# Legal Regulation of the Right to Information About One's Health

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#### ABSTRACT

The article is devoted to the private-legal study of the right to information on health, taking into account recent changes in the material, the doctrine of information as the object of rights in general and the right to information on health. The author's definition of «information about the state of their health» is given, the notion «producers of information about the state of health» is developed. The object of the right to information on the state of one's health with an emphasis on the information itself and the right to it was investigated, the specificity of the subjective right to information about the state of his health was revealed; The concept and content of the right to information on the state of one's health, as well as the grounds for their appearance, are detailed. The general provisions on the exercise of such rights are defined, the limits and limitations on their implementation, forms, means and means of protection of the right to such information are determined.

#### **INTRODUCTION**

The procedure and features of exercising such a subjective right as the right to information on the state of one's health are quite important for understanding it. It is confirmed by the fact that the satisfaction of the needs of an individual in information about the state of their health is not the result of the existence of this right but the result of the commission of certain actions that should be directed to it. Thus, the practical value of any person's rights is the ability to transform the possibilities defined in the norms of law (the content of law) into reality.

However, the exercise of certain powers arising from the content of the law cannot take place in a chaotic, disordered, and spontaneous manner, that is why the legislator imposes certain requirements, which are obligatory for their consideration when exercising the right to information on the state of one's health, as well as to its bearer. That is the implementation of the rules of law in the activities of the subjects of the right to information on the state of their health by observing: prohibitions, the usage of subjective rights, the fulfillment of legal obligations (legalization), as well as the requirements of ethics, principles of reasonableness and justice, secrecy, and professional responsibilities.

#### MAIN TEXT

The exercise of the right to information on one's health is a rather complex process that takes place in time. It involves not only parties, the bearers of subjective rights and responsibilities, but also the state in the person of Keywords: subjective right; secrecy; turnover; information; health; the exercise of rights.

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various bodies: law-making, law-executing, lawenforcing. Thus, the exercise of the right to information on the state of the health is of certain types:

- a direct realization, when the subjects of law independently, without any external intervention or assistance, implement the rules provided by the norms of law, in their behavior, perform certain subjective legal obligations (exercise the right to information on the health with the help of technical means of collecting information at home (measuring blood pressure, pulse, etc.), data mining;

- a law-enforcing realization, which takes place when subjective rights and legal obligations cannot be realized without additional intervention, assistance from other subjects (in certain cases - when the realization of the right to information on the state of one's health is impossible without the help of health care bodies that provide medical information about the state of health of a certain person as a result of conducting certain inspections, carrying out courses of treatment, rehabilitation; and also in the cases provided by law when a minor is limited in capacity, then in accordance with Part 2 of Art. 285 of the Civil Code of Ukraine, parents (adoptive parents), guardians, tutors are involved in order to exercise the right to information on the state of one's health.

In case when the subjects of the right to information on the state of the health independently exercise it and perform legal duties, the realization of such a right can be presented in two main forms: active (active actions for the implementation of this right); passive (assumes the implementation of the norms containing prohibitions, due to the retention of the subject from the actions for which legal responsibility is established). According to Part 2 of Art. 11 of the Law of Ukraine "On Information", it is not allowed to collect, store, use, and disseminate the confidential information about a person without their consent, except in cases specified by law, and only in the interests of national security, economic welfare, and protection of human rights.

Thus, the notion of "exercising the right to information on one's state of health" should be understood as all possible forms of behavior of the subject of the right to information on one's state of health (both active and passive) that are aimed at the implementation (direct and law-enforcing) of certain powers, namely: to seek medical help and record the consequences and reasons for treatment; to get acquainted with it and to demand the corresponding explanations; to collect (search) and systematize; to oppose in case of doubt; to use to improve one's health and to exercise other rights, where such information is integral; to distribute by providing to others, if necessary; to store and protect information about the state of one's health; to protect such information from an unlawful acquaintance, usage and dissemination. It is envisaged to exercise this right fully or partially but in the form prescribed by law.

