PATIENT RIGHTS IN THE EU
LITHUANIA

EUROPEAN ETHICAL - LEGAL PAPERS N° 12
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Within the Centre for Biomedical Ethics and Law of the Catholic University of Leuven - one of the leading bioethical and legal research centres in Europe - we are involved as coordinator, partner or participant in different European research projects. Biomedical ethics and law are rapidly evolving disciplines. Although there exists already a great number of specialized peer reviewed journals and series of books in both disciplines we felt a growing need for a medium through which the results of our research can directly be presented to the research community and the interested community at large. To meet this need we decided to start the *European Ethical-Legal Papers*. Such papers will also contribute to the transparency we owe to society that finances our research efforts. We also hope that it will contribute to the discussion and the exchange of information and ideas among researchers in Europe and elsewhere.

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I. INTRODUCTION

EuroGentest is a five-year EU funded program that aims to develop the necessary infrastructure, tools, resources, guidelines and procedures that will lead to the establishment of harmonized, qualitative genetic testing services in Europe. Within EuroGentest we are dealing with the ethical and legal issues of genetic testing. Harmonization of the technical aspects of genetic services in Europe requires a legal and ethical framework that respects cultural, religious, philosophical and other domestic characteristics of a given country and its population(s), but at the same time conforms to basic and universally accepted human rights. To continuously supervise the legal and ethical developments regarding the promotion and protection of the rights of patients and users of health services and to make the results of our research publicly available, is a permanent challenge. This publication in the European Ethical-Legal Papers aims to contribute to it.

Opened for signature more than 10 years ago (in Oviedo, Spain, on 4 April 1997), the European Convention on Human Rights and Biomedicine is now becoming increasingly important as a standard to evaluate the efforts and the progress made by the Member States of the European Union to promote and protect the rights of patients and users of health services. In this twelfth issue we present the results of this evaluation for Lithuania, one of the EU Member States that have ratified the Convention.

The content of this publication is as follows.
In an introductory chapter we briefly describe Lithuania with respect to some of its main features related to its political and legal background and its health care system.
This is followed by an encompassing overview of the rights of patients in Lithuania. In a first paragraph the legal status of the Biomedicine Convention is situated against the background of Lithuanian constitutional law. Then we turn to a description of the national legislation on patient rights. Many different enumerations of patient rights exist. Since we are particularly interested in the way the
Biomedicine Convention has been received by the Member States of the European Union, we follow the structure of the Convention. The right to informed consent (articles 5, 6, 8 and 9 of the Convention) comes first, followed by different aspects of the right to private life and the right to information (article 10 of the Convention) such as: patient rights regarding the medical file, the right to medical secrecy/confidentiality and the right to privacy and protection of private life. This part of the analysis ends with the right to complain in case of unlawful infringement of a patient right (article 23 of the Convention) and the right to compensation for undue damage (article 24 of the Convention). In the next chapter we look at the rights of patients as users of genetic services: are the rights of patients complemented by more specific rights for users of genetic services? (articles 11 and 12 of the Convention). With some concluding remarks we finish this paper N° 12 of the Ethical-Legal Papers.

Without the help of Andrius Kabisaitis (Faculty of law, Vilnius University) we could not have accomplished this work. He provided us with valuable information on the status of patient rights in Lithuania and answered our questions accurately and patiently. In the footnotes we refer to the information provided by him as “personal communication of”. The possible mistakes and wrong interpretations are our responsibility. We are also aware of the limitations of this endeavor not the least because of differences in languages. Nevertheless we hope that this publication will stimulate the discussion on the promotion and protection of patient rights in Lithuania. Therefore we welcome all reactions on www.cbmer.be.

Leuven, November 2007

The research for this publication was supported by the Eurogentest Network of Excellence of the EU, FP6 – 512148 and its coordinator Prof. Dr. J.J. CASSIMAN
II. BRIEF DESCRIPTION OF LITHUANIA

§ 1. Political and legal system

Lithuania is defined as a parliamentary republic, but also with the characteristics of a semi-presidential regime. That is why the role of the President of Lithuania is somewhat different to that of the majority of other presidents of republics in Europe. He is not the head of executive power, but assumes some of its functions. The President of the Republic is elected for a period of five years and cannot carry out more than two consecutive mandates. According to the Lithuanian Constitution, the President is the head of the State and has relatively extensive powers. Among these are the designation and dismissal, on condition that the Seimas (Parliament) gives its consent, of the Prime Minister, each of the ministers and the Commander-in-Chief of the armed forces. The President also has certain powers with regard to foreign policies.

The Parliament of Lithuania, the Seimas, is a one-chamber parliament. The Seimas consists of 141 MPs who are elected for a four-year term. The Seimas elects its Chairpersons and Deputy Chairpersons.

Relations between the President of the Republic and the Seimas, are established with a view to ensuring the equilibrium and separation of the powers. On the one hand, the new Seimas is convoked to its first plenary session by the President of the Republic. On the other hand, it announces the date of presidential elections. This ensures continuity in the management of the State. One of the most important responsibilities of the President is the promulgation of laws. According to the Constitution he must sign the laws voted for by the Seimas within 10 days. If he does not agree with the law, either he does not sign it or he can make use of his right to veto it. In the case of the former, the law is signed by the President of the Seimas. If the Seimas wants to overcome the veto, it must vote for the law a second time and adopt it with a majority – a minimum of 71 votes out of 141. The President can also propose laws.
The President of the Republic’s role is very important during periods of government formation in transitional periods, (i.e. in the event of government resignation, change of ministers etc.), in other words, the President must ensure the continuity of governmental action. Even though the President is part of the executive power, unlike in France, he does not participate in Cabinet meetings. Under the Constitution, the ministers are responsible before the Seimas and the President and are directly dependent on the Prime Minister. The President is neither a member of the Government nor is he the head of the Government. Contrary to the Seimas who can initiate a questioning procedure, the President does not have effective powers (apart from his moral authority), for dismissing a minister or Prime Minister without the agreement of the Seimas.

