

# REGULACIÓN JURÍDICA INTERNACIONAL DEL ACCESO A LA INFORMACIÓN SANITARIA Y EL DERECHO A LA PRIVACIDAD

## INTERNATIONAL LEGAL REGULATION OF ACCESS TO HEALTH INFORMATION AND THE RIGHT TO PRIVACY

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### Resumen

Este artículo examina la intersección entre la información sanitaria y el derecho a la privacidad, centrándose en las implicaciones legales y éticas de la protección de datos personales de salud. Si bien el derecho internacional garantiza el derecho universal al respeto a la vida privada, el derecho a acceder y proteger la información sanitaria se aborda principalmente en las directrices consultivas emitidas por organizaciones internacionales gubernamentales y no gubernamentales. El artículo argumenta que, si bien los derechos relacionados con la salud no se definen explícitamente como parte del derecho a la privacidad en la mayoría de los instrumentos jurídicos, existe una fuerte conexión entre el derecho de acceso a la información sanitaria y la obligación de salvaguardarla mediante mecanismos de confidencialidad. Esta relación se rige en gran medida por el derecho indicativo (soft law), que proporciona orientación sin carácter vinculante. Además, el artículo profundiza en la jurisprudencia en evolución del Tribunal Europeo de Derechos Humanos, analizando sentencias clave que demuestran cómo la información sanitaria se reconoce cada vez más como parte integral del derecho más amplio al respeto a la vida privada. A través de este análisis, el artículo destaca el creciente reconocimiento de que la protección de la información sanitaria es esencial para garantizar la privacidad y defender los derechos individuales.

**Palabras clave:** Información sanitaria, datos personales confidenciales, tratamiento y protección de datos personales, privacidad

### Abstract

This paper examines the intersection of health information and the right to privacy, with a focus on the legal and ethical implications of protecting personal health data. While international law guarantees the universal right to respect private life, the right to access and protect health information is primarily addressed in advisory guidelines issued by international governmental and non-governmental organizations. The paper argues that, although health-related rights are not explicitly outlined as part of the right to privacy in most legal instruments, a strong connection exists between the right to access health information and the obligation to safeguard it through confidentiality mechanisms. This relationship is largely governed by “soft law,” which guides without binding force. Additionally, the paper explores the evolving jurisprudence of the European Court of Human Rights, examining key rulings that demonstrate how health information is increasingly recognized as an integral part of the broader right to respect for private life. Through this analysis, the paper highlights the growing recognition that protecting health information is essential for ensuring privacy and upholding individual rights.

**Keywords:** health information, confidential personal data, processing and protection of personal information, privacy.



## INTRODUCTION

Legal regulation in private life has always been controversial in legal science (Akramov et al., 2024; Petrov et al., 2024; Basi et al., 2025). Everyone's private life is secured, guaranteed, and protected by law from intrusion and interference (Bikku et al., 2024), and health information is just one of the components of private life that is inextricably linked to it (Turanin et al., 2024). The proposed study is relevant because one must consider the international legal aspects of regulating health information (Neznamova et al., 2020; Vargas-Chaves, et al., 2024). The paper seeks to begin to investigate and also critically analyze the now recognized fundamental human right within the category of information about health. This paper considers the lawful, moral, and realistic aspects of health data. It seeks to uncover how health information is personal and sensitive and how it affects an individual's privacy.

The study will explore the extent to which international legal instruments, including human rights frameworks, address the protection and access to health information, and how these laws intersect with the right to privacy. In particular, the paper will consider the evolving interpretations of privacy by international bodies, such as the European Court of Human Rights, and evaluate how health data, often considered a vulnerable area of personal information, is safeguarded under privacy protections. Through this exploration, the paper intends to highlight the importance of health information as a core component of the right to private life, emphasizing the need for robust protections to prevent unauthorized access, misuse, and breaches of confidentiality. The goal is to shed light on the increasing recognition of health data as integral to an individual's privacy and to discuss the legal obligations of states in ensuring its protection (Eflova et al., 2024). Considering the specifics of health information, approaches have been developed at the international legal level that define specific legal guidelines that can be applied primarily in healthcare (Anbari et al., 2022; Van Heel et al., 2023; Rodchenko et al., 2025).

The study of the international legal regulation of access to health information in the context of the right to privacy was carried out using general scientific research methods, the main one of which was document analysis.

