Patients' Rights Act No 74/1997 (with amendmentsaccording to Acts 77/2000, 40/2007, 112/2008 and 55/2009)

NB. references to Acts in effect link to original Icelandic versions on Alþingi's website

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Patients' Rights Act

1997 no. 74, 28 May

Took effect 1 July 1997. Amended by Act 77/2000 (took effect 1 Jan. 2001), Act 40/2007 (took effect 1 Sept. 2007), Act 112/2008 (took effect 1 Oct 2008, except item 12 art. 59, which took effect 25 September 2008; implemented as provided in para. 2 art. 56) and Act 55/2009 (took effect 1 May 2009).

SECTION I

Introduction

Objective

Art. 1

The objective of this Act is to ensure specific rights for patients in accordance with general human rights and human dignity and thus strengthen their legal status vis-à-vis the health service, and to support the confidential relationship which must exist between patients and healthcare practitioners.

It is prohibited to discriminate against patients on grounds of gender, religion, beliefs, nationality, race, skin colour, financial status, family relationship or status in other respect.

Definitions

Art. 2

Patient: A user of the health service.
[*Healthcare practitioner:* Person working in health services, licensed by [the Medical Director of Health][1] to use to the professional title of a authorised health profession.][2]
Treatment: A test or examination, operation or other [healthcare service][3] rendered by a physician or other healthcare practitioner in order to diagnose, cure, rehabilitate, nurse or care for the patient.
Scientific research: Research conducted with the aim to add to knowledge *inter alia* to facilitate improvement of health and curing of diseases. Evaluation of the research by the National Bioethics Committee or an ethics committee under Art. 29 must have revealed that scientific and ethical principles do not oppose its implementation.
[1] *Act 112/2008, art. 63,* [2] *Act 41/2007, art. 24,* [3] *Act 55/2009, art. 26.*

Quality of the Health Service

Art. 3

The patient has the right to the best health service available at each time.

The patient has the right to service appropriate to his/her condition and prognosis at each time and the best knowledge available. The healthcare practitioner shall endeavour to establish a sound relationship with the patient.

The patient has the right to continuity of service and cooperation between all healthcare practitioners and institutions involved in the treatment.

Access to Information on Patients' Rights

Art. 4

The [Ministry of Health][1)] shall ensure that information is available concerning patients' rights, patients' associations and [health insurance].[1)] This information shall be made accessible to patients on the premises and places of work of health institutions and self-employed healthcare practitioners. Furthermore, an endeavour shall be made to inform the public of the causes and consequences of illnesses in children and adults.

[1)] *Act 112/2008, art. 63.*

SECTION II

Information and Consent

Information on Health and Treatment

Art. 5

A patient has the right to information regarding:

a. his/her state of health, including medical information on his/her condition and prognosis,
b. the proposed treatment, as well as information on its course, risks and benefits,
c. possible remedies other than the proposed treatment, and the consequences of refraining from treatment,
d. the possibility of seeking the opinion of another physician or other healthcare practitioners, as appropriate, regarding treatment, condition and prognosis.

It shall be entered in the health record of the patient that information under this Article has been provided.

Information under this Article shall be provided whenever there is reason to do so and in such a manner and under such circumstances that the patient can understand it.

If the patient does not understand Icelandic or uses sign language, interpretation of the information under this Article shall be provided.

Exemptions from the Principle on Information on Health and Treatment

Art. 6

Information under Art. 5 shall be withheld if the patient so requests. A patient can appoint another person to receive the information in his/her place.

It shall be entered in the health record if the patient declines information on his/her health and prognosis or appoints another person in his/her place. The identity of the person receiving the information shall likewise be entered, cf. para. 1 of this Article and Arts. 7 and 25.

In the case of a patient unable to understand the information under Art. 5, the information shall be given to a close relative or, if the patient has been deprived of legal competence to his/her legal guardian.

Art. 7

The right of the patient to decide whether he/she will accept treatment shall be respected. The provisions of the Act on Legal Competence apply to the consent to treatment of patients who, due to lack of intelligence or for other reasons provided for by that Act, are incapable of making a decision regarding treatment. In such cases the patient shall nevertheless be consulted as far as possible.

No treatment may be given without the consent of the patient, cf. paras. 1 and 2, but cp. Art. 9. Consent shall be in writing whenever possible and indicate the information provided to the patient, and that he/she has understood the information.

Refusal of Treatment

Art. 8

If the patient refuses to accept treatment, a doctor shall inform him/her about the possible consequences of his/her decision.

The patient may discontinue treatment at any time, unless otherwise provided by other legislation. If a patient refuses to accept treatment, his/her physician or the healthcare practitioner supervising the treatment shall inform him/her of the possible consequences of the decision. Refusal of treatment for sick children is subject to the provisions of art. 26.