The Lithuanian court system consists of common courts, dealing with civil and criminal matters: the Supreme Court, the Courts of Appeals, district courts and local courts. In the beginning of 1999, the system of specialised administrative courts was established to investigate administrative litigations. The latter system consists of the following courts: the Highest Administrative Court, the Higher Administrative Court, district administrative courts.

Judges of the Supreme Court are appointed by the Seimas, while judges of the Court of Appeals are appointed by the President upon approval by the Seimas. Judges of the district and local courts are appointed by the President.

The doctrine of precedent was not acknowledged in Lithuanian law. Nevertheless, the Senate of the Supreme Court, in order to promote equitable decisions, analysed court practice and adopted recommendations, which, however, were not binding on the courts as in common law countries. Now Lithuanian *stare decisis* is in process of development as from April 1998 interpretations of law in the published decisions of plenary sessions or chambers of the Supreme Court must be taken into consideration by other courts, governmental and non-governmental institutions.

The Constitutional Court of the Republic of Lithuania is not a part of the court system, but is an independent judicial body with the
authority to determine whether the laws and other legal acts adopted by the Seimas are in conformity with the Constitution, and whether the legal acts adopted by the President and the Government conform to the Constitution or laws.

§ 2. Health care system

Since 1996 the health care system in Lithuania has been in the process of moving away from an integrated model and towards a contract model. Significant changes in the system have been prompted by two major factors: the appearance of a third party payer in the form of a statutory health insurance system and the enforcement of legislation redefining property rights and the status of health care institutions. Nowadays the vast majority of Lithuanian health care institutions are non-profit-making enterprises. Public health care institutions are financed by the Statutory Health Insurance Fund (SHIF). Property rights and administrative functions fall under the jurisdiction of the central government (Ministry of Health), its ten county branches (the county administration), or the 56 municipalities. In addition to publicly provided health care, a private sector has developed, providing mostly outpatient health care services which are paid for out-of-pocket. The Ministry of Health is responsible for general supervision of the entire health care system. It is strongly involved in drafting legal acts and issuing the consequent regulation for the sector. It also runs a few health care facilities. With the decline in scope of directly administered health care institutions, maintenance and development of tertiary health care became the focus of the administrative activities of the Ministry of Health. It has an overall responsibility for the public health system’s performance. Through the State Public Health Centre it manages the public health network including ten county public health centres with their local branches.

At the regional level each of the ten counties has a County Governor who is appointed by the Lithuanian Government and is responsible for implementation of state policy in a number of spheres including health care. The health care function is carried out by the post of County Physician. Some health care providers (county hospitals, specialised
health care facilities) are governed by the county administration. Decision-making in this network of providers requires participation of the Ministry of Health. The counties are in charge of enforcement of the state health programs in their respective regions. The municipalities are responsible for providing primary health care to their local populations. They have been granted property rights for outpatient facilities and nursing homes. Municipalities are engaged in running small and medium sized hospitals within their localities, in accordance with legislation which has delegated this function to them.

The Lithuanian healthcare sector has been facing problems, some of which are inherited such as a paternalistic approach towards patients and unofficial payments, and some that have occurred as a result of technology, privatization and other modern trends in health care. Healthcare reform in Lithuania lacks the active participation of patients and the public.\(^1\)

In a recent case the European Court of Human Rights has concluded that the Lithuanian State has violated article 8 (right to private life) of the European Convention on Human Rights. The Court found that the circumstances of the case reveal a limited legislative gap in gender-reassignment surgery which leaves the applicant in a situation of distressing uncertainty vis-à-vis his private life and the recognition of his true identity. Whilst budgetary restraints in the public health service might have justified some initial delays in implementing the rights of transsexuals under the Civil Code, over four years have elapsed since the pertinent provisions came into force and the necessary legislation, although drafted, has yet to be adopted. Given the few individuals involved (some 50 people, according to unofficial estimates) the budgetary burden on the State would not be expected to be unduly heavy. Consequently, the Court considered that a fair

balance has not been struck between the public interest and the rights of the applicant.²

Lithuania inherited the soviet model of health care provision which is characterized by the dominance of bureaucracies over a whole society. In the soviet context, physicians assumed control over patients and there was no movement for patient rights. As a result, present Lithuania faces problems in terms of patients’ perceived quality of health care.³

The Parliamentary Ombudsman also has expressed his worries concerning the quality of health care services and notably the lack of publicity in discussing the failures and mistakes of doctors. It is often the case that even hospital staff avoids discussing painful incidents, and in the wider circle of specialists, failures and mistakes are not analysed systematically and taken as a lesson. On the contrary, they are not only repeated, but also become more frequent and the financial and moral damage is becoming intolerable. Only a systematic approach to mistakes and undesirable incidents will enable identification of their causes and remedies. Yet on the national level there is no system for managing undesirable incidents in the health care field (registration, recording, analysis and prevention). Creation of such a system would reduce the number of mistakes and the grave incidents in the health care system and the damage caused to patients, and would stop the growing hostility between society and the medical profession. After these recommendations of the Ombudsman, the State Medical Audit Inspectorate of the Ministry of Health would start to record, process and assess statistical data in this area.⁴

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III. GENERAL PATIENT RIGHTS

§ 1. Legal status of the Convention on Human Rights and Biomedicine


Ratified international instruments “have a direct binding character” in the Republic of Lithuania.⁵ Article 138 §3 of the Constitution of the Republic of Lithuania provides that “international treaties ratified by the Seimas (Parliament) of the Republic of Lithuania shall be an integral part of the legal order of the Republic of Lithuania”. According to KABISAITIS this means that all (italics by authors) provisions of the Biomedicine Convention may be applied directly.⁶ BIRMONTIENE shows more cautiousness as she writes: “The Constitutions of the Baltic States provide that binding international treaties take precedence in some cases (italics added by authors) over domestic law and should be respected by courts, being important sources of law”.⁷

There have been several laws passed by the Lithuanian Parliament which cover ‘bioethically sensitive’ areas of biomedicine and health care. These are, for example, the laws on patient rights (see below), transplantation of human organs and tissues⁸, mental health, critical care and diagnosing death and biomedical research. In particular, Lithuania has passed a law on ethical review of biomedical research. This law reflects the basic principles of the Biomedicine Convention.

