Rights

Art. 4: 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. 5: The patient has the right to freely choose from among different treatment procedures and providers on the basis of adequate information.

Declaration on the Promotion of Patients’ Rights in Europe

Art. 3.1: The informed consent of the patient is a prerequisite for any medical intervention.

Art. 3.2: A patient has the right to refuse or halt a medical intervention.

European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (2001) stated that “every 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.”

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. See also Explanatory Report, paras. 34-40 (interpreting the general rule of consent found in the European Convention on Human Rights and Biomedicine).

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	Treaty Body Interpretation
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.	CESCR General Comment No. 14(1): Explaining that “Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity.”
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>HRC General Comment No. 6 (1 and 5): 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.”</p> <p>HRC [Jurisprudence]: The Committee considered whether the State party had failed in its obligations regarding Articles 6 and 2 of the Covenant in connection with the death of the author’s son as a result of inadequate medical treatment. The Committee found that there was insufficient evidence before it to attribute direct responsibility to the State for failure to meet its obligation under article 6 of the Covenant. Nevertheless, it found that there had been a breach of the State party’s obligation under the Covenant to properly investigate the death of the victim and take appropriate action against those responsible, which amounted to a violation of Article 2, paragraph 3, in conjunction with article 6 of the Covenant. <i>Novakovi v. Serbia</i>, Communication No. 1556/2007, CCPR/C/100/D/1556/2007.</p>

Human Rights Standards	Case Law
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>ECtHR: holding that a violation of the right to life occurs “where 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.” <i>Cyprus v. Turkey</i>, 25781/94 (May 10, 2001), para. 219. See also, <i>Nitecki v. Poland</i>, 65653/01 (March 21, 2002) (stating same principle of law).</p> <p>ECtHR: The applicants’ son, who sought medical assistance for nausea and itching skin, died in hospital after he was injected with drugs to which he was allergic. The applicants complained that their son died because of medical negligence and that there had been no effective investigation into his death. The Court found that “the domestic authorities failed to deal with the applicants’ claim arising out of their son’s death with the level of diligence required by Article 2,” finding that its procedural aspects had been violated. <i>Silih v. Slovenia</i>, 71463/01 (April 9, 2009).</p> <p>ECtHR: “The Grand Chamber . . . finds that the embryos created by the applicant and J. do not have a right to life within the meaning of Article 2 of the Convention” <i>Evans v. United Kingdom</i>, 6339/05 (April 10, 2007).</p>

Table 5: (cont.)**Other Interpretations**

Colombia: The Colombian Constitutional Court established that “the right to health was enforceable when it was inextricably related to enabling a life of dignity – and not merely preventing imminent death” and on this doctrine has ordered antiretroviral and cancer medications, financing treatment abroad for acute leukemia, treatment of severe depression, post-mastectomy breast implants, administration of growth hormones, and care for severe vision problems.

Table 6: Patient Care and the Right to the Highest Attainable Standard of Physical and Mental 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 that their tests and treatment remain of high quality. Hospitals fail to meet the needs of patients who require religious or psychological support, or do not 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	Treaty Body Interpretation
<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>ICESCR 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: . . .</p> <p>(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;</p> <p>(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.</p>	<p>CESCR General Comment No. 14 (3-4): explaining that Art. 12(1) speaks of “the highest attainable standard of physical and mental health” and that this standard might depend on economic capacity and capabilities and will hardly ever reach a state in which all persons are entirely healthy.</p> <p>CESCR General Comment No. 14 (4): explaining that “[t]he right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life.”</p> <p>CESCR General Comment No. 14 (12): explaining that, “[a]s 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....”</p> <p>CESCR: pointing to a need for federal legislation on patient rights in Russia, including redress for medical errors. E/C.12/1/ADD.94 (CESCR, 2003).</p>
<p>CEDAW 12(1) States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.</p> <p>(2) Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.</p>	<p>CEDAW Committee [Jurisprudence]: finding Brazil in violation of Art.12 (2). The applicant's daughter was pregnant and died because of a delay in obtaining proper emergency care during a complicated pregnancy. The Committee noted that Brazil had adopted policies to address maternal health but referred to “general recommendation No. 28 (2010) on the core obligations of States parties under article 2 of the Convention and notes that the policies of the State party must be action- and results-oriented as well as adequately funded.” The Committee found that “the State party violated its obligations under article 12 (in relation to access to health), article 2 (c) (in relation to access to justice) and article 2 (e) (in relation to the State party's due diligence obligation to regulate the activities of private health service providers), in conjunction with article 1, of the Convention, read together with general recommendations Nos. 24 and 28.” The Committee recommended, among other things, that the State party must “[e]nsure women's right to safe motherhood and affordable access for all women to adequate emergency obstetric care, in line with general recommendation No. 24 (1999) on women and health.” <i>Alyne da Silva Pimentel v. Brazil</i>, CEDAW/C/49/D/17/2008.</p>

Table 6: (cont.)

