

## Fourth generation human rights in the context of health care

Anastasiia Mernyk<sup>1</sup>, Yevhen Hetman<sup>2</sup>, Heorhii Mishcheriakov<sup>2</sup>, Viacheslav Politanskyi<sup>2</sup>

<sup>1</sup>YAROSLAV MUDRYI NATIONAL LAW UNIVERSITY, KHARKIV, UKRAINE

<sup>2</sup>NATIONAL ACADEMY OF LEGAL SCIENCES OF UKRAINE, KHARKIV, UKRAINE

### ABSTRACT

**Aim:** The aim of the article is to analyze the place and development of the right to health care in the fourth generation concept of human rights, to study the relationship between the formation of new generation rights and the development of science and technology, to investigate the current state of recognition and consolidation of the new concept of rights at the international level and some aspects of application of related international legislation in practice.

**Materials and Methods:** The authors study the right to health care, its interaction with new technologies and its evolution in the context of scientific and technological progress. General scientific methods such as systematic analysis and dialectical methods were used for the study. The research is based on international legal acts and agreements, scientific articles, and the case law of the ECHR.

**Conclusions:** In the process of the study, the authors conclude that the main idea of the concept of fourth-generation rights is to find a balance between the introduction of the benefits of technological progress into human life and human dignity and identity. Also, the authors conclude that the classical three generations of rights are insufficient to solve all the problems of modern legal science. Finally, the authors conclude that some important issues of modern law, such as euthanasia and assisted suicide, are not recognized and internationally enshrined in any way.

**KEY WORDS:** right to health care, fourth generation of human rights, technological development

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## INTRODUCTION

Modern technological development is breathtaking in its speed and coordination of changes. New biotechnologies, genetic engineering, and neurotechnologies make possible what was only yesterday the stuff of science fiction writers. But at the same time, the rapid development of technology and science raises many complex issues and challenges in the field of ethics, philosophy, and law. It is believed that today we are already on the verge of the fourth industrial revolution, which is ready to completely change our way of life [1]. One of the most likely directions of these changes may be the widespread introduction of cyber-physical systems, i.e. the integration of electronic computing machines with objects of the surrounding world, including biological ones. This direction of development of modern science alone can raise a number of issues and create a lot of challenges for legal science. However, it is already clear today that modern human rights catalogs are becoming insufficient for all pos-

sible situations that the modern world with its rapid development may create. All this is the reason why the concept of fourth-generation rights, the concept of protecting human dignity and integrity in the context of modern technological changes, is rapidly taking shape in legal science. The relevance to research and analyze this topic is dictated by the need to consider such phenomena as editing the human genome, the use of artificial intelligence in diagnosis and treatment, the technology of integrating computer chips into the human nervous system, etc. from the point of view of legal science.

### AIM

The aim of the article is to analyze the place and development of the right to health care in the fourth generation concept of human rights, to study the relationship between the formation of new generation rights and the development of science and technology,

to investigate the current state of recognition and consolidation of the new concept of rights at the international level and some aspects of application of related international legislation in practice.

## **MATERIALS AND METHODS**

The article examines the right to health care, its relationship with new technologies and its development in the context of scientific and technological progress. The research is based on such general scientific methods as system analysis and the dialectical method. The comparative legal and technical legal method was used to study international legal norms and the case law of the European Court of Human Rights on the recognition, consolidation and practice of the use of fourth generation rights. The methods allowed us to identify common features, differences and gaps in the legal regulation of these rights. The historical and legal method was used to study the prerequisites for the emergence and historical development of the concept of generations of human rights. The systemic analysis was used for a comprehensive study of the right to health care in the fourth generation human rights system. The logical-formal method was used to define the conceptual apparatus and establish clear definitions of terms and concepts in the paper. The method of legal interpretation was used to interpret the provisions of international legal acts with regard to their application in modern conditions. To achieve the purpose of the study, the authors used the following materials: international legal acts and treaties, scientific articles, and the case law of the ECHR. For example, the article by Shevchuk O. et al. analyzes the legal aspects of the use of smart technologies and virtual reality in various healthcare areas. Schickhardt, C. et al. analyze the ethical and legal aspects of patients' access to their raw genetic data. Tarasevych T. et al. analyze in their article the problems of protecting the rights of the fourth generation through the practice of the ECHR. Baroni MJL. examines in his article the insufficiency of the first three generations of human rights to address the problems posed by the current state of scientific and technological progress and emphasizes the need to recognize the fourth generation. All sources used in this literature review are publicly available.