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⁶ Personal communication A. KABISAITIS.
The Lithuanian Bioethics Committee\(^9\) gave a positive opinion on the Convention. It should be noted, however, that public debate on important bioethical issues not always reaches the level of informed and active public discourse. For example, there was no public debate on the Biomedicine Convention comparable to that taking place in Germany or the UK.\(^10\)

Lithuania did not made restrictions on the exercise of rights contained in the Convention.

\section*{§ 2. National legislation on patient rights}

The rights of patients are regulated by the Constitution of the Republic of Lithuania, the Civil Code (2000), the Law on the Rights of Patients and Compensation of the Damage to their Health (1996)\(^11\) and other laws.\(^12\)

The new Civil Code of Lithuania was adopted in 2000 and came into effect as of 1 July 2001. The health law issues regulated by the new Civil Code may be classified into two major groups. The first group deals with the rights of patients as basic human rights. The second group deals with the rights of patients as one of the essential elements of a so called “contract for health services”. These rights are also regulated in the Law on the Rights of Patients and Compensation of the Damage to their Health of 1996 that was not abrogated when the new Code came into effect. There are a lot of discussions about the application of both laws and their inter-relatedness. This problem is slightly mitigated by the fact that there are almost no essential differences in terms of the concept of these rights if we compare the Civil Code with the Law on the Rights of Patients, as they are in line with the generally accepted standards of patient rights. However, the

\begin{footnotes}
\item[9] See http://be.sam.lt/dok/eng. This website contains an English translation of the laws mentioned in this paragraph.
\item[12] \textquote{Patient Rights} on www.sam.lt/en/ (website of the Ministry of Health).
\end{footnotes}
interpretation of certain rights slightly differs. Moreover, according to BIRMONTIENE, the fact that the rights of patients are currently regulated by the Civil Code of Lithuania, should considerably belittle the significance of the 1996 law.

According to BIRMONTIENE “the Convention is an inspiration for Lithuania to legislate in this field”. Also the WHO Declaration on the Promotion of the Rights of Patients in Europe 1994 has influenced the 1996 Law on the Rights of Patients. For the working group that prepared the 1996 law it was a very big support to have a Declaration on the Promotion of Patient Rights in Europe. Consequently many provisions of the Lithuanian draft law were based on this Declaration. It is also interesting to note that the regulation of the patient rights in the Civil Code as one of the elements of a contract for reimbursable services can be regarded as an example of the reception of the Dutch civil law by Lithuania. (See also in this respect Estonia)

The implementation of laws is a complicated process and requires resources, time and the fulfillment of preconditions necessary for legislation to function in a specific country. A major proportion of Lithuanian respondents from a representative sample believed that patient rights had not been implemented and more than 40% said that the rights to information and privacy had not been implemented. There is no independent mechanism to defend the rights of patients.

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13 T.BIRMONTIENE, “Changes in the Lithuanian Health Law and the Influence of the Netherlands Civil Code”, European Journal of Health Law 2002, vol. 9, n°4, 381, 385, 386. See also p. 387-388 : “the provisions of the law on the rights and injuries of patients are currently being harmonized with the provisions of the Code, because the law should not provide for a different, less-favourable regulation for individuals than the code”. According to our information this harmonization is not yet finished.


According to RIDER and MAKELA “Lithuania’s comprehensive law does not address the patient’s right to information, choice, voice, environmental health, dignity, privacy or confidentiality. Neither consumer responsibilities nor enforcement of patient’s rights are included. The focus of the law is on non-discrimination (care available to all) and redress/remedy”. While the latter is correct, the first sentence thus not reflects correctly Lithuanian law (see below).

§ 3. Right to informed consent

<table>
<thead>
<tr>
<th>Article 5 of the Biomedicine Convention:</th>
</tr>
</thead>
<tbody>
<tr>
<td>An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.</td>
</tr>
<tr>
<td>This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks.</td>
</tr>
<tr>
<td>The person concerned may freely withdraw consent at any time.</td>
</tr>
</tbody>
</table>

A. Right to informed consent as a basic requirement

The right to informed consent is formulated in a negative way in both the Law on Patient Rights and the Civil Code. Article 8 of the Law on Patient Rights provides that a patient may not be treated or be provided any other health or nursing care against his will while article 6.729 (1) of the Civil Code also stipulates that the patient may not be treated or be provided any other healthcare and/or nursing against his will, unless otherwise established by legislation.

B. Contents of information preceding informed consent

According to article 6 (4) of the Law on Patient Rights a physician, in providing information regarding the treatment, must explain to the

patient the course of the treatment, possible results of the treatment, possible alternative methods of treatment and other circumstances, which may have an effect upon the patient’s decision to accept or refuse the proposed treatment and also the possible consequences of refusal of the proposed treatment.

According to article 6.727 of the Civil Code the provider of personal healthcare services must inform the patient, in a form comprehensible to the latter and with an explanation of the special medical terms involved, of the condition of his health, disease diagnosis, possible treatment methods, prognosis of the treatment and other circumstances which may have an effect upon the patient’s decision to consent or refuse the proposed treatment, as well as of the effects, in case the patient would refuse the proposed treatment.

According to the Human Rights Monitoring Institute the patient’s right to receive information has been further violated. The patient is rarely provided with easily-understood terminology and explanation of diagnoses, potential side-effects of medicines, alternative methods and likely prognoses.¹⁹

C. Form of informed consent

Lithuanian law does not require a written form as a general requirement for a patient’s consent.²⁰ According to article 6.729, second sentence of the Civil Code the laws may provide for the cases where a written consent of the patient is required for the provision of healthcare services to the patient. An example can be found in article 2.25 (2) of the Civil Code itself that provides “consent to a surgical operation shall be given in writing”. The same article requires a written consent for medical experiments and removal of organs and body parts.