Human Rights Standards	Case Law
<p>ACHPR 16(1) Every individual shall have the right to enjoy the best attainable state of physical and mental health.</p> <p>ACHPR 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>ACHPR (Committee): “African jurisprudence places a premium on both the right to health care and the right to the underlying conditions of health. In the Purohit case, the African Commission held that the right to health in the African Charter on Human and Peoples’ Rights includes the right to health facilities, access to goods and services to be guaranteed to all without discrimination of any kind. (<i>Purohit and Moore v. The Gambia</i>, Communication 241/2001, para 80.) It has been confirmed that the underlying conditions for achieving a healthy life are protected by the right to health. Thus lack of electricity, drinking water and medicines amount to a violation of the right to health. The Zaire case, 2(<i>Free Legal Assistance Group and Others v Zaire</i>, Communications No 25/89, 47/90, 56/91, 100/93) concerning Article 16 of the African Charter on Human and Peoples’ Rights, confirmed that the failure of the government of Zaire to provide the mentioned basic services amounted to an infringement of the right to health.” IHRDA and Open Society Justice Initiative (OSJI) (on behalf of children of Nubian descent in Kenya) <i>v Kenya</i>, Communications No 002/09.</p> <p>ACHPR (Commission): “The State’s responsibility in the event of detention is even more evident to the extent that detention centres are its exclusive preserve, hence the physical integrity and welfare of detainees is the responsibility of the competent public authorities. Some prisoners died as a result of the lack of medical attention. The general state of health of the prisoners deteriorated due to the lack of sufficient food; they had neither blankets nor adequate hygiene. The Mauritanian state is directly responsible for this state of affairs and the government has not denied these facts. Consequently, the Commission considers that there was a violation of [the right to health].” <i>Malawi African Association, Amnesty International, Ms Sarr Diop, Union interafricaine des droits de l’Homme and RADDHO, Collectif des veuves et ayants-Droit, Association mauritanienne des droits de l’Homme / Mauritania</i>, Communication No. 54/91-61/91-96/93-98/93-164/97-196/97-210/98.</p>

Other Interpretations

Declaration of Lisbon on the Rights of the Patient, Principle 1: Right to medical care of good quality.

- a. Every person is entitled without discrimination to appropriate medical care.
- b. Every patient has the right to be cared for by a physician whom he/she knows to be free to make clinical and ethical judgements without any outside interference.
- c. The patient shall always be treated in accordance with his/her best interests. The treatment applied shall be in accordance with generally approved medical principles.
- d. Quality assurance should always be a part of health care. Physicians, in particular, should accept responsibility for being guardians of the quality of medical services.
- e. In circumstances where a choice must be made between potential patients for a particular treatment that is in limited supply, all such patients are entitled to a fair selection procedure for that treatment. That choice must be based on medical criteria and made without discrimination.
- f. The patient has the right to continuity of health care. The physician has an obligation to cooperate in the coordination of medically indicated care with other health care providers treating the patient. The physician may not discontinue treatment of a patient as long as further treatment is medically indicated, without giving the patient reasonable assistance and sufficient opportunity to make alternative arrangements for care.

Declaration on the Promotion of Patients’ Rights in Europe, Art. 5.3: “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.”

European Charter of Patients’ Rights.

International Alliance of Patients’ Organizations: Declaration on Patient-Centered Health Care (March 30, 2007), (www.patientsorganizations.org/).

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	Treaty Body Interpretation
<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>HRC [Jurisprudence]: The author claimed that by preventing her daughter, who has a permanent mental impairment, from obtaining a termination of pregnancy, as permitted under the State's criminal law, the State party violated her rights under the ICCPR. The State's criminal law permits female rape victims with a mental disability the right to terminate a pregnancy. The Committee found a violation of Art. 7, Art. 17 and Art. 2(3) in relation to Arts. 3, 7 and 17. <i>L.M.R. v. Argentina</i>, CCPR/C/101/D/1608/2007 (2011).</p> <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>

Human Rights Standards	Case Law
<p>ECHR 3 No one shall be subjected to torture or to inhuman or degrading treatment or punishment.</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. <i>Hurtado v. Switzerland</i>, 17549/90 (January 28, 1994).</p> <p>ECtHR: The applicant did not receive timely prenatal genetic testing that would have allowed her to make a decision to legally abort her pregnancy. The Court found that the determination of whether she should have access to genetic testing “was marred by procrastination, confusion and lack of proper counselling and information given to the applicant” and that the lack of regard of the patient’s rights and her suffering amounted to a violation of Art. 3. <i>R.R. v. Poland</i>, 27617/04 (May 26, 2011).</p> <p>ECtHR: holding that the failure to respond adequately to the prisoner’s deteriorating mental health amounted to inhuman or degrading treatment or punishment. <i>Keenan v. United Kingdom</i>, 27229/95 (April 3, 2001).</p> <p>ECtHR: holding “that there has been a violation of Article 3 of the Convention as regards the lack of adequate medical treatment and assistance provided to the applicant while he was detained, amounting to degrading treatment.” <i>Nevmerzhitsky v. Ukraine</i>, 54825/00 (April 5, 2005).</p> <p>ECtHR: in discussing what constitutes a violation of Article 3 for prisoners, “[t]he Court observes that there are three particular elements to be considered in relation to the compatibility of an applicant’s health with his stay in detention: (a) the medical condition of the prisoner, (b) the adequacy of the medical assistance and care provided in detention, and (c) the advisability of maintaining the detention measure in view of the state of health of an applicant . . .” The applicant in this case suffered “chronic and severe mental disorders including schizophrenia” and was held in an ordinary detention center without special medical attention. The Court held “that the nature, duration and severity of the ill-treatment to which the applicant was subjected are sufficient to be qualified as inhuman and degrading.” <i>Musial v. Poland</i>, 28300/06 (January 20, 2009).</p>

Table 7: (cont.)

Human Rights Standards	Case Law
ECHR 3 No one shall be subjected to torture or to inhuman or degrading treatment or punishment.	ECtHR: examining whether there was a violation of Art. 3 after the applicant was held in a police station cell despite his psychological disorders, which were registered by public authorities as a second-degree disability. The Court found that the authorities were “under an obligation to have him examined by a psychiatrist as soon as possible in order to determine whether his psychological condition was compatible with detention, and what therapeutic measures should be taken” and that this lack of medical attention violated Art. 3. <i>Rupa v. Romania</i> , 58478/00 (December 16, 2008).