Given the above, we believe that the exercise of the right to information on one's health is impossible without the presence of a certain existing health care system and information that embodies it in life and transforms it from the sphere of the proper into the sphere of the existing. As noted in the legal literature, the existence of a scientific problem is indicated by the presence of contradictions between the spheres of "proper", "existing", and "knowledge of existing and proper". In general, taking such an approach, we methodologically build our research in the same sequence (the sphere of "proper", "existing", and "knowledge of existing and proper") [1].

Existing ( $\delta v \tau \sigma \varsigma$ ) is translated from Greek as that which exists (is). In turn, in accordance with the exercise of the right to information on the state of one's health, this is what is true, it is a ready-made legal reality, reflected in the norms of law, which are mandatory to take into account in the exercise of the aforementioned right. Proper (appropriate), according to the Academic Interpretive Dictionary, is what it should be, it is the ideal construction of the future, necessary legal reality. In the legal sphere, the question of "as is" and "as it should be" has always been raised and compared, an analysis of interconnection, mutual coordination, as well as the existing discrepancy in the current legal norms of the existing and the proper has been carried out. In order to determine the discrepancy between the existing and the proper in the exercise of the right to information on the state of one's health, it is necessary to analyze the essence of what is existing and what is proper in considering the exercise of this right, taking into account the practice of exercising the right to information on one's state of health - the sphere of "knowledge of the existing and the proper".

Thus, the right of an individual to information about the state of their health is enshrined in the Law of Ukraine "On Protection of Personal Data", the Civil Code of Ukraine, in the Basics of Legislation on Health of Ukraine and other normative-legal acts, is a positive right, which is exercised by a person independently or on a professional basis through professionals.

First of all, it should be noted that in Ukraine, when applying to health care facilities, an individual (patient) agrees to the processing of their personal data in accordance with the Law of Ukraine "On Protection of Personal Data". According to it, the consent of the subject of personal data is a voluntary expression of the will of the individual (on condition of their awareness) regarding the granting of permission for the processing of their personal data in accordance with the stated purpose of its processing, expressed in writing or in a form that allows making a conclusion about its granting [2].

At the same time, if the information about the disease of an individual can worsen the state of their health or worsen the state of health of individuals, defined in part 2 of Art. 285 of the Civil Code of Ukraine (parents (adoptive parents), guardians, or tutors), or harm the process of treatment, the medical works have the right to provide incomplete information about the state of health of an individual, to limit the possibility of their acquaintance with certain medical documents (part 3 of Art. 285 of the Civil Code of Ukraine).

At present and as it has always been, the question of "as is" and "as it should be" has been raised and compared in the legal sphere, an analysis of interconnection, mutual coordination, as well as the existing discrepancy in the current legal norms of the existing and the proper has been carried out. As noted in the legal literature, the existence of a scientific problem is indicated by the presence of contradictions between the sphere of "proper", "existing", and "knowledge of existing and proper". Thus, there are certain contradictions regarding the absence of a coordinated fixation of a certain age requirement of individuals, who are given the right to information on the state of their health, which indicated the existence of a certain scientific problem.

In general, taking such an approach, we shall methodologically consider the existing problem in the same sequence (the sphere of "proper", "existing", and "knowledge of existing and proper") [1].

Having made a certain analysis of Art. 285 of the Civil Code of Ukraine (Art. 39 of the "Fundamentals of the legislation of Ukraine on health care"), we have good reason to point out the differences and inconsistencies between them and other rules of law established by the Civil Code of Ukraine and existing legislation of Ukraine, which provides legal regulation of such a subjective right as the right to information on the state of one's health, namely:

1) there is a discrepancy between Part 1 of Art. 285 of the Civil Code of Ukraine and Part 2 of Art. 284 of the Civil Code of Ukraine "The right to medical care", which states that an individual who has reached the age of fourteen, has the right to choose a doctor and choose methods of treatment in accordance with the recommendations of the doctor of their choice.

The conflict between them lies in the fact that the right to receive reliable and complete information about their health, including access to relevant medical documents relating to their health (part 1 of Art. 285 of the Civil Code of Ukraine), is given to an adult. In turn, a person who has reached the age of fourteen and sought medical care has the right to choose a doctor and methods of treatment in accordance with the recommendations of the doctor of their choice. That is, there is a situation according to which a fourteen-year-old person cannot get information about their health due to the fact that they at this age are not mature enough physically, mentally, and socially, i.e. ready for objective perception of the information about the state of their health, but ready to exercise the right to choose a doctor and methods of treatment in accordance with their recommendations.