Furthermore article 6.730 (1) Civil Code states the following: “The provider of personal healthcare services must include information on all actions undertaken (personal healthcare services), to which the patient has given his consent, into the medical documents of the

²⁰ Personal communication A. KABISAITIS.
patient, and the patient or his representative must attest these documents by their signature”.21

D. Exceptions to the requirement of informed consent

**Article 8 Biomedicine Convention**

*When because of an emergency situation the appropriate consent cannot be obtained, any medically necessary intervention may be carried out immediately for the benefit of the health of the individual concerned.*

Article 8 (3) of the Law on the Rights of Patients relates to the case that the patient is unconscious or that his will cannot be known for some other reason and that a serious threat is being posed to his life or health. In such a case vital (first or urgent) medical assistance must be rendered without his consent. Article 8 (5) deals with the situation that in an urgent situation the consent of the legal representative of the patient cannot be obtained in time or that the legal representative refuses to give his consent, while according to the treating physician or nursing staff member, the rendering of medical assistance is in accordance with the interests of the patient. Also in such a case the vital medical assistance may be given without the consent of the legal representative. Article 6.745 of the Civil Code contains a comparable provision as article 8 (5) of the Law on the Rights of Patients: “Where pursuant to article 6.744 of this Code, instead of the patient’s consent, the consent of the person indicated in the said article is required for the provision of healthcare services, the services may be provided without the consent of such person provided that there is insufficient time to receive the consent of the said person in cases where immediate action is needed to save the life of the patient”.

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21 According to the personal communication of A. KABISAITIS this equals a written consent although it might also be the case that the consent of the patient and his signature are only included in his file after the medical activity has intervened in which case it is not equal to a written consent that has to be given in advance.
E. Refusal and withdrawal of consent

According to article 8 (4) of the Law on the Rights of Patients patients have the right to withdraw a consent in a written form at any time. Article 8 of this law is titled “the right to refuse treatment”. Thus, also the right to refuse is explicitly recognised. Article 6.739 (2) of the Civil Code provides: “The patient shall have the right to terminate the contract at any time”. No formal requirements are provided for.

F. Previously expressed wishes

**Article 9 Biomedicine Convention**

>The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.

There is no regulation in Lithuanian health law which provides for previously expressed wishes.

According to article 9 of the Biomedicine Convention they have to be taken into account.
G. Informed consent in case of minor patients

**Article 6 Biomedicine Convention**

1. Subject to Articles 17 and 20 below, an intervention may only be carried out on a person who does not have the capacity to consent, for his or her direct benefit.

2. Where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.

The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.

With respect to the legal position of minor patients there is a clear difference between the regulations in the Law on the Rights of Patients and the Civil Code. First of all, article 1 (2) of the former law stipulates that a minor is a patient younger than 18 years whereas the Civil Code explicitly states that a minor who has reached the age of 16 may consent himself to treatment. Indeed, article 6.726 (1) of the Civil Code stipulates: “A minor who has reached the age of 16 may in his own name enter into the contract for personal healthcare services and perform other legal actions directly related to such a contract”. Thus, according to the Civil Code, medical majority exists once the minor has reached the age of 16. As the Civil Code is more recent than the Law on the Rights of Patients it should take priority.\(^2\)

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\(^2\) L.STULTIENS, et al., “Minors and Informed Consent”, *European Journal of Health Law* 2007, vol. 14, n°1, 30-33. According to the personal communication received from A. KABISAITIS, article 8 § 1 of the Law on the Rights of Patients does provide for a medical majority rule as of 16 years as it reads “Patients as well as those aged between 16 and 18, may be treated or provided any other healthcare and/or nursing only with the consent of the patient.” This version of article 8 § 1 has not been reflected in the official translation of the Law on the Rights of Patients and Compensation for the Damage to their Health of 1996 published on the website of the Lithuanian Parliament (“Seimas”) to be consulted on: http://www.lrs.lt.
If a patient has not reached the age of 16, the health care provider must fulfill his obligations towards the parents of the minor or towards the guardian [article 6.744 (1) Civil Code]. This will also be the case if a minor, although having reached the age of 16 years, is considered not to be capable of reasonably appraising his interests [article 6.744 (2) Civil Code]. However, if such a patient objects to the provision of health care services to him (to which his parents have already given their consent) health care services may only be provided if this is necessary in order to avoid serious harm to the patient [article 6.744 (6) Civil Code]. Patients who are younger than 16 years may not be treated or be provided any other healthcare and/or nursing against the will of one of the parents or their statutory representative, unless the law provides otherwise. Also, if their age and the level of development permit a correct appraisal of the condition of their health and proposed course of treatment, patients younger than 16 years may not be treated against their will unless the law provides otherwise [article 6.729 (2) Civil Code]. Thus, according to the Civil Code, below the age of medical majority the competence of a minor in health matters should be evaluated on a case-by-case basis.

The Law on the Rights of Patients provides in this respect: “A minor patient, 23 who in the opinion of the physician is capable of accurately appraising the condition of his own health, shall have the right to independently initiate and decide the treatment that has been proposed for him. Upon request by the parents or custodians of the minor patient, the treating physician must advise the legal representatives of the minor, regarding the treatment. However such information may also remain withheld, with the minor having requested this, if this might harm the interests of the minor patient considerably, or if other laws do not establish otherwise. If the minor is hospitalised, his parents or custodians must be advised of this” [article 6 (8) Law on the Rights of Patients]. And: “A minor patient must be informed of the treatment and, with his age and level of development permitting a correct appraisal of the status of his health and proposed course of treatment (the treating physician shall decide this), the minor may not be treated against his will, unless provided otherwise by the laws of the Republic of Lithuania. The physician shall select the methods of

23 In view of the Civil Code the definition of a “minor patient” in the Law on the Rights of Patients is now to be read as not having reached the age of 16.
treatment which shall most suit the interests of the minor” [article 8 (2) Law on the Rights of Patients].