## **REVIEW AND DISCUSSION**

The French-Czech lawyer Karel Vasek was the founder of the concept of human rights generations. The concept characterizes human rights according to their

historical development and, in the classical version, contains three generations: the first - political and civil rights inherent in a person from birth (the right to life, free movement, personal integrity, as well as electoral rights, freedom of speech, etc.), the second - economic, social and cultural rights (positive, i.e. those that the state must ensure. The right to work and rest, social security, housing, etc.), and the third is collective or solidarity rights (the right to peace, a clean environment, etc.) [2]. The expansion of the classical concept to include the fourth generation is dictated by scientific and technological progress, which gives rise to qualitatively new human rights issues that are not fully covered by the traditional three [1].

In modern legal science, there is no clear list and content of fourth generation rights. One of the leading and most discussed concepts of modern rights is the concept of somatic rights. In essence, somatic rights are the recognition of a person's inalienable right of ownership of his or her own body and imply the freedom of will to dispose of one's own body, its parts, organs, and tissues, including those already separated from the body [3]. In general, in medical law, it is customary to attribute to the newest generation of law that is in one way or another related to the integration of scientific and technological advances in various sciences, including medical science, into the healthcare sector. There are many aspects of healthcare that are being changed. An example is the current rapid digitalization of the healthcare sector and the gradual introduction of artificial intelligence for diagnosis and treatment. This raises many questions about the protection of personal medical data, privacy of the individual, and the legal regulation and development of standards for algorithms used in diagnosis and treatment. Another example is the rights in the field of biomedicine and genetics. This raises issues of legal regulation of genetic testing, genome editing, cloning, etc. Also at the crossroads of medical rights and the right to life is the problem of legal regulation of such phenomena as euthanasia, resuscitation, and artificial life support. Another debatable area of development is the introduction of virtual reality into medicine. VR can be used in the healthcare sector in many areas, such as education and training of medical personnel, simulation of surgical interventions, psychotherapy and mental rehabilitation, ophthalmology, telemedicine and sports medicine, etc. This is another promising area of medicine using breakthrough technologies, which also requires legal regulation of such aspects as security, confidentiality, protection of medical and private data, etc. [4].

Also, a feature of the concept of fourth-generation rights is that they not only supplement legal science with new definitions and add new ones to the existing list of rights, but also expand long-known rights with new aspects. Thus, the right to life, in the context of the fourth generation, has been supplemented by the concept of “the right to a decent life,” which implies the absence of physical and moral suffering and control over one’s own life, including the possibility of consciously leaving it. The right to privacy now includes genetic integrity.

Given that the fourth generation rights do not currently have a clear list and scientific discussions about whether a particular right belongs to the new generation are still ongoing, it is important to highlight the general principle on which this generation should be based. Thus, the first two generations were based on the principles of freedom and equality, the third generation - on the principle of solidarity and collectivity. Some authors suggest that the fourth generation be based on the principle of human identity [1]. This means that the development of technologies, genetics, biomedicine, neurotechnology and their implementation in human life is possible only on condition that a person remains a person in the genetic, personal and cultural sense. This principle should prevent uncontrolled interference of science in human life, regardless of the ultimate goal and value of such interference for humanity as a whole.

In the context of medical law, there are several main areas associated with the fourth generation rights. Most of them are currently enshrined in the Oviedo Convention [5]. The first of these is the right to genetic integrity. Its content is the recognition of the human genetic code as unique and inviolable, that is, as the one that cannot be altered or copied. In practice, this means a ban on cloning and a ban on changes to the genome that are transmitted to descendants.