The given conflict is also marked on the official web portal of the judiciary of Ukraine, namely by the Deputy Chief of Staff of the Lokhvytsia District Court of Poltava Region, where it points to the "need to make changes to pp. 2, 3 of Art. 284 of the Civil Code of Ukraine and their wording as follows: Part 2 of Art. 284 of the Civil Code of Ukraine: "An adult natural person who has applied for medical care shall have the right to choose a doctor and the methods of treatment recommended by a doctor", and Part 3 of Art. 284 of the Civil Code of Ukraine: "Medical aid for an adult natural capable person shall be provided upon their consent" [3].

2) the established differences in the age requirement of individuals who are entitled to receive information about their health, namely, Part 1 of Art. 285 of the Civil Code of Ukraine (Part 1, Art. 39 of the Law of Ukraine "Fundamentals of the legislation of Ukraine on health care") from Part 4 of Art. 7 of the Law of Ukraine "About counteraction to spread of the diseases caused by the human immunodeficiency virus (HIV) to both legal and social protection of the people living with HIV" [4].

Thus, the Law of Ukraine "About counteraction to spread of the diseases caused by the human immunodeficiency virus (HIV) to both legal and social protection of the people living with HIV" states that a health worker has the right to pass information on the state of one's health before the person reaches the age of fourteen to their parents or other legal representatives. Therefore, the information about the presence of HIV infection in a person will be provided to them when they reach the age of fourteen, rather than the age of eighteen, as is generally the case. From our point of view, the legislator referred to the provision of information to a person who has reached the age of fourteen about the presence of HIV infection, in connection with the existence of certain statutory cases according to which an individual acquires full legal capacity from the age of fourteen, for example, marriage (according to Art. 23 of the Family Code of Ukraine [5]).

According to M.V. Antokolska, the lack of information of one of these persons about the presence of serious diseases in another person, such as HIV, infection, tuberculosis, etc., can lead to irreversible consequences [6]. We consider it expedient in case of detection of HIV infection in a fourteen-year-old person to pass information about the state of their health not only directly to them, but also to their parents, due to the fact that such a person may not always be aware of the complexity of the disease, and also unable to independently carry out the full set of actions aimed at treating this disease.

3) there are differences in the age of individuals who are entitled to receive information about their health in Part 1 of Art. 285 of the Civil Code of Ukraine and Art. 30 of the Family Code of Ukraine "Mutual Awareness of Persons that Have Filed an Application for Marriage. Registration of the State of Health". As mentioned above, an individual may marry from the age of fourteen by a court decision, as a result of which they acquire full legal capacity (in accordance with Art. 23 of the Family Code of Ukraine), which also leads to certain differences between Part 1 of Art. 285 of the Civil Code of Ukraine and Art. 30 of the Family Code of Ukraine.

4) According to Art. 30 of the Civil Code of Ukraine, brides (who have filed an application for registration of

marriage of the body of registration of acts) are obliged to inform each other about the state of their health. That is, a fourteen-year-old person can receive information about their health (according to a medical examination of brides) in order to inform a person with whom they wish to marry. However, an additional condition should be defined here, namely, filing an application for registration of marriage.

Therefore, based on the aforementioned and taking into account the possibility of an individual to obtain full legal capacity from the age of fourteen, as well as in order to eliminate the existing conflicts, we consider it expedient to amend Part 1 of Art. 285 of the Civil Code of Ukraine, enshrining in it the right to receive information about the state of their health by individuals who have reached fourteen years of age, but thus not restrict the right to receive information about the state of health of children and foster parents (adoptive parents), guardians, and tutors.