Regarding the provision of information the Law on the Rights of Patients furthermore stipulates that “information to a patient who is a minor, his parents and guardians must be furnished in a form comprehensible to them. If differences are present between the minor and his parents or guardians, the treating physician, in presenting the information, must be guided by the interests of a patient who is a minor” [article 6 (7) Law on the Rights of Patients].

In case the legal representative of a minor refuses to give consent the Law on the Rights of Patients stipulates: “Should the legal representative of a patient refuse to give his consent for treatment, which is not urgent and the treating physician be of the opinion that the treatment being provided is in the interests of the patient, the medical ethics commission of the health care institution or the Committee for Medical Ethics of Lithuania has the right to give consent for such treatment. The administration of the health care institution or the treating physician shall have the right to appeal to this commission or committee” [article 8 (6) Law on the Rights of Patients]. The Civil Code contains more general provisions in this respect: “The provider of personal healthcare services shall fulfill his obligations to the patient’s statutory representatives as provided for in paragraphs 1 and 2 of this Article, as well as to persons listed in paragraph 3 above, provided that the fulfillment of such obligations complies with the degree of care that is expected from an honest provider of personal healthcare services” [article 6.744 (4) Civil Code]. “The person established in this section, to which the provider of personal healthcare services must discharge his obligations pursuant to paragraph 2 or 3 of this Article, must act with such care which is expected from an honest representative. In the discharge of his obligations the person must involve the patient as much as possible.” [article 6.744 (5) Civil Code].

In case of an emergency situation, medical assistance may be provided without consent of the legal representative if consent cannot be obtained in time or if the legal representative refuses to give consent. It must concern required (first aid or urgent) medical assistance which — according to the treating physician or nursing staff member — is in the interests of the patient [article 8 (5) Law on the Rights of Patients].
The Civil Code contains the following provision regarding emergencies: “[..] the services may be provided without the consent of such person [legal representative] provided there is insufficient time to receive the consent of the said person in cases where immediate action is needed to save the life of the patient” [article 6.745 Civil Code].

H. Informed consent in case of incapacitated adults

**Article 6 Biomedicine Convention**

1. Subject to Articles 17 and 20 below, an intervention may only be carried out on a person who does not have the capacity to consent, for his or her direct benefit.

3. Where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law. The individual concerned shall as far as possible take part in the authorisation procedure.

Article 6.744 (3) Civil Code provides the following in this respect: “when an adult patient may not be considered as being reasonably capable of appraising his interests, and neither a curator nor a guardian has been appointed in respect of such person, all obligations of the provider of personal healthcare services to the patient have to be discharged to the person who is authorised in writing by the patient to act on behalf of the patient. In the absence of the authorised person or on failing by the authorised person to take the necessary actions, the obligations have to be discharged to the patient’s spouse or partner. In the absence of the patient’s spouse or partner or when he/she refuses that, the obligations have to be discharged to the patient’s parent or child, unless he/she refuses that.” The Law on the Rights of Patients does not contain a comparable provision.

According to article 6.744 (4) Civil Code the provider of personal healthcare services has to fulfil his obligations to the persons listed in
the previous paragraph provided that the fulfillment of such obligations complies with the degree of care that is expected from an honest provider of personal healthcare services. And also the representative of the patient to whom the provider of personal healthcare services must discharge his obligations must act with the degree of care which is expected from an honest representative [article 6.744 (5)]. The combination of article 6.744 (4) and (5) authorises the physician to deviate from the decision taken by the representative of the patient if according to the physician this decision does not correspond to what an honest representative would have decided. This seems to be a much more flexible regulation of conflicts between a representative of a patient and the physician than the one contained in the older Law on the Rights of Patients. Article 8 (6) of that law provides that when the legal representative refuses to give his consent for a treatment which is not urgent while the treating physician is of the opinion that it is in the interests of the patient that the treatment is provided, the medical ethics commission of the health care institution or the Committee for Medical Ethics of Lithuania has the right to give consent for such treatment at the request of the management of the health care institution or the treating physician. Probably the more practical rules contained in the Civil Code have now precedence.

The final sentence of article 6.744 (5) Civil Code provides that in the discharge of his obligations the representative of an incompetent patient must involve the patient as much as possible. This is in line with article 6 (3), last sentence of the Biomedicine Convention. This requirement is less stronger than the one contained in article 8 (6) of the Law on the Rights of Patients: “if the patient objects to the provision of healthcare services to him, to which his representative had already given their consent, such services may be provided only if this is undoubtedly required for the purpose of avoiding serious harm to the patient.”
§ 4. Right to information about his or her health

### Article 10 Biomedicine Convention

2. Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.

3. In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraph 2 in the interests of the patient.

A. Right to information about his or her health as a basic requirement

The right of the patient to information about his or her health is regulated as a basic requirement in article 6 (1) of the Law on the Rights of Patients and article 6.727 (1) Civil Code, both cited above.

B. Right not to know

Article 6 (4) of the Law on the Rights of Patients recognizes the so-called right not to know: “The information should not be supplied to the patient against his will; however, his will must be clearly expressed and his medical file should contain a mention of his wish.” Also article 6.727 (1) Civil Code accepts the right not to know, be it in different terms: “The information provided for in paragraph 1 of Article 6.727 of this Code shall not be provided to the patient against his will. The will of the patient must be clearly expressed and attested by his signature”. Thus, instead of a clearly expressed will and a reference in the medical file, the Civil Code requires a written and signed request.

This right not to know is not an absolute one. According to article 6.728 (2) Civil Code: “the restrictions on the provision of information to the patient, as provided for in paragraph 1 above, shall not apply where the patient’s reluctance (refusal) to receive information may result in harmful effects upon the patient or other individuals”.

Thus,
either in the interest of the patient himself or in the interest of others the right not to know has not to be respected. The Law on the Rights of Patient does not contain a comparable provision so that under this law the right not to know has always to be respected. Once more however, the Civil Code will take probably precedence over the Law on the Rights of Patients, being more recent and also more specific.