Other Interpretations

Committee Against Torture: Noting overcrowding, inadequate living conditions, and lengthy confinement in **Russian** psychiatric hospitals, which may be “tantamount to inhuman or degrading treatment.” CAT/C/RUS/CO/4 (CAT, 2006), para. 18.

World Medical Assembly, Declaration of Tokyo: Guidelines for Physicians Concerning Torture and other Cruel, Inhuman or Degrading Treatment or Punishment in Relation to Detention and Imprisonment (www.wma.net/en/20activities/10ethics/20tokyo/index.html).

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, G.A. Res. 37/194, UN Doc. No. A/RES/37/194 (Dec. 18, 1982) (<http://www2.ohchr.org/english/law/medicaethics.htm>).

Istanbul Protocol: Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment (1999) (www.ohchr.org/Documents/Publications/training8Rev1en.pdf).

Code of Conduct for Law Enforcement Officials, G.A. Res. 34/169, UN Doc. A/RES/34/169 (Dec. 17, 1979) (<http://www2.ohchr.org/english/>).

The European Charter of Patients' Rights, Art. 11: 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 treatments and simplifying patients' access to them.

Declaration on the Promotion of Patients' Rights in Europe, Art. 5.10: Patients have the right to relief of their suffering according to the current state of knowledge. Art. 5.11: Patients have the right to humane terminal care and to die in dignity.

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	Treaty Body Interpretation
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>CESCR General Comment No. 14 (43): 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”</p> <p>CESCR General Comment No. 14 (54): explaining that “[p]romoting 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.”</p>

Table 8: (cont.)

Other Interpretations

Ljubljana Charter on Reforming Health Care, World Health Organization (1996), Fundamental Principle 5.3: “Health care reforms must address citizens’ needs taking into account, through the democratic process, their expectations about health and health care. They should ensure that the citizen’s voice and choice decisively influence the way in which health services are designed and operate. Citizens must also share responsibility for their own health.”

The European Charter of Patients’ Rights, Rights of Active Citizenship (Part III): Citizens have the “right to participate in the definition, implementation and evaluation of public policies relating to the protection of health care rights.”

Alicia Ely Yamin, “The Right to Health Under International Law and Its Relevance to the United States.” *American Journal of Public Health* 95(7) (July 2005), doi: 10.2105/AJPH.2004.055111.: “Realization of the right to health further implies providing individuals and communities with an authentic voice in decisions defining, determining, and affecting their well-being. Public health has a long tradition of recognizing that participation is integral to health promotion.”

Table 9: Patient Care and the Right to Non-Discrimination and Equality

Examples of Human Rights Violations

- Members of certain communities are treated in separate ways 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	Treaty Body Interpretation
<p>ICESCR 2(2) The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenants will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.</p> <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>CESCR General Comment 20: In explaining “other status” under ICESCR 2(2), CESCR explains “Health status refers to a person’s physical or mental health. States parties should ensure that a person’s actual or perceived health status is not a barrier to realizing the rights under the Covenant. The protection of public health is often cited by States as a basis for restricting human rights in the context of a person’s health status. However, many such restrictions are discriminatory, for example, when HIV status is used as the basis for differential treatment with regard to access to education, employment, health care, travel, social security, housing and asylum. States parties should also adopt measures to address widespread stigmatisation of persons on the basis of their health status, such as mental illness, diseases such as leprosy and women who have suffered obstetric fistula, which often undermines the ability of individuals to enjoy fully their Covenant rights. Denial of access to health insurance on the basis of health status will amount to discrimination if no reasonable or objective criteria can justify such differentiation.” E/C.12/GC/20 (June 10, 2009).</p> <p>CESCR General Comment 14: “With respect to the right to health, equality of access to health care and health services has to be emphasized. States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds in the provision of health care and health services, especially with respect to the core obligations of the right to health.”</p> <p>CESCR General Comment No. 14 (14): Explaining that “health facilities, goods and services must be accessible to all [without discrimination], especially to the most vulnerable and marginalized sections of the population . . .” The Committee stated that this included the health care access needs of “ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities and persons with HIV/AIDS.”</p>

Table 9: (cont.)

Human Rights Standards	Treaty Body Interpretation
<p>CEDAW 12(1) States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.</p>	<p>CEDAW Committee General Recommendation No. 19 (19-20): explaining that “States parties are required by Article 12 to take measures to ensure equal access to health care. Violence against women puts their health and lives at risk. In some States there are traditional practices perpetuated by culture and tradition that are harmful to the health of women and children. These practices include dietary restrictions for pregnant women, preference for male children and female circumcision or genital mutilation.”</p>

Other Interpretations

Declaration of Lisbon on the Rights of the Patient: Principle 1: Right to medical care of good quality:

- a. Every person is entitled without discrimination to appropriate medical care.
- e. In circumstances where a choice must be made between potential patients for a particular treatment that is in limited supply, all such patients are entitled to a fair selection procedure for that treatment. That choice must be based on medical criteria and made without discrimination.

Declaration of Alma-Ata: (V) Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. ... (VIII) All governments should formulate national policies, strategies and plans of action to launch and sustain primary health care as part of a comprehensive national health system and in coordination with other sectors. To this end, it will be necessary to exercise political will, to mobilize the country's resources and to use available external resources rationally.