To carry out the desk research, a comprehensive literature and legal document review was conducted using a combination of thematic keywords and phrases, including: "health information," "confidential personal data," "processing and protection of personal information," and "privacy." These search terms were selected to capture both the legal and ethical dimensions of access to and protection of health data. The search process involved querying a range of authoritative international academic databases and repositories, such as Scopus, Web of Science, ResearchGate, and Google Scholar.

The second group of materials comprised key international legal frameworks, including significant legislative documents and conventions that address human rights, bioethics, and related issues. These include the Universal Declaration of Human and Civil Rights from 1948 (United Nations, 1948), a landmark document that established the fundamental principles of human dignity, equality, and the inalienable rights of all individuals. It marked a pivotal moment in global human rights discourse, outlining

core freedoms and protections to which all people are entitled, regardless of nationality, ethnicity, or background. Following this, the International Covenant on Civil and Political Rights (ICCPR) ([United Nations, 1966a](#)) was adopted to provide a legally binding framework that expanded on the rights set forth in the Universal Declaration, specifically focusing on political and civil rights. These include the rights to life, liberty, coupled with security, as well as freedom of speech. They also include the right to a fair trial as well as protection from any torture and arbitrary detention.

In parallel, the International Covenant on Economic, Social, and Cultural Rights (ICESCR) ([United Nations, 1966b](#)) was introduced to ensure that individuals' economic, social, and cultural needs are also protected. This covenant highlights rights such as access to education, fair working conditions, an adequate standard of living, and the freedom to participate in cultural life. Together, these three key documents form the backbone of modern international human rights law, establishing a comprehensive framework for protecting the civil, political, economic, and social rights of individuals worldwide. These instruments also underscore the interconnectedness of human rights, where the enjoyment of political and civil rights is intrinsically linked to the realization of economic, social, and cultural rights.

Further, the UN Convention on the Rights of the Child ([United Nations, 1989](#)) emphasized the protection of children's rights, ensuring their well-being and development. The European Convention for the Protection of Human Rights and Fundamental Freedoms (ECPHR) ([Council of Europe, 2013](#)) built upon these international standards, focusing on the rights and freedoms of individuals within European states. The European Convention on Bioethics ([Council of Europe, 1996](#)) addressed the intersection of human rights with biomedical ethics, ensuring respect for human dignity in medical practices.

In addition, the Universal Declaration on Bioethics and Human Rights ([UNESCO, 2005](#)) further expanded the dialogue on the ethical application of biotechnology, stressing the importance of human rights in bioethical matters. Similarly, the Universal Declaration on the Human Genome and Human Rights ([UNESCO, 1997](#)) dealt with the ethical implications of genetic research and its impact on human rights. The International Declaration on Human Genetic Data ([UNESCO, 2003](#)) concluded this series of documents by addressing the specific issues related to genetic data, emphasizing the protection of individuals' genetic privacy and human dignity in scientific research. These documents collectively form a robust international framework aimed at safeguarding human rights across diverse spheres, including civil liberties, medical ethics, and genetic research.

The third block included materials from the judicial practice of the European Court of Human Rights (ECHR) regarding access to health information and the right to privacy.

A step-by-step analysis of these materials allowed us to determine the international legal aspects of regulating access to health information regarding the right to privacy, including considering the ECHR's law enforcement practice.

## DISCUSSION

### *International legal aspects of the regulation of access to health information in the aspect of the right to privacy*

When discussing human rights at the universal level and their consolidation in international legal sources, it is first necessary to note the documents adopted under the auspices of the UN.

The right to health information is an integral part of the right to respect for private life, and the Universal Declaration of Human and Civil Rights of 1948 ([United Nations, 1948](#)) can be identified as the primary source of this right through article 12 that prevents unfair interference with a person's private and family life. Article 17 of the ICCPR ([United Nations, 1966a](#)) conveys the same sentiment. Article 12 of the ICESCR recognizes everyone's right to the highest possible level of physical and mental health (Part 1) and outlines the steps that countries should take to ensure this right.

It is noted that neither the Universal Declaration of Human Rights nor the ICCPR and ICESCR contain explicit provisions concerning health information. Nevertheless, any discussion of private life inevitably involves considerations of an individual's health and well-being. Primarily, this pertains to information related to a person's state of health ([Mendoza de la Espriella et al., 2021](#)).