C. Therapeutic exception

Article 6.727 (2) Civil Code clearly contains the therapeutic exception. A provider of personal healthcare services has the right – thus not an obligation - to withhold the information mentioned in article 6.727 (1) (see A) from the patient only in those instances where such notification would have a detrimental effect upon the patient (id est, would cause harm to the health of the patient or even endanger his life). In such instances, all such information has to be submitted to the patient’s representative\(^\text{24}\) and is considered as information supplied to the patient. The said information has to be communicated to the patient as soon as the risk of causing the said harm to the patient by the notification of such information is eliminated.

On its turn, article 6 (5) of the Law on the Rights of Patients provides that: “if the patient so desires, he must be supplied with the history of his illness or other medical documents, with the exception of instances wherein this may have a basic effect upon the patient’s health and even endanger his life (this shall be decided by the physician treating him, or a physicians’ consilium). In such instances, the treating physician shall note in the disease case history the limitations of the supply of information”. This seems more a restriction of the right to access the medical file (see below) than a restriction of the right to information \textit{sensu strictu}.

\(^{24}\) We have reasons to presume that this is an incorrect translation and that in fact reference is made to a person of confidence or the like. When a patient is incompetent the question of therapeutic exception does not arise.
§ 5. Patient rights regarding the medical file

**Article 10 Biomedicine Convention**

1. *Everyone has the right to respect for private life in relation to information about his or her health.*

2. *Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.*

A. Right to a medical file

The right of the patient to a medical file is formulated in terms of an obligation for the healthcare providers both in the Civil Code and in the Law on the Rights of Patients. Article 6.733 Civil Code (titled: “necessity of patient’s medical documents”) states that “providers of personal healthcare services must keep at their disposal (process and fill in) patients’ medical documents of the established form and type (patient history, other medical documentation), fill in the said documents and store them in accordance with the procedure prescribed by laws”. Article 11 of the Law on the Rights of Patients contains a very comparable provision.

B. Contents of the medical file

No regulations on the content of the medical file were found.

C. Right to access and copy the medical file

i. Right to access the medical file

Article 6.735 (1) Civil Code gives the patient a right to access his medical file although at a first reading it is more formulated as a right to obtain the original documents. According to article 6.735 (1) the patient shall, at his request, be provided with all his medical documents. Also in this case a therapeutic exception might be
invoked: “with the exception of the cases when this may be harmful to the patient’s health or even endanger his life. In the said instances, the restrictions on the provision of information shall be noted in the medical documents of the patient”.

Article 6 (5) of the Law on the Rights of Patients – already cited at p.19 - contains a similar provision.

Lithuanian law does not require any mediation or involvement of any professional to get access to medical records; the patient has the right of direct access to all documents.25

ii. Right to copy the medical file

According to article 6.735 (2) Civil Code a patient has the right to request that copies of his medical documents be made against payment of the cost of it. This right of the patient may be restricted only in accordance with the procedure prescribed by law. The provider of personal healthcare services must explain to the patient the meaning of the records contained in his medical documents.

iii. Post mortem access by relatives

No regulations on post mortem access by relatives were found.

D. Right to correction, erasure and/ or destruction

With regard to the destruction of a medical file at the request of the patient, article 6.734 (1) Civil Code provides that a provider of personal healthcare services has to destroy the medical file within a period of three months after the destruction is requested by the patient, with the exception of derogations established by the relevant laws. According to article 6.734 (2) Civil Code this right does not apply if the request for destruction concerns stored documents which may reasonably be considered as having a certain legal or medical value to other individuals than the patient, as well as in cases where the destruction of the documents is forbidden by the relevant law.

25 Personal communication of A. KABISAITIS.
With regard to correction and erasure, article 6.735(2) Civil Code that has already been cited above in relation to the right to have a copy of the medical file, provides in its last sentence: “If the request of the patient is based on reasonable grounds, the doctor must rectify, complete, eliminate, clarify and (or) change the inaccurate, not exhaustive or equivocal data, or the data which is not related to the diagnosis, treatment or nursing”.

§ 6. Right to medical secrecy/ confidentiality

**Article 10 Biomedicine Convention**

1. *Everyone has the right to respect for private life in relation to information about his or her health.*

A. Right to medical secrecy and confidentiality as a basic requirement

Article 6.736 (1) Civil Code stipulates that the provider of personal healthcare services may not furnish any other persons with the information on the patient without the latter’s consent and may not give access to copies of the medical documentation referred to in article 6.733 of the Code. If information is nevertheless provided to other persons, it may be provided in so far as this does not cause any harm to the private life of the patient or any other person. Information on the patient must be furnished if the provision of information is prescribed by law.

In line with this, article 10 (2) of the Law on the Rights of Patients provides that: “all the information concerning the condition of the patient’s health, diagnosis, prognosis and treatment, and also all the other information of a personal nature concerning the patient, must be held as confidential, even after the patient’s death. The laws of the Republic of Lithuania and legal acts of the Ministry of Health shall determine the procedure of safe keeping of such confidential information. Confidential information may be furnished to other
individuals, only upon the written consent of the patient, or if this is stipulated by this and other laws of the Republic of Lithuania”.

Although the law provides for the right to protection of confidential information, an absence of detailed regulations obstructs its implementation in practice. This leads to situation in which physicians may be unsure of how to protect patients’ confidentiality.26

B. Disclosure of medical information to a third party

With regard to the disclosure of medical information to a third party, it follows from the articles cited under A that the (written) consent of the patient is required as a rule (unless the privacy of the patient is not harmed or a law allows or obliges the disclosure). Moreover both the Civil Code and the Law on the Rights of Patients allow for the disclosure of medical information without the consent of the patient in the following case.