European Convention on Human Rights and Biomedicine, Art. 3: Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality. See also Explanatory Report, paras. 24-27 (interpreting the right to equitable access to health care provided by article 3 of the European Convention on Human Rights and Biomedicine).

Covenant on the Rights of the Child in Islam, as adopted by the Organization of the Islamic Conference (OIC), art. 15. The child [regardless of minority status] is entitled to physical and psychological care.

3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION, AND PROGRAMMING?

What is a human rights-based approach?

“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”⁴³

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”⁴⁴ They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).⁴⁵ With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”⁴⁶

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

⁴³ Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

⁴⁴ For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf.

⁴⁵ Ibid.

⁴⁶ Ibid.

What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, 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?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.⁴⁷ Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

⁴⁷ Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

How can a human rights-based approach be used?

- A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:
- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS-BASED WORK IN THE AREA OF PATIENT CARE?

This section contains **five examples** of effective human rights-based work in the area of patient care and human rights. These are:

1. Litigating to protect private patient medical records in Ukraine
2. Monitoring and advocacy on patient rights at the European level
3. Training and litigation guides: The Practitioner Guide project
4. Human rights in patient care course initiative
5. Uganda National Health Consumers' Organisation: Developing a patients' charter

Example I: Litigating to protect private patient medical records in Ukraine

Ukraine Court Decision: Medical Certificate and Privacy

<http://cop.health-rights.org/teaching/54/Ukraine-Court-Decision--Medical-Certificate-and-Privacy>

Project Type

Litigation

The Organization

Vinnitsa Human Rights Group (Vinnitsa) is a civil society organization concerned with promoting the rule of law, as well as heightening individual political and legal awareness. The organization works to facilitate the harmonization of Ukrainian law with European human rights standards, with a particular focus on the rights of patients and refugees. In this case, Vinnitsa facilitated a civil action brought by a Ukrainian citizen whose right to patient privacy had been violated.

The Problem

To receive disability benefits in Ukraine at the time this case was first heard, an applicant's medical certificate documenting his/her diagnosis had to be forwarded to his/her employer. Mrs. Svitlana Yuriyivna Poberezhets, a Ukrainian citizen seeking disability benefits, challenged the release of her private medical information to her employer on the basis of the Ukrainian Constitution, the European Convention for the Protection of Human Rights and Fundamental Freedoms, and various Ukrainian civil codes.

Procedure

Vinnitsa Human Rights Group brought an administrative claim in the Pecherskyi District Court in Kyiv on behalf of Poberezhets. The claim was brought against the Ministry of Health of Ukraine, the Ministry of Labor and Social Policy of Ukraine, the Social Insurance Fund for Temporary Disability, and the Social Insurance Fund for Industrial Accidents and Occupational Disease of Ukraine.

Rights Violations

Ukrainian Const. Art. 32: The collection, storage, use, and dissemination of confidential information about a person without his or her consent shall not be permitted, except in cases determined by law, and only in the interest of national security, economic welfare, and human rights. Ukrainian Constitution:

www.ccu.gov.ua/en/doccatalog/list?currDir=12083.

EHCR Art. 8: Everyone has the right to respect for his private and family life, his home and his correspondence. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

EHCR: <http://tinyurl.com/3ydyjvo>.

Ukrainian Civil Code: Ukraine adopted a new civil code, which entered into force on January 1, 2004. The code provided numerous protections for private data, which this court interpreted to include patient diagnosis. Ukrainian Civil Code: <http://zakon2.rada.gov.ua/laws/main/en/annot>.

Arguments and Holding

Poberezhets sought a declaration that inclusion of her specific disease on her medical certificate constituted dissemination of confidential information, in violation of her rights under Article 32 of the Ukrainian Constitution. Article 32 states, “The collection, storage, use and dissemination of confidential information about a person without his or her consent shall not be permitted, except in cases determined by law, and only in the interest of national security, economic welfare and human rights.” As the court noted, the medical certificate was available for use in civil matters as a ground to release an employee from their responsibilities to their employer. It was also available for use in public relationships as a basis for disability benefits. Therefore, release of a medical certificate in this case constituted dissemination of information.

Moreover, there were no security, economic welfare, or human rights grounds to justify the release of information. Therefore, since Article 8 of the ECHR and various provisions of the Ukrainian Civil Code clearly established that a person’s diagnosis is private, confidential information, the requirement that the applicant’s specific medical status be disclosed to her employer was in violation of her rights under Article 32 of the Ukrainian Constitution. The administrative bodies could not force patients to turn over information related to their diagnosis as a condition for receiving disability benefits.

Historical Note

Ukraine’s Soviet past has had a strong influence on its law and judicial procedure. The Constitution of the USSR protected privacy in principle (Article 56: “The privacy of citizens, and of their correspondence, telephone conversations, and telegraphic communications is protected by law”). However, provisions of the Soviet Constitution were not directly enforceable law, and the Soviet Union had little interest in enacting statutes protecting an individual’s right to privacy—indeed, “individual” was a taboo term. Moreover, Soviet-era courts only enforced rights where a specific statute existed establishing those rights. The courts did not venture out to balance laws or fill in the gaps within the statutory framework.

Now, Ukraine has ambitions to join the European Union, and patient confidentiality is a more pressing concern. Harmonization with the European human rights framework is an important goal of the Ukraine Government. Therefore, Ukraine is a more hospitable venue for human rights litigation, like the action taken by Vinnitsa, than it once was.