A patient's decision to refuse or discontinue treatment shall be recorded in his/her health record and it shall be confirmed that he/she has received information on the possible consequences of his/her decision.

Exemptions from the Principle of Consent to Treatment

Art. 9

If a patient is unconscious or his/her condition is such that he/she is unable to express his/her will regarding urgent treatment, consent shall be assumed, unless it is known with certainty that he/she would have refused treatment.

Consent to Scientific Research

Art. 10

A patient shall give his/her formal consent prior to participation in scientific research. Before such consent is given detailed information shall be provided on the scientific research, the possible risks and benefits involved and what participation entails. It shall be explained to the patient that he/she can refuse to participate in scientific research and that he/she can cease participation at any time after it has commenced. Access to information contained in health records, including biological samples, for the purposes of scientific research, is subject to the provisions of Art. 15 [and the provisions of the Health Records Act]. [1)]

It is prohibited to conduct scientific research on a patient which does not fulfil the conditions of para. 4 Art. 2.

[1)] *Act 55/2009, art. 26.*

Participation in the Training and Tuition of Students

Art. 11

The patient must be informed if students in the health sector are to be present during his/her treatment, as part of their training and tuition. A patient can refuse to take part in such training and tuition.

SECTION III

Duty of Confidentiality

Art. 12

Healthcare Practitioners' Duty of Confidentiality

A healthcare practitioner shall maintain the utmost confidentiality regarding anything of which he/she becomes aware in the course of his/her work regarding the health, condition, diagnosis, prognosis and treatment of a patient, as well as other personal information. The duty of confidentiality persists after the death of a patient and after cessation of the practitioner's employment. The practitioner may provide information for exigent reasons, with due regard to the wishes of the deceased and the interests of those concerned. When a practitioner is in doubt, he/she can seek the opinion of the Medical Director of Health.

Exemptions from Duty of Confidentiality

Art. l3

Confidentiality under Art. 12 does not apply to incidents on which a healthcare practitioner must report under other legal provisions, such as the provisions of the Child Protection Act. In those cases, a practitioner must report the incident to the appropriate authorities.

A practitioner may be released from the duty of confidentiality by consent of the patient or his/her guardian.

Obligations of a healthcare practitioner to testify in a court of law are subject to the provisions of the Physicians Act.

SECTION IV

Handling of Information in Health Records

Access to Health Records

Art. 14

[Handling of information in health records is subject to the provisions of the Health Records Act.][1)]
[1)] *Act 55/2009, art. 26.*

Art. 15 ...[1)]

...[1)]

The [Data Protection Authority][2)] is authorised, under the Act on the Protection of Privacy as regards the Processing of Personal Data, to provide access to information from health records, including biological samples, for purposes of scientific research, provided that the research meets the conditions for scientific research, cf. para. 4 Art. 2 of this Act. Such access may be made contingent upon conditions considered necessary at each time.

Every time a health record is examined for the purpose of scientific research, this shall be entered in the record, and the provisions of paras. 1 and 2 shall be complied with.
[1)] *Act 55/2009, art. 26,* [2)] *Act 77/2000, art. 46.*

Art. 16 ...[1)]

[1)] *Act 55/2009, art. 26.*

SECTION V

Treatment
Respect for the Human Dignity of the Patient

Art. 17

Healthcare practitioners, or other individuals who on account of their work have to communicate with the patient, shall treat him/her with respect.

Only those directly involved in the treatment of a patient shall participate in it. A healthcare practitioner shall take care to administer the necessary treatment out of sight of outside parties, and to ensure that information regarding treatment is inaccessible to individuals other than the healthcare practitioners involved.

Waiting for Treatment

Art. 18

If a patient has to wait for treatment, the physician concerned shall explain the reasons for the delay and provide him/her with information on the estimated waiting time.

If it is possible to receive the necessary treatment sooner elsewhere, the patient must be made aware of the fact.

Prioritisation

Art. 19

If it proves necessary to place patients waiting for treatment in order of priority, the order should be based primarily on medical grounds, and other professional criteria, as the case may be.

Choice of a Healthcare Practitioner

Art. 20

Notwithstanding the division of the country into [health regions][1)] under the Health Service Act, a patient has the right to consult the physician most convenient for him. A patient also has the right to seek the opinion of another physician regarding diagnosis, treatment, condition and

prognosis. The same applies to other healthcare practitioners.
[1)] *Act 40/2007, art. 39.*

The Patient's Responsibility for His/Her Own Health

Art. 21

A patient is responsible for his/her own health in so far as that is within his/her powers, and as his/her condition permits. He/she should, as far as possible, be an active participant in treatment to which he/she has consented.