Article 6.736 (2) Civil Code stipulates that persons directly participating in the performance of the contract for the provision of healthcare services as well as the person who acts as an auxiliary of such persons, provided that the information is necessary to act as an auxiliary, are not to be considered as “other persons” in the sense of article 6.736 (1). According to article 6.736 (3) Civil Code the same holds for those persons whose consent for the provision of personal healthcare services is required in accordance with article 6.729 and 6.744 of this Code, in other words the legal representatives of the patient.

Article 10 (3) of the Law on the Rights of Patients contains a comparable provision.

§ 7. Right to privacy/ protection of private life

Article 10 Biomedicine Convention

1. Everyone has the right to respect for private life in relation to information about his or her health.

According to article 10 (1) of the Law on the Rights of Patients the private life of patients is inviolable.

Article 6.738 Civil Code deals with another aspect of the right to protection of private life. A provider of personal healthcare services has to provide services in the absence of other persons unless the patient has expressed his consent to the presence of external observers at the time of the provision of healthcare services. Persons whose professional assistance is required for the provision of healthcare services under the contract are not considered as “other persons”.

A. Processing of data concerning health

Processing of personal data is regulated by the Law on the Legal Protection of Personal Data of 21 January 2003, as amended on 13 April 2004. Article 5 (2) prohibits to process special categories of personal data of which health data are part, save when the data subject has given his consent. According to article 5 (3) the data about a person’s health may also be processed for the purposes and in the manner specified by article 10 of this law and the laws pertaining to health care. Article 10 (1) provides that personal data on the person’s health may be processed by an authorised health care professional, subject to professional secrecy under the Civil Code, the laws regulating the health care system or patient rights and other legal acts.

B. Right to access and right to receive a copy

Article 19 (2) of the Law on the Protection of Personal Data deals with the data subject’s right of access to his personal data and to receive a copy: “Upon request of the data subject concerning the processing of his data, the data controller must provide to the data subject the requested data within 30 calendar days of the date of the receipt of the data subject’s enquiry. On request such information must be provided to the data subject in writing. Once a calendar year the data controller shall provide such information to the data subject free of charge. When such information is disclosed for a fee, the amount of the fee shall not exceed the expenses of the disclosure of the data.”

According to article 23 the State Data Protection Inspectorate assists the data subject in exercising his right of access to his personal data. According to the Human Rights Monitoring Institute this Inspectorate is part of the Executive Branch and therefore lacks independency. An independent data protection agency has yet to be established.28

C. Right to correction, erasure and/or destruction

Article 20 of the Data Protection Law regulates the data subject’s right to request rectification, destruction or restriction of further processing of his personal data:

“1. Where the data subject, after access to his personal data, finds that his data are incorrect, incomplete and inaccurate and applies to the data controller, the latter must check the personal data without delay and, at the request of the data subject, oral or written or in any other form, immediately rectify the incorrect, incomplete and inaccurate personal data and/or restrict further processing of such personal data except its keeping.

2. Where the data subject, after access to his personal data, considers that his data are processed unlawfully and unfairly and applies to the data controller, the latter must check without delay and free of charge the lawfulness and fairness of the processing of personal data and, at the data subject’s request in writing, immediately

destroy the personal data collected unlawfully and unfairly or restrict further processing of such personal data except its keeping.

3. When, upon the request of the data subject, further processing of his personal data is restricted, the personal data further processing of which has been restricted must be kept until their rectification or destruction either at the request of the data subject or upon expiry of the period of their keeping. Any other actions of processing of such personal data may be performed solely:
   1) for the purposes of giving proof of the circumstances due to which further processing of the data was restricted;
   2) where the data subject gives his consent for the further processing of his personal data;
   3) where the rights or legitimate interests of third parties have to be protected.

4. The data controller must immediately notify the data subject of the performed or not performed rectification, destruction of the personal data or restriction of their further processing in response to the application of the data subject.

5. Personal data shall be rectified and destroyed or their further processing shall be restricted in response to the application of the data subject and on the basis of documents confirming his identity and his personal data.

6. If the data controller questions the correctness of the personal data submitted by the data subject, he must restrict further processing of such personal data, check the data and update them. The contested personal data may be used solely for checking their correctness.

7. The data controller must inform forthwith data recipients of the personal data rectified or destroyed and of the restriction of further processing at the request of the data subject except where providing such information might be impossible or too difficult due to an excessively large number of the data subjects, the period covered by the data and unreasonably high costs. If such is the case, the State Data Protection Inspectorate must be immediately notified.”
§ 8. Right to complain and to compensation

A. Right to complain

**Article 23 Biomedicine Convention**

*The Parties shall provide appropriate judicial protection to prevent or to put a stop to an unlawful infringement of the rights and principles set forth in this Convention at short notice.*

Article 9 of the Law on the Rights of Patients contains rules regarding the right to complain. A patient who is dissatisfied with the health care provided has the right to complain to an administrative staff member of the health care institution, who is responsible for health care within this institution. The staff member of the institution must reply to the complaint of the patient within five working days. A patient has also the right to lodge a complaint against a health care institution before the Ministry of Health, other controlling institutions and the courts.

In the Annual Report on 2006 the Parliamentary Ombudsman notes “that patients are filing more complaints about the negligent work of medical personnel. Patients start litigation in which they claim compensation for damages or seek the assistance of the Seimas Ombudsmen’s Office after facing indifference of doctors and administrators”.29

B. Right to compensation

**Article 24 Biomedicine Convention**

*The person who has suffered undue damage resulting from an intervention is entitled to fair compensation according to the conditions and procedures prescribed by law.*

Chapter 4 of the Law on the Rights of Patients (called: “Principles and procedures for compensation of damage inflicted upon the patients’ health”) contains very detailed rules with regard to the compensation of damage caused by the provision of health care. Article 14 (1) defines the damage that can be compensated under the compensation scheme. It regards damage that has resulted as a consequence of the treatment of patients or medical research; that has resulted due to infection or inflammation in connection with the examination or treatment of patients; that has resulted from a diagnostic procedure or incision, if this gives rise unfoundedly, to long-term health disorders or that has resulted from structural shortcomings in the medical equipment or upon malfunctioning of the medical equipment or something similar. According to article 14 (2) the consequences of a treatment based upon universally accepted principles or standards of medical practice and science, which could not have been avoided through the use of an equally effective method of treatment, is not considered as damage inflicted upon a patient. Also, according to article 14 (3) the damage suffered by a patient as a result of the culpable actions of a physician or a nursing staff member are compensated in accordance with the procedure established by the Civil Code. This means that this kind of damage is still governed by the principles of classic civil liability (fault – damage - causation).
IV. RIGHTS OF USERS OF GENETIC SERVICES