At the international level, this right is enshrined in the Additional Protocol to the Oviedo Convention of January 12, 1998. The Protocol emphasizes that “the intentional creation of genetically identical human beings is incompatible with the concept of human dignity” [6]. Regarding genome modifications, Article 13 of the Oviedo Convention states that they are possible “only for therapeutic, prophylactic and diagnostic purposes and provided that the genome of the descendants is not altered” [5]. All these norms aim to protect the genetic identity and integrity of the individual and prevent uncontrolled interference with the human genome. The second direction is the protection of the confidentiality of biomedical

data. Sensitive information about a person’s physical condition, characteristics and diseases has always required special protection. At the international level, this is reflected in Article 10 of the Oviedo Convention [5]. The development of medical science requires the storage and processing of an increasing amount of personal biological data. Various medical registries and databases for machine learning AI, etc. are being created, which makes privacy protection particularly important and requires looking at it from a different angle. This area can be called the right to the protection of biomedical data, which can be seen as part of a much broader right to privacy in the digital age. Given the value and sensitivity of biomedical data, their storage, processing, and access can trigger entire scientific discourses. An example is the issue of patients’ access to their own genomic data. The specific nature of this data can create a conflict of interest between the patient, their close relatives, researchers and doctors. On the one hand, a patient has the right to know any information related to his or her body, but the complexity of interpreting and understanding genomic data without proper explanation by a specialist can lead to the lack of meaning of such knowledge or to direct harm to the patient due to incomplete or incorrect interpretation of such data. Researchers and research institutions, under the obligation to provide patients with their genome data, may incur additional financial costs and reputational risks, while, again, the data is not useful to the patient. Since the patient’s relatives share about half of the patient’s genes, the patient’s transmission of genetic information about, for example, genetic predisposition may violate their right to informational self-determination [7]. The next area is protection against discrimination on the grounds of genetic heredity, which is enshrined in Article 11 of the Oviedo Convention [5]. An example of such discrimination is the use of genetic tests for health insurance purposes, which is proposed to be prohibited by all Council of Europe states in the recommendation CM/Rec(2016)8 [8] of October 26, 2016. The next right, also defined in Chapter II of the Oviedo Convention [5], is the right to informed consent. It means that no intervention in a person’s body can be carried out without the person’s informed consent. In the context of a new generation of rights, this right also extends to cases of “digital” interventions, namely telemedical consultations, monitoring of the body’s condition through remote sensors or gauges, the use of robotic systems for diagnostics or surgical interventions, etc. Also in the same context, one can highlight the right to refuse

any digital interventions. For example, to refuse the use of algorithms for diagnosis or for developing a treatment plan, or to refuse to enter data into digital registries if the person finds it unacceptable. In this case, the right to traditional methods of treatment or medical records should also be taken into account. For example, a person should be able to receive a paper version of a prescription or his or her appointment sheet even if digital medical records are widespread. This is to ensure that people are not discriminated against if they are unwilling or unable to use digital technologies.

The main document that defines most of the fourth generation rights in the field of medicine at the international level is the Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine, also known as the Oviedo Convention [5]. This is currently the only legally binding document for the states that have ratified it, which establishes legal and ethical norms for the use of scientific and technological achievements in biology and medicine. Having entered into force in 1999, it became the basis of biolaw in European states. The document declares its purpose to protect fundamental rights and freedoms in the context of biology and medicine. The most significant norms established by the Convention, in our opinion, are the norms of Article 2 on establishing the priority of human interests over the interests of society and science. This fundamental statement is very important because it puts an end to the philosophical and scientific discourse on the question of whether the interests of one person can be sacrificed for the sake of scientific and technological progress in the interests of society as a whole. Another equally important achievement is the enshrining of the norm of informed consent in Chapter II of the Convention. No science, no matter how important it is for humanity, should use results obtained in violation of human rights and dignity. Also interesting is the provision of Article 10, which enshrines not only the right to receive comprehensive information about one's health but also the right not to know it, thus recognizing a person's right to informational self-determination. This is very important because it gives people with incurable diseases the right to choose, for example, to live a few years of a decent life without knowing about their illness. Also, in Articles 11 and 12, the Convention prohibits discrimination on genetic grounds and emphasizes that genetic testing can only be used in the interests of health. These norms are intended to prevent the misuse of