Analysis and Commentary

Privacy and individual autonomy are the building blocks of democratic society. Over the past century, there has been an unusual strain on the right to privacy. On the one hand, technological advances lead to increasingly powerful and sophisticated means of collecting and distributing private data. At the same time, however, people gain greater respect for individuality and privacy, and they demand that legal systems protect their private medical data. Indeed, privacy is a broad term that evolves with the evolution of society, including the development of ever larger and more easily transmitted medical data depositories.

The protection of private medical information is of pressing concern in Ukraine today. Although Ukraine’s information technology infrastructure still lags behind EU member states, it is modernizing at an astonishing rate. In 2006, 4.4% of Ukraine’s population used the Internet. In 2011, that number was 30% (World Bank). Establishing a right to privacy with respect to medical data is especially important given the rapid pace of technological development in Ukraine and the corresponding potential for abuse of patient privacy.

Vinnitsa Human Rights Group, Ukraine

E-mail: vpg@ukr.net, Web: <http://www.vpg.org.ua/>

Example 2: Monitoring and advocacy on patient rights at the European level

Project Type

Advocacy

The Organization

Created in December 2001, Active Citizens Network (ACN) is a network of European civil society organizations working to encourage active public participation in European policymaking. ACN's policies center on the issues of health and corporate social responsibility. They conduct education and training at the regional level.

The Problem

While European Union countries valued the right to universal access to health care, ACN noted that budgetary restraints brought into question the quality of the health care system. Most notably, patients' rights were compromised and violated in health care provision, which is in contradiction to the social model of health care promoted by the European Union countries. ACN noted that “[b]udgetary constraints, however justified, cannot legitimize denying or compromising patients' rights.”

It is important to note that other trends also helped shape development of ACN. These developments included: increasing expense and rationing of health care services; the emergence of a consumer movement in Europe, and the demand for patients to play a more active role in managing their care and shaping their treatment; and increasing freedom of movement in the EU, which lead to interest in harmonization of basic standards.

Actions Taken

Drafting the European Charter of Patients' Rights. In 2002, the ACN and 15 citizens' organizations worked together to draft the European Charter of Patients' Rights. The principles of the charter aim to guarantee a “high level of human health protection” (Article 35 of the Charter of fundamental rights of the European Union). The purpose of drafting the charter was to raise awareness of patients' rights, which were at risk throughout Europe due to financial constraints on the health care system.

Surveying implementation of the European Charter of Patients' Rights. In 2005, ACN conducted its first survey study of hospitals throughout the European Union (excluding Luxembourg) to measure the implementation of the European Charter of Patients' Rights. In 2007, ACN presented the final report in Brussels on the occasion of the First European Day of Patients' Rights. A follow-up monitoring was conducted from May to October 2010. [That monitoring report is available here.](#)

Establishing a European Day of Patients' Rights. ACT established a day to discuss patients' rights across Europe. The European Parliament, EU Commission, and ESCC participated and provided support for this first European Day. In 2011, the EU Commission decided to officially support the Fifth European Day of Patients' Rights.

European Charter of Patients' Rights

1. Right to preventive measures
2. Right of access
3. Right to information
4. Right to consent
5. Right to free choice
6. Right to privacy and confidentiality
7. Right to respect of patients' time
8. Right to the observance of quality standards
9. Right to safety
10. Right to innovation
11. Right to avoid unnecessary suffering and pain
12. Right to personalized treatment
13. Right to complain
14. Right to compensation

Results and Lessons Learned

Since publishing the European Charter of Patients' Rights, there has been a dramatic improvement in the discussion of patients' rights across Europe, including significant publications by public institutions, citizens' organizations, and independent experts. Patients' rights are now a part of the European policy agenda. Public institutions are increasingly aware of their obligations to patients' rights. Finally, there is a greater recognition of the need to create common standards of medical practice to protect patients' rights across Europe.

Active Citizenship Network (ACN), Rome, Italy

E-mail: info@activecitizenship.net, Web: www.activecitizenship.net

Example 3: Training and litigation guides: The Practitioner Guide Project

Project Type

Training and Litigation

The Organization

The Practitioner Guide Project is an Open Society Foundations (OSF) project spearheaded by the Law and Health Initiative (LAHI) of the Public Health Program in collaboration with the Human Right and Governance Grants Program; Health Media Initiative; Roma Health Project; Russia Project; and National Foundations in Armenia, Georgia, Kazakhstan, Kyrgyzstan, Macedonia, Moldova, and Ukraine.

OSF works to build vibrant and tolerant democracies whose governments are accountable to their citizens. Working with local communities in more than 70 countries, OSF supports justice and human rights, freedom of expression, and access to public health and education.

The Public Health Program aims to build societies committed to inclusion, human rights, and justice, in which health-related policies and practices reflect these values and are based on evidence. The program works to strengthen the capacity of organizations and leaders who represent marginalized communities to advocate for better health policies and practices. It also pushes for greater government accountability and transparency in health care.

LAHI supports the use of legal strategies to advance the health and human rights of marginalized and vulnerable groups. It advances this mission by applying the health and human rights framework to new issues and priority regions; developing individual and organizational leadership in the field of health and human rights; piloting innovative access to justice tools as health-related human rights interventions; advocating for rights-based legal environments that support the health of marginalized groups; and leveraging sustainable funding for efforts that advance this mission. The crux of this initiative is focused on the implementation of laws that protect the rights of both patients and providers.