Avoiding restrictions on the right to receive information about the health of children and foster parents (adoptive parents), guardians and tutors is as follows: despite the fact that minors already have a certain amount of capacity (for example, can independently manage their earnings, scholarships or other income), but mostly do not provide for themselves, i.e. unable to commit to the cost of both medical services and medicines needed for certain treatments, and even more so to have the amount of knowledge needed to determine the necessity for medical care, and to protect their personal non-property rights in case of medical intervention. It once again indicates that minors have a certain but not necessary amount of civil capacity to exercise both the right to medical care and the right to information on their health. This can also be confirmed by the fact that has been rightly proven by M.O. Stafanchuk: that the exercise of subjective civil rights is possible and should take place under the following basic conditions: a) a person must be endowed with the necessary civil capacity; b) the person must be endowed with the necessary amount of civil capacity; c) the conduct of the exercise of their civil rights must comply with the principles of the exercise of subjective civil rights [7]. Therefore, we consider it expedient to make changes in Part 1 of Art. 285 of the Civil Code of Ukraine, and not to change Part 2 of Art. 285 of the Civil Code of Ukraine, which enshrines the right to information on the health of the child or ward of parents (adoptive parents), guardians, and tutors.

Based on the aforementioned and in order to eliminate conflicts in the current legislation of Ukraine, namely Art. 285 of the Civil Code of Ukraine (Art. 39 of the Law of Ukraine "Fundamentals of the legislation of Ukraine on health care"): in Part 2 of Art. 284 of the Civil Code of Ukraine "The right to medical care"; Part 4 of Art. 7 of the Law of Ukraine "About counteraction to spread of the diseases caused by the human immunodeficiency virus (HIV) to both legal and social protection of the people living with HIV"; Art. 30 of the Family Code of Ukraine "Mutual Awareness of Persons that Have Filed an Application for Marriage. Registration of the State of Health", which provides for the provision of information about the state of health from the age of fourteen, we propose to establish the same age requirement for persons entitled to receive information about their health (their spouse's health), namely - 14 years.

There arise certain problems with the exercise of the right to information on one's health due to the lack of a legally established list of actions that fall under the notion

of "acquaintance with the relevant medical documents related to one's health". The right of an adult individual to review the relevant medical documents relating to their health is established in Part 1 of Art. 285 of the Civil Code of Ukraine and in Part 1 of Art. 39 "Fundamentals of the legislation of Ukraine on health care".

To acquaint (according to the dictionary) is to provide information, to inform about something [8]. So, the process of getting information about one's health involves providing data. But how this information should be provided to the person (orally, in writing, by allowing copying of both primary medical records and test results, permission to copy medical history, doctor's prescriptions, etc.). In this regard, disputes often arise between individuals (patients) who request the copies of medical records and directly health professionals who do not provide it for various reasons (for example, motivate their refusal by the fact that copies can only be provided at the request of the court, lawyers or law enforcement agencies). Thus, there are cases when medical workers purposefully protect medical information in order to conceal their unqualified or illegal activities, violate the rights of patients or other persons entitled to receive it.

The legislator has not yet paid much attention to this conflict. Although there is a legal position of the European Court of Human Rights, which is reflected in the judgment "K.H. and Others vs. Slovakia" (2009), where the court pointed to a violation of Art. 8 of the Convention for the Protection of Human Rights and Fundamental Freedoms [9], which resulted in the applicants not being allowed to make photocopies of their medical records, and Part 1 of Art. 6 of the Convention for the Protection of Human Rights and Fundamental Freedoms, which manifested itself in the restriction of the applicants' effective access to court due to the impossibility for them or their representatives to obtain copies of their medical records [10]. In Ukraine, the Decision of the Constitutional Court of Ukraine (the case of K.G. Ustimenko) of 30.10.1997 states that in case of refusal to provide or intentionally conceal the medical information from a patient, their family members, or a legal representative, they may appeal against the actions or inaction of a doctor by applying directly to a court or medical institution or health care body [11].