genetics for the purpose of employee selection or insurance purposes, etc. Article 13 limits genome editing to medical purposes, provided that there is no change to the genetic lineage of descendants. This is intended to protect humanity from possible selection of human beings and genetic enhancement.

In 1998, a protocol on the prohibition of cloning was adopted to the Convention. It states that while cloning can contribute to scientific and technological progress and solve complex questions in medical science, the creation of genetically identical beings is contrary to human dignity [6]. The following three additional protocols to the Convention regulate the issues of transplantation [9], biomedical research [10] and genetic testing [11]. All of them contain rules designed to protect the rights of people in the face of advances in biology and medicine.

The Oviedo Convention was signed by Ukraine on March 22, 2002, but has not yet been ratified. Although signing this Convention indicates an intention to comply with its provisions, the lack of ratification and harmonization of national legislation with the Convention's provisions creates gaps in bio-law legislation.

Also, among the international documents on bio-law there is a UNESCO declaration: Universal Declaration on the Human Genome and Human Rights of 1997 [12]. The 1997 Declaration recognizes the human genetic code as the common heritage of humanity and also contains provisions prohibiting discrimination on the basis of genetic characteristics and prohibiting cloning [12]. However, these provisions are declarative and recommendatory in nature, do not contain obligations, but rather express the agreement of the international community with respect to the phenomena described.

Also, when analyzing the implementation of modern medical law, it is important to consider the related decisions of the European Court of Human Rights. In the practice of the ECHR, there are quite a few decisions related in one way or another to bio- and medical law. Although the ECHR is guided in its practice by the European Convention on Human Rights, which mainly contains the rights of the first two generations, in most cases it is sufficient to consider bio-law cases, although such an interpretation does not always accurately reflect the essence. An interesting example of bio-law cases is the 2002 case of *Mikulić v. Croatia* [13]. In this case, the court was faced with the task of finding a balance between the applicant's right to know her parentage and the right of her alleged father not to undergo a genetic test. The court found a violation

of the right to genetic identity under Article 8 of the European Convention on Human Rights, considering it a violation of the right to respect for private and family life. Another example of the clash between the right to know one's origins and the right of an individual to refuse a genetic test can be found in the case of *Yaggi v. Switzerland* [14]. In this case, the court sided with the plaintiff, considering the refusal to perform a paternity test on a deceased person as a violation of Article 8 of the Convention, and noted that taking DNA tests from a deceased person cannot be considered an interference with his private life.

There are also several cases in the ECHR's practice on the protection of medical and genetic information. For example, the 2008 case of *S. and Marper v. the United Kingdom* [15], in which the applicants complained about the authorities' retention of their fingerprints, cell samples and DNA even after the criminal proceedings against them had been closed. The court considered the fact of storing a person's biological materials regardless of the existence of a criminal case and without the possibility of the acquitted person to delete data about himself or herself and destroy the materials as an interference with privacy in violation of Article 8 of the Convention. In the 2008 case of *K. and T. v. Finland*, the ECHR found that the leaking of information about the applicant's HIV status to her colleagues was a violation of Article 8 of the Convention [16].