Rules on Admission and Discharge

Art. 22

When a patient is admitted to a health institution, the healthcare practitioners attending to him/her shall introduce themselves and their respective fields of work. Furthermore, he/she shall be informed about the relevant rules and practices which apply in the institution.

The patient shall be informed about the identity of the doctor who is in charge of his/her treatment in the health institution.

Before the patient is discharged, his/her circumstances shall be explored and adequate home service or other measures provided, as far as possible.

On discharge from a health institution a patient shall be given, as deemed necessary, instructions on important matters regarding follow-up treatment, such as drug administration, diet, therapy and exercise. The instructions shall be in writing if requested.

Medical letters and certificates issued in relation to illness, accidents, hospitalisation etc. shall be provided without undue delay.

Easing of Suffering and Presence of Family and Friends

Art. 23

The patient's suffering shall be eased to the best of current ability.

A patient has the right to receive support from family, relatives and friends during his/her treatment and stay. The patient and his/her closest relatives have the right to mental, social and religious support.

Treatment of Terminal Patients

Art. 24

A terminal patient has the right to die with dignity. If a terminal patient unambiguously indicates that he/she declines further life-prolonging treatment, or resuscitation efforts, his/her physician shall respect his/her decision.

If a terminal patient is mentally or physically too ill to take part in a decision on treatment, the physician shall endeavour to consult the patient's relatives, and his/her colleagues, before he/she decides on the continuation or cessation of treatment.

SECTION VI

Special Rules on Sick Children
Information on the Health and Treatment of Sick Children

Art. 25

If a patient is under 16 years of age, information under Art. 5, as well as other information under this Act, shall be given to parents.

Sick children shall be given information appropriate to their age and maturity. However, they have the same right as others to decline information, cf. Art. 6.

Consent to the Treatment of Sick Children

Art. 26

Custodial parents of a child shall give their consent to the necessary treatment of a patient under 16 years of age. Sick children shall be consulted as far as possible and always if they are over 12 years of age.

If a custodial parent of the child refuses consent for necessary treatment, cf. para. 1, a physician or other healthcare practitioner shall invoke the assistance of child protection authorities, as provided in the Child Protection Act.

If time is not sufficient to seek the assistance of child protection authorities, cf. para. 2, with regard to urgent life-sustaining treatment for a sick child, the child's health must be the determining factor and the necessary treatment must be started immediately.

Various Rules Concerning Sick Children

Art. 27

Everything possible must be done to enable a sick child to develop and enjoy life, in spite of illness and medical treatment, as far as the child's condition permits.

Children shall be spared unnecessary tests and procedures.

Sick children staying in a health institution are entitled to be accompanied by their parents or other close relatives, who shall be provided with facilities, as far as possible.

Circumstances permitting, siblings and friends can visit a sick child in a health institution.

Sick children of compulsory school age [6-16 years][1)] shall be provided with tuition suited to their age and state of health.

Surroundings and care of sick children in health institutions shall be suited to their age, maturity and condition.

[1)] *Translator's note.*

SECTION VII

Right to Complain
Comments and Complaints about Treatment

Art. 28

The patient's comments regarding the service of a health institution shall be directed to the management of the institution concerned.

[Should a patient wish to make a complaint about treatment, he/she may direct the complaint to the Medical Director of Health.] [1)]

Staff of health institutions must provide guidance to a patient, or a relative, who wishes to put forward comments or make a complaint. Furthermore, the management of a health institution is obliged to investigate notifications from staff who believe that the rights of patients are being infringed on.

A patient shall receive a reply to his/her comments and complaints in writing at the earliest opportunity.
1) Act 41/2007, art. 24. The paragraph was also amended by item 4b, art 39, Act 40/2007, which took effect at the same time as Act 41/2007. The paragraph is there worded thus: Should a patient wish to make a complaint with regard to treatment, he/she may submit his/her complaint to the Medical Director of Health in accord with the provisions of the Medical Director of Health Act.

SECTION VIII

Provisions Regarding Entry into Force etc.
Minister's Authority to Issue Regulations

Art. 29

The Minister shall issue regulations[1)] on scientific research in the health sector. They shall *inter alia* contain provisions on a National Bioethics Committee and ethics committees under para. 4, Art. 2. Furthermore, the Minister is authorised to issue regulations on the implementation of this Act.
1)Regs. 286/2008

Entry into Force

Art. 30

This Act enters into force on 1 July 1997.

Patients' Rights Act No. 74, was issued on 28 May 1997
Origianl text on Alþingi's website with ammendments (in Icelandic)