Currently, it is possible to get information about one's health (copies of medical documents are available on the basis of a request for access to personal data to the owner of the database or administrator, which are health care facilities according to Art. 2, Part 2 or Art. 4 of the Law of Ukraine "On Protection of Personal Data" [12], which are health care facilities of all forms of ownership, in accordance with the agreement concluded in writing. In accordance with Para 4 of Part 2 of Art. 8 of the Law in question, a person shall be able to receive information about the state of their health (personal data) no later than 30 calendar days from the date of receipt of this request. During this period, any distortion of information about the state of health of this person, its partial destruction, and other illegal actions with it are possible. Based on the above, we consider it expedient to make changes to pp. 1, 2, 4 of the Civil Code of Ukraine,

changes to pp. 1, 2, 4 of the Civil Code of Ukraine, expanding the capabilities of individuals referred to in Art. 285 of the Civil Code of Ukraine, on the collection of information about the state of health, the ability to copy medical documents provided to them for review:

So, if there is an advantage in the need to provide health information to an individual over the "right of an individual not to be informed" and this need is due to the need for effective preventive treatment or the protection of others, health professionals should provide information on the state of health of an individual in a delicate form, but despite this form, the amount of this information must be complete to ensure that the person makes the right decisions. At the same time, O. Kostetska noted that by providing the patient with incomplete information about their health, the doctor limits the real possibilities of such a patient to exercise other rights (for example, the examination in another medical institution, choice of treatment, right to examination by another specialist), and in this case, there is an opportunity to hide the mistake made during treatment, made by the same health worker, which leads to abusing the right to provide the patient, in certain cases, with limited information about their health, by doctors and health professionals [13].

In this case, the information that will be provided to the patient must be confirmed by medical documents, which [18], if necessary, the person can copy, because the circumstances that limit the rights of a person not to be informed about their health are quite serious and need documentary evidence. Therefore, based on the above, we consider it expedient to supplement Part 3 of Art. 285 of the Civil Code of Ukraine in the second paragraph and state it as follows:

"Individuals and persons defined in Part 2 of the Article in question have the right not to be informed about the state of their health, the health of a child or a ward, and if the need to provide information about the state of health is due to the need for effective preventive treatment, or dictated by the interests of the protection of others, health professionals must provide information about the health of the individual in a delicate form, but in full, and read some medical documents, ensuring the possibility of copying them.

Therefore, an individual has the right not to be informed about the state of their health, based on the fact that obtaining such information shall lead to a significant aggravation of their health".

Thus, considering the content of Part 4 of Art. 285 of the Civil Code of Ukraine, we consider it expedient on the basis of the need to expand the capabilities of individuals specified in Art. 285 of the Civil Code of Ukraine on the collection of information about the state of one's health, the ability to copy medical documents provided to them for review, we have proposed to add the words "(and obtain copies if necessary)" after the words "causes of death" and set it out as follows:

"4. In the event of the death of an individual, the members of their family or other individuals authorized by them have the right to be present at the investigation of the causes of death and to read the conclusions on the causes of death (and obtain copies if necessary) and the right to appeal the conclusions to the court".

In connection with the amendments to Art. 285 of the Civil Code of Ukraine, in order to avoid conflicts in the legislation, a certain list of amendments to Art. 39 of the Law of Ukraine "Fundamentals of the legislation of Ukraine on health care" has been provided. There are also many issues directly related to the scope of "existing" due to the lack of enshrinement of the right of third parties to information about the health of another person (for example, in surrogacy - the right to information on the health of the surrogate in the event of the death of an individual, members of their family or other individuals the right to information on the state of health of the person at the time of death, the conditions under which their death occurred) in the current legislation of Ukraine. Regarding the right to information of third parties about the state of health of another person in surrogacy, we note the following: Ukraine is one of the few countries where surrogacy is permitted by law.

A woman who is carrying a child, a surrogate mother, may or may not have a genetic link (biological relationship) with the unborn child, but in both situations, she intends to leave the child with prospective parents who assume the parental responsibility for the child. M.M. Maleina argues that biological kinship is determined by genetic material, not the birth of the embryo in a woman's body. There is a kind of biological connection between a woman giving birth and a fetus. but a biological connection is not a biological relationship. The biological connection is terminated from the moment of birth, and the biological kinship is preserved and passed down from generation to generation [14].