§ 1. Introductory remark

In Lithuania, genetic testing is mainly regulated through the legal framework that applies to health services as a whole. The regulations on patient rights are mutatis mutandis applicable as rights of users of genetic services. Because of the ratification of the Biomedicine Convention, this Convention is now part of Lithuanian positive law and binding for any relevant legislative initiative pursuant to article 138 §3 of the Constitution. In this respect, the provisions of the Convention related to genetic services30 are applicable.

A. Informed consent

The right of a patient to consent to diagnostic procedures (such as genetic tests) is established by article 8 of the Law on Patient Rights and article 6.729 (1) of the Civil Code. Patients have the right to refuse or withdraw their consent. Both laws also guarantee the right to be informed prior to giving consent.

30 See V. KUCINSKAS, “Medical genetics in Lithuania”, European Society of Human Genetics, May 2004, Newsletter N° 10. He writes: “The Act N° VIII-1679/2000 has passed a law on bioethics, which regulates genetic testing in humans. Genetic testing in Lithuania can only be carried out for medical, scientific or forensic purposes. Essential precondition for genetic testing for diagnostic and/or research procedures is a written informed consent obtained from the individual or his/her legal representative”. In the English version of the law on ethics of biomedical research no specific rules related to genetic testing can be found. See www.lrs.lt.
B. Right to information

The right of the patient to information about his or her health is regulated as a basic requirement in article 6 (1) of the Law on the Rights of Patients and article 6.727 (1) Civil Code. Article 6 (4) of the Law on the Rights of Patients recognizes the so-called right not to know: “The information should not be supplied to the patient against his will; however, his will must be clearly expressed and his medical file should contain a mention of his wish”. Also article 6.727 (1) Civil Code accepts the right not to know, be it in different terms: “The information provided for in paragraph 1 of Article 6.727 of this Code shall not be provided to the patient against his will. The will of the patient must be clearly expressed and attested by his signature”. Thus, instead of a clearly expressed will and a reference in the medical file, the Civil Code requires a written and signed request.

This right not to know is not an absolute one. According to article 6.728 (2) Civil Code: “the restrictions on the provision of information to the patient, as provided for in paragraph 1 above, shall not apply where the patient’s reluctance (refusal) to receive information may result in harmful effects upon the patient or other individuals”. Thus, either in the interest of the patient himself or in the interest of others the right not to know has not to be respected. The Law on the Rights of Patients does not contain a comparable provision so that under this law the right not to know has always to be respected. However, the Civil Code will take probably precedence over the Law on the Rights of Patients, being more recent and also more specific.

C. Right to privacy

Apart from article 10 of the Biomedicine Convention pertaining specifically to the protection of personal information which applies in Lithuanian law, the law on Data Protection of 2003/2004 is applicable. Lithuanian law does not single out genetic information as a distinct
data group. It seems that genetic information is covered by the regulations covering health data.  

§ 2. Prohibition of discrimination on grounds of genetic heritage

Article 11 Biomedicine Convention

*Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited*

Article 29 of the Constitution of the Republic of Lithuania provides that “all persons shall be equal before the law, the courts and any other State institutions and officers. No one’s rights may be restricted nor any privileges may be granted to anyone on any grounds such as sex, race, nationality, language, origin, social status, religion, convictions or opinions”.

According to article 3 (1) of the Law on the Rights of Patients these rights may not be restricted in health care institutions because of gender, age, race, nationality, language, social status, faith, beliefs or convictions.

§ 3. Use of predictive genetic tests

Article 12 Biomedicine Convention

*Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling.*

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No specific legislation for genetic testing exists. Like other provisions of the Biomedicine Convention, article 12 is directly applicable in Lithuania.

Article 100 (1) of the Law on Insurance of 18 September 2003 prohibits an insurer from requesting in any form the policyholder, the insured person and other persons to provide to him genetic data.
V. CONCLUDING REMARKS

1. Lithuania has signed and ratified the *Convention* which entered into force on 1 February 2003.

2. Lithuania belongs to three Central-East EU Member States where the Biomedicine Convention already had *a significant impact* upon patient rights legislation and policies before the ratification: Estonia, Hungary and Lithuania. A privileged witness has testified that the Convention was already before the ratification “an inspiration for Lithuania to legislate in this field”.

3. Compared to other EU Member States the available information in English on the status of the rights of patients and users of genetic services is rather limited. Nonetheless we may conclude that Lithuanian law on the protection of patient rights is in general *in accordance to the Biomedicine Convention*. This is not a surprise given that the provisions in the new Civil Code, which came into effect in July 2001, have been inspired by the Dutch Medical Treatment Act. The Law on the Rights of Patients and Compensation of the Damage to their Health (1996) is still applicable but its significance is belittled by the fact that patient rights are governed by the new Civil Code.

4. The *implementation of laws* is a complicated process and requires resources, time and the fulfillment of preconditions necessary for legislation to function in a specific country. A major proportion of Lithuanian respondents from a representative sample believed that patient rights had not been implemented and more than 40% said that

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the rights to information and privacy had not been implemented.35 There is no independent mechanism to defend the rights of patients.36 Also the independence of the State Inspectorate for Data Protection has been questioned.37

5. Lithuania has no specific law on genetic testing. The patient rights provisions in the Civil Code are mutatis mutandis applicable to users of genetic services.

6. Article 100 (1) of the Law on Insurance of 18 September 2003 prohibits an insurer from requesting in any form the policy holder, the insured person and other persons to provide him genetic data.