The Problem

Human rights norms are an increasingly important component of the delivery of quality medical care. OSF's work on behalf of society's most marginalized persons—people with disabilities, people living with HIV, people who use drugs, sex workers, Roma and other ethnic minorities—has shown that health systems can too often be places of punishment, coercion, and violations of basic rights to privacy and confidentiality, rather than places of treatment and care. At the same, health providers suffer from a lack of independence, decent working conditions, and due process protections. Laws in Eastern Europe and Central Asia have the potential to ensure accountability and address these violations, but they are rarely implemented. Additionally, in many of these countries, laws are rapidly in flux, and there is a dearth of materials providing updated guidance to navigate the various laws, as well as procedures for protection of rights through both the formal court system and alternate mechanisms, such as ombudspersons and ethics review committees.

Actions Taken

LAHI, in collaboration with OSF partners, has supported the development of a series of Practitioner Guides and companion websites for lawyers interested in taking human rights in patient care cases—albeit patient rights or provider rights cases. The Practitioner Guides are practical how-to manuals covering both litigation and alternative dispute mechanisms. They examine patient and provider rights and responsibilities and procedural mechanisms at the national, regional, and international levels. Guides have been or are being produced in Armenia, Georgia, Kazakhstan, Kyrgyzstan, Macedonia, Moldova, Serbia, Romania, Russia, and Ukraine. They can be accessed at <http://cop.health-rights.org/PractitionerGuides>.

Results and Lessons Learned

Once published, Practitioner Guides are used as a basis for training and litigation support. They show particular potential as a resource in clinical legal education programs. Although legal practitioners are the primary audience for these guides, they are also useful for medical professionals, public health managers, Ministry of Health and Justice personnel, patient advocacy groups, and patients themselves.

Follow-up activities for this project include trainings for lawyers and judges, patient-friendly versions of the guides with a focus on marginalized populations, and potential law reform to address gaps identified by the Practitioner Guide working groups.

Since human rights in patient care are constantly evolving, electronic versions of the guides are periodically updated. The international home page, www.health-rights.org, links to country websites, which provide additional resources gathered by the country working groups that prepared each guide. These resources include relevant laws and regulations, case law, tools and sample forms, and practical tips for lawyers. The websites also provide a way to connect lawyers, health providers, and patients concerned about human rights in health care. Each website provides a mechanism for providing feedback on the guides.

Open Society Foundation, Public Health Program, New York, USA

Web: <http://www.opensocietyfoundations.org/about/programs/public-health-program>

Health Rights: Human Rights in Patient Care

<http://www.health-rights.org>

Health Rights: Practitioner Guides

<http://cop.health-rights.org/PractitionerGuides>

Example 4: Human rights in patient care courses initiative

Project Type

Advocacy

The Organization

The Law and Health Initiative (LAHI), a division of the Open Society Foundation's Public Health Program, supports the use of legal strategies to advance the health and human rights of marginalized and vulnerable groups. It advances this mission by applying the health and human rights framework to new issues and priority regions; developing individual and organizational leadership in the field of health and human rights; piloting innovative access to justice tools as health-related human rights interventions; advocating for rights-based legal environments that support the health of marginalized groups; and leveraging sustainable funding for efforts that advance this mission.

LAHI supports collaborations between health and legal practitioners with a view to advancing mutually shared goals of human rights, human dignity and open society. LAHI both builds the capacity of health providers to use the law to advance their advocacy objectives and supports legal practitioners in expanding their remit to include public health. This initiative was undertaken by LAHI in collaboration with the Human Rights and Governance Grants Program, Roma Health Project, Russia Project, and National Foundations in Armenia, Georgia, Kazakhstan, Kyrgyzstan, Macedonia, Moldova, Serbia, and Ukraine of the Open Society Foundations.

The Problem

Human rights norms are an increasingly important component of the delivery of quality medical care. OSF's work on behalf of society's most marginalized persons—people with disabilities, people living with HIV, people who use drugs, sex workers, Roma and other ethnic minorities—has shown that health systems can too often be places of punishment, coercion, and violations of basic rights to privacy and confidentiality, rather than places of treatment and care. At the same time, doctors and health practitioners in many Eastern European and Central Asian (EECA) countries are constrained in their ability to provide quality care to their patients, or are unaware of how to incorporate ethical and human rights norms into their work. Similarly, legal professionals have limited experience in working in health and trying to address the abuses that occur. There is a need to address this gap so that the next generation of doctors and health practitioners receive basic human rights training and legal professionals are equipped to work at the intersection of law and health.

Actions Taken

LAHI, in collaboration with OSF partners, has sought to respond to this need by supporting the development of courses on human rights in patient care in nine EECA countries. In 2007, LAHI hosted a Salzburg seminar bringing together academics from EECA medical, public health, and law schools along with key partner NGOs and patient advocates for an intensive week to explore critical human rights in patient care topics and think creatively about how to structure a course addressing these issues. LAHI and OSF partners subsequently funded the development and piloting of over a dozen courses in Armenia, Georgia, Kazakhstan, Kyrgyzstan, Macedonia, Russia, Serbia, and Ukraine. Different courses target medical students, medical practitioners, health managers, public health students, and law students.

Results and Lessons Learned

While the courses are self-sustaining and a regular part of the offerings at each university, faculty have requested the opportunity to share experiences and materials and continue to strengthen their teaching. To meet this need, LAHI and partners organized a series of workshops over the past few years. Workshops provided faculty with an opportunity to share lessons with each other, sharpen their interactive teaching methodology, and develop lesson plans and case studies. Faculty were also exposed to cutting edge health and human rights topics, such as access to sex reassignment surgery, access to maternal care for women who use drugs, coercive sterilization of women living with HIV, health care privatization and human rights, and dual loyalty conflicts faced by health practitioners. Additionally, LAHI and OSF's Health Media Initiative supported the development of an online "Community of Practice" for ongoing collaboration among faculty. Please find the Community of Practice web page at: <http://cop.health-rights.org/>.