Currently, in the medical field, the usage of assisted reproductive technologies, including the use of surrogacy, is carried out in accordance with the Order of the Ministry of Health of Ukraine #787 "Instruction on Procedures for Assisted Reproductive Technologies" dated Sept 9, 2013 [15]. In accordance with the procedure for the usage of assisted reproductive technologies in Ukraine, namely in accordance with paragraph 6.3 of Section VI of the Order of the Ministry of Health of Ukraine #787 dated Sept 9, 2013, the examination of a surrogate mother is carried out on general grounds for treatment with assisted reproductive technologies. The results of the examination are entered in the primary accounting documentation "Medical card of an outpatient" (form 025/0). In the future, the medical staff will decide on the possibility of being a surrogate mother according to the state of health of a certain person. However, the information about the physical health of the surrogate mother is only in their usage. Future parents do not have any access to it, due to the fact that information about their health is confidential.

In Ukraine, a surrogate mother should not have a direct genetic link to the child. Pregnancy is allowed by close relatives of future parents (mother, sister, cousin, etc.) [16]. Therefore, the very existence of a biological connection between a surrogate mother and child, which arises from the moment of fertilization and exists before its birth, requires enshrining the right of third parties (future parents) to information about the health of another person (surrogate mother) in the current legislation of Ukraine.

If the surrogate mother is married, according to the above-mentioned order, her husband must consent to the wife's participation in the surrogacy program, which states his obligation to fulfill the terms of the contract between the recipients and the wife [19]. However, the law does not stipulate the obligation of the surrogate mother to undergo a medical examination, which, in our opinion, must take place. This need can be explained by the fact that the surrogate mother, carrying the fetus, must be protected from the emergence of certain sexually transmitted infections and other diseases that can threaten the fetus.

Due to the fact that the health of an individual also means their mental health, in exercising the right of third parties to information about the health of another person (such as a surrogate mother), which must be enshrined in law, we consider it expedient for the third parties (future parents) to receive not only the information about the physical but also the mental health of the person, and not only directly to the surrogate mother, but also in the case of her marriage - the information about the mental health of her spouse. Although the mental state of an individual does not affect the biological processes (biological relationship) between the surrogate mother and the child, it can lead to deplorable consequences - the loss of the fetus.

According to Art. 6 of the Law of Ukraine "On Psychiatric Care" [16], the person or their legal representative shall have the right to receive and use confidential information about the mental health of a person and provide them with psychiatric care, and in accordance with Art. 24 of the Law in question, a person has the right to notify any person of their psychiatric care at their choice.

Due to the current lack of a special legal act detailing all aspects of surrogacy, this method of assisted reproductive technologies has come to the attention of lawyers, as surrogacy in Ukraine is accompanied by a contract. And due to the fact that in the case of surrogacy, the process of childbearing affects the interests of many people, and this service is paid, the use of this reproductive technology is closely linked to jurisprudence. Thus, in Ukraine, the relationship between the biological parents and the surrogate mother is determined by an agreement. It must be drawn up in accordance with the provisions of current legislation of Ukraine, taking into account the individual requirements, wishes and capabilities of the spouses and the surrogate mother [17]. Thus, for the time being, the biological parents can exercise their right to receive information about the health status of the surrogate mother, both physically and mentally, as well as in the case of the surrogate mother's marriage (her spouse) only through certain wishes established by the contract [19]. This does not always guarantee the receipt of truthful information from an individual (surrogate mother or her husband), and medical workers, in turn, guided by Part 3 of Art. 286 of the Civil Code of Ukraine "The Right to Health Secrecy", even having some information about the improper state of health of the surrogate mother (and in some cases understanding it as a condition that does not harm the physical condition of the person), will not be able to provide it without permission from her.

### CONCLUSION

In the exercise of the right in question, we have identified certain differences between the existing and the proper, which arise from the duality of law as a social phenomenon, and the lack of clear consistency of law both civil and health law, and directly between them. The essence of duality is that the functional purpose of the right to information on the state of one's health acts as a regulator of both public relations in general and relations in the field of health care, but is also a form of these relations, the result of their regulation, a form of existing society as a human activity, both in the social and medical spheres. It indicates that there is no complete coincidence between the general regulator (legal norms) and the actual relations that have developed both in public relations and in relations that are related to the field of health care. The activities of the individual are regulated internally and externally, therefore, at the individual level, regulators and actual human behavior do not coincide.

Thus, the exercise of the right to information on one's health is multifaceted and depends on the bearer of the right, doctors, and medical institutions. Such exercise is a special case of civil rights and does not always involve free discretion.

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