The ECHR's decisions on informed consent and the patient's right to control his or her own life are also noteworthy. In the 2004 case of *Glass v. the United Kingdom*, the Court considered a complaint by a mother whose sick child, during a severe seizure, was given a drug that could have hastened the death, assuming that the child would not recover anyway. The mother did not agree with the doctors' conclusions and did not give her consent to these manipulations. The child later recovered and was discharged home. The ECHR considered the doctors' actions as a violation of Article 8 of the Convention [17]. In the case of *Pretty v. the United Kingdom*, a seriously ill woman asserted her right to assisted suicide. Since she was unable to commit suicide due to complete paralysis caused by her serious illness, her lawyer appealed to the state authorities for guarantees that her husband would not be held criminally liable if he assisted her. The Court decided that although the right to voluntary cessation of life may fall within the concept of "respect for private life", the refusal of state authorities not to prosecute cannot be regarded as a violation of Article 8 of the Convention, since the assessment of the risks of

abuse in the event of permission to commit suicide falls within the competence of the state [18].

Cases concerning reproductive technologies can also be found in the case law of the European Court of Human Rights. For example, in the case of *Evans v. the United Kingdom* in 2007, the Court held that the reluctance of the applicant's partner, who withdrew his consent to the implantation of an embryo artificially fertilized with his biological material, was fully compatible with his right to private life [19]. In the 2012 case of *Costa and Pavan v. Italy*, the Court considered Italy's ban on pre-implantation embryo screening as denying a family the opportunity to have a healthy child, i.e. as a violation of the right to private life [20].

## CONCLUSIONS

Given the above, a number of conclusions can be drawn. Firstly, the concept of fourth-generation rights in the field of medicine emerged as a response to new challenges created by the implementation of the results of scientific and technological progress in the field of human health. Their main meaning is to find a balance between the development of science, technology and society and human dignity and identity. All international documents on modern human rights are permeated with the idea of the inadmissibility of a situation in which, after all changes to the human body or genetic code, even for the purpose of treatment and prevention, a person ceases to be a person in the genetic and personal sense. Uncontrolled implementation of scientific achievements in the field of healthcare can lead to abuses that contradict human dignity, such as gender selection or external data of the future child, attempts to improve human qualities, etc. On the other hand, editing technologies open up great opportunities in the treatment of previously incurable diseases. Neurotechnology through the implantation of a neuroimplant may also be the only method of treating some diseases of the nervous system, but can't a neurochip be used to control a person? Euthanasia is a salvation for terminally ill people who are doomed to die in pain and humiliation, but can't it be used for legalized murder? Answers to such questions should be embodied in legislation at the international and national levels. It is the search for a balance between the interests of the individual and society as a whole that is the main idea of fourth generation rights.

Secondly, the traditional human rights of the first three generations are no longer sufficient to protect against all possible challenges of today. That is why the rights of the fourth generation require the earliest

possible detailed analysis, cataloguing, and constant adaptation of international and national legislation to them. Given the rapid development of science and technology, this will be an increasingly difficult task every year.

Third, some important rights, such as the right to euthanasia and assisted suicide, are not in any way enshrined at the international level. That is, no international document recognizes it as a separate

right and does not oblige states to recognize it. Euthanasia and assisted suicide are only allowed in some countries on the basis of national legislation. The ECHR considers these concepts as part of the right to life and the right to respect for private life. Given the importance of this right for society and its prevalence in the legislation of European countries, it would be advisable to recognize and consolidate it at the international level.

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## CONFLICT OF INTEREST

The Authors declare no conflict of interest

### **CORRESPONDING AUTHOR**

**Anastasiia Mernyk**

Yaroslav Mudryi National Law University  
77 Hryhoriy Skovorody St, 61024 Kharkiv, Ukraine  
e-mail: Mernik.n@gmail.com

### **ORCID AND CONTRIBUTIONSHIP**

Anastasiia Mernyk: 0000-0002-9762-3057 **A** **D** **F**

Yevhen Hetman: 0000-0002-1801-7252 **E**

Heorhii Mishcheriakov: 0009-0005-5036-3074 **B** **D**

Viacheslav Politanskyi: 0000-0002-4664-8537 **B**

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**A** – Work concept and design, **B** – Data collection and analysis, **C** – Responsibility for statistical analysis, **D** – Writing the article, **E** – Critical review, **F** – Final approval of the article

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