Open Society Foundations, Public Health Program, New York, USA

Web: <http://www.opensocietyfoundations.org/about/programs/public-health-program>

Example 5: Uganda National Health Consumers' Organization: Developing a patients' charter

Project Type

Advocacy

The Organization

Uganda National Health Consumers' Organization (UNHCO) is a health rights advocacy organization that empowers citizens to demand and hold service providers and policy makers accountable. It uses the rights-based approach to raise community awareness on the right to health, so that citizens view health as an entitlement and not a privilege. This approach also aims to make communities aware of the standards and guidelines at each level of service delivery, so they know what to demand, and what their responsibilities are for effective delivery of health services. Using this approach, communities are empowered to demand and participate in improving quality service delivery at each level of the health care system.

UNHCO establishes and strengthens mechanisms for engagement between consumers, service providers, and policy makers. The mechanisms include community dialogue meetings, suggestion boxes, and Health Unit Management Committees (HUMCs). Community members use the mechanisms to provide feedback about health service delivery. UNHCO also builds capacity of the community structures both existing and new including health workers, local politicians, partner Community Based Organizations (CBOs), and community advocates. The community structures are empowered to monitor and hold duty bearers accountable. They also increase health consumers' awareness about their rights and responsibilities, standards, and feedback and redress mechanisms.

In an effort to empower communities to engage service providers and policy makers, UNHCO employs social accountability tools in different communities of operation. The tools include citizens' report card and community score cards to generate issues for advocacy but also to cause duty bearers to address identified gaps in health care delivery.

Right to High-Quality Health Care

Uganda Const. (Social and Economic Objective No. XX of the 1995): "The State shall take all practical measures to ensure the provision of basic medical services to the population."

Source: *Eastern Africa Centre for Constitutional Development*, www.kituoachakatiba.org

Patients' Charter

"The objective of the [P]atients' [C]harter is to empower health consumers to demand high quality health care, to promote the rights of patients and to improve the quality of life of all Ugandans and finally eradicate poverty nationwide."

The Republic of Uganda, Patients' Charter (2009), <http://unhco.or.ug/library/?did=11>

To create a critical mass for advocacy for addressing community concerns both at the community and national level, UNHCO has led the formation of coalitions and alliances as need arises. UNHCO is currently leading the following coalitions: Voices for Health Rights (VHR), Coalition to Stop Maternal Mortality in Uganda, Communities of Change, CSO Coalition on Pharmaceutical Procurement and Supply Chain Management (PSM) for Accountability in Uganda, and the Health Accountability Platform.

The Problem

According to the World Health Organization, Uganda ranks among the world's lowest in health status. Almost 30 years since the National Resistance Movement came to power in 1986, destruction of health infrastructure and loss of human resources continue to depress health care statistics. Indeed, Uganda attempts to provide health care services to a larger and rapidly growing population with fewer resources than it had in the 1970s. Moreover, the spreading of disease (particularly malaria, HIV/AIDS, tuberculosis, diarrhea, cholera, measles, and non-communicable diseases) and a general unawareness of legal rights make the delivery of health care in Uganda a particular challenge.

Actions Taken

In an effort to legalize the right to health in Uganda, UNHCO spearheaded the development of the Patients' Charter, whose objective is to provide a policy and legal framework for empowerment of health consumers, enabling them to demand for high quality health care and promote accountability in the health sector. UNHCO continues to use the Patients' Charter as a tool for legalizing the right to health in Uganda.

UNHCO sits on different Ministry of Health committees to inform policy and practice. These include the Health Policy Advisory Committee (HPAC), Public Private Partnership in Health (PPPH), Sector Working Groups, and Quality Assurance Committees. Under these committees, UNHCO works to ensure that consumer concerns are part of the planning of the sector. It also ensures that the sector uses the rights-based approach in policy implementation.

UNHCO was instrumental in developing the Patients' Charter. The Charter adopts a rights-based approach to health care delivery and provides a policy and legal framework for health care consumers—enabling them to demand high quality care and accountability. The Ugandan Government adopted the Charter, and the Ugandan Ministry of Health (MOH) working in conjunction with UNHCO, is now taking steps towards implementing it.

Patients' Charter—Patients' Rights:

1. The Right to Medical Care
2. Prohibition of Discrimination
3. Participation on Decision-making
4. A Healthy and Safe Environment
5. Proper Medical Care
6. Treated by a Named Health Care Provider
7. Participation in Training and Research (Voluntary, Informed and with Written or Verbal Consent)
8. Right to Safety and Security
9. Right to Receive Visitors
10. Right to Informed Consent
11. Limitations on Medical Care Without Consent
12. Right to Refuse Treatment
13. Right to Referral for Second Opinion
14. Continuity of Care
15. Right to Confidentiality and Privacy
16. Right to Medical Information
17. Custody of Medical Records
18. Medical Records Retention (Medical Archives)
19. Right to Redress

Source: <http://unhco.or.ug/wp-content/uploads/downloads/2011/02/Patients-Charter.pdf>

Results and Lessons Learned

The Ugandan Government's commitment to working with civil society organizations to formulate a new health policy that provides greater access, transparency, and accountability is a great step toward better health care. The Charter specifically lays out the obligations of health care providers and the rights of health care consumers; however, considerable efforts are necessary to narrow the gap between health care policy and implementation.

For this reason, UNHCO began innovative work to ensure the implementation of the Patients' Charter, including an effort to spell out the rights and obligations contained therein to the health Sector Strategic Investment Plan III (HSSIP) (2010/11-2014/15). UNHCO also monitors HSSIP and the national budget to measure the extent to which they comport with the priorities of the HSSIP.

Uganda National Health Consumers' Organization (UNHCO), Kampala, Uganda
E-mail: info@unhco.or.ug, Web: <http://unhco.or.ug/>

5. WHERE CAN I FIND ADDITIONAL RESOURCES ON PATIENT CARE AND HUMAN RIGHTS?

A list of commonly used resources on patient care and human rights follows organized according to key topics highlighted within the text. It is organized into the following categories:

It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. General Resources
- D. Health Workers and Human Rights
- E. Right to Life
- F. Right to Information
- G. Right to Participate in Public Policy
- H. Right to Non-Discrimination and Equality
- I. Cross-Border Health In Europe
- J. Journals
- K. Websites

A. International Instruments

- International Alliance of Patients' Organizations, *Declaration on Patient-Centered Health Care* (March 30, 2007). www.patientsorganizations.org/showarticle.pl?id=712;n=312. Available in Spanish.
- UN Office of the High Commissioner for Human Rights, Istanbul Protocol: Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (2004). <http://www.ohchr.org/Documents/Publications/training8Rev1en.pdf>.
- UN Office of the High Commissioner for Human Rights. *Standard Minimum Rules for the Treatment of Prisoners* (adopted 1955). <http://www2.ohchr.org/english/law/treatmentprisoners.htm>.
- UNESCO General Conference, *Universal Declaration on Bioethics and Human Rights*, (October 19, 2005). www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/.
- UN General Assembly, *Body of Principles for the Protection of All Persons Under Any Form of Detention*, Resolution 43/173 (December 9, 1998). <http://www2.ohchr.org/english/law/bodyprinciples.htm>.
- UN General Assembly, *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*, Resolution 37/194 (December 18, 1982). <http://www2.ohchr.org/english/law/medicalethics.htm>.
- World Health Organization, *Declaration of Alma-Ata* (September 6-12, 1978). www.who.int/publications/almaata_declaration_en.pdf.
- World Medical Association, *Declaration of Helsinki—Ethical Principles for Medical Research Involving Human Subjects* (June, 1964). www.wma.net/en/30publications/10policies/b3/index.html.
- World Medical Association, *Declaration of Lisbon on the Rights of the Patient* (September/October, 1981). www.wma.net/en/30publications/10policies/l4/.

- World Medical Association, *Declaration on Medical Care for Refugees* (October, 1998). www.wma.net/en/30publications/10policies/m10/.
- World Medical Association, *Regulations in Times of Armed Conflict and other Situations of Violence* (October, 1956). www.wma.net/en/30publications/10policies/a20/.

B. Regional Instruments

- Active Citizen Network, *European Charter of Patients' Rights* (2002). www.eesc.europa.eu/self-and-core-ulation/documents/codes/private/085-private-act.pdf.
- African Commission on Human and Peoples' Rights, *Resolution on Access to Health and Needed Medicines in Africa*, ACHPR/Res.141 (XXXVIII) 08: (November 2008). www.achpr.org/sessions/44th/resolutions/141/.
- Council of Europe, *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* (1997). <http://conventions.coe.int/Treaty/EN/Treaties/Html/164.htm>.
- Council of Europe, *Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data*, C.E.T.S. No. 108 (entered into force January 28, 1981). <http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=108&CL=ENG>.
- WHO: Regional Office for Europe, *A Declaration on the Promotion of Patients' Rights in Europe* (March, 1994). www.who.int/genomics/public/eu_declaration1994.pdf.

C. General Resources

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6. WHAT ARE THE KEY TERMS RELATED TO PATIENT CARE AND HUMAN RIGHTS?

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 to the interests of a third party such as an employer, insurer, or the state. The conflict may be express or implied, real or perceived.

E

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.

H

Health

Complete physical, mental, and social well-being, rather than merely the absence of disease or infirmity (World Health Organization).

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). *See also* “patient care.”

Health care facility

Any health care institution such as a hospital, clinic, primary care center. May also be referred to as a medical facility.

Health care professional

Physicians, nurses, pharmacists, dentists, midwives, physician assistants, dieticians, paramedics, psychologists, therapists, or other health professionals.

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

Individual rights in patient care

Rights that, when made operation, can be made enforceable on behalf of an individual patient. Individual rights in patient care are more readily expressed in absolute terms than are social rights in health care (Declaration on the Promotion of Patients' Rights in Europe, World Health Organization, 1994). See also "social rights in health care" and "patients' rights."

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.

Inpatient

A patient whose care requires a stay in a 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 that almost exclusively affect underprivileged rural communities in low-income countries; such diseases generally receive inadequate attention and resources.

O

Outpatient

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).

A person in contact with the health system, seeking attention for a health condition (European Observatory on Health Systems and Policies).

Patient autonomy

A patient's right to make decisions about his or her 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 holding 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

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.

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 caused by 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.

Public health

Collective actions of a society to ensure conditions in which people can be healthy (Institute of Medicine).

S

Secondary health care

General health services available in hospitals.

Social Rights in Health Care

Category of rights that relate to the societal obligation undertaken or otherwise enforced by government and other public or private bodies to make a reasonable provision of health care for the whole population. These rights also relate to the equal access to health care for all those living in a country or other geopolitical, cultural, social, or psychological. Social rights in health care are enjoyed collectively (Declaration on the Promotion of Patients' Rights in Europe, World Health Organization, 1994). *See also* "individual rights in patient care."

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.