Article 12 of the ICESCR focuses on ensuring equal access to health services and minimum health care guarantees in the event of illness ([Martinez, 2024](#)). Textually, there are no provisions regarding the rights to health-related information. It is logical to ask whether the right to information about health and the right to secrecy about health are integral parts of the right to health.

To address this question, attention should be given to the UN Committee on Economic, Social, and Cultural Rights, which monitors states' compliance with the ICESCR and is authorized to issue "general comments" that interpret the provisions of the treaty.

The legal nature of the general comments is the subject of scientific debate. Although such comments are not legally binding ([Hunt, 2016](#)), the UN ESCR Committee widely uses them when hearing and analyzing reports from the ICESCR member states. These general observations can be considered an authoritative interpretation of individual human rights and the nature of states' obligations. They are a definite guideline for the practical implementation of human rights ([Matsuoka et al., 2022](#); [Vaslavskiy, 2023](#); [Hartono et al., 2025](#)).

General Comment No. 14 highlights that access to information is a key part of the right to health ([United Nations, 2000](#), clause 3). This includes the right to seek, receive, and share health-related information, while ensuring personal medical data remains private ([United Nations, 2000](#), clause 12). According to [Da Silva, M. \(2018\)](#), among other things, one can name elements of the right to health that simultaneously fall within the scope of other human rights, such as access to health-related information. Instead, the right to information in the patient-doctor relationship system should not be included in the scope of the right to health ([Overchuk et al., 2024](#); [Di Novi et al., 2024](#)). [Patterson \(2024\)](#) highlights that the right to receive reliable and timely information about health-

related factors is included in the right to health (Yahoubour, Dadashzadeh Asl 2021; Dahal & Aoun, 2023). This narrows the right to health information content.

Speaking about access to information, the provisions of Part 2 of Article 19 of the ICCPR states that everyone has the right to freedom of expression, which includes the freedom to receive information. In this regard, attention is drawn to the position of the Human Rights Committee (United Nations, 2002) concerning, among other issues, access to medical data. The Committee stated that denying access to medical information was grounds for recognizing a violation of the Covenant's article on humane treatment and respect for dignity (Article 10 of the ICCPR). This position caused a discussion among the members of the Human Rights Committee who considered the case.

The UN Convention on the Rights of the Child states that children should not face unjust interference with their privacy or attacks on their honor and reputation (United Nations, 1989, part 1, Article 16). Unlike the provisions of other international instruments to be examined further, the child is considered not as a subject, but rather as an object of protection against arbitrary or unlawful interference in the exercise of the right to privacy. This is because it is challenging to discuss a child's sufficient level of development and ability to make informed decisions at an early age.

The Preamble to the UN Convention on the Rights of the Child emphasizes that children require special protection, including legal safeguards both before and after birth. Without detracting from the broader discourse on the child's right to privacy (Mühlhoff, 2021; Sakenov et al. 2022), attention is focused here on healthcare and information related to the child's health. Parents or guardians have always limited children's ability to perform specific actions or refrain from them (Lupton & Williamson, 2017). It is acknowledged that parenting, which includes, among other aspects, the creation of opportunities and favorable conditions for the child's physical and mental development, is not possible without a certain degree of parental intervention in the child's personal life (Talosa et al., 2024). However, such an intervention should and can only be carried out considering the child's best interests (Alieksiienko et al., 2022; Shurygin et al., 2024).

It is impossible to assert that the rights to health information relate to the right to respect for private life. However, their relationship should not be excluded. It is advisable to talk about two aspects of health information regarding the right to respect for private life: 1) the right to access health information and/or information related to health issues and 2) the right to protect health information due to confidentiality.

The right to access information about the state of health and/or information related to health issues is an integral part of the right to health. The right to health belongs to the private legal sphere (with some exceptions related primarily to the provision and protection of public health). Da Silva (2018) does not consider the confidentiality relationship between a patient and a doctor as a right to health. This position deserves attention, but the provisions of further international legal instruments at the regional level indicate that confidentiality is the most important component of health information.

At the regional level, attention should be focused on the legal provisions established by the Council of Europe. Article 8 of the ECPHR guarantees the right to personal life, which can only be limited by public authorities if required by law for reasons like

national security, public safety, crime prevention, health protection, or safeguarding others' rights.

The Convention on Human Rights and Biomedicine (HRB Convention) ([Council of Europe, 1996](#)), another international document on the relationship between the right to health information and the right to respect for privacy, establishes only more fundamental principles. Additional standards and more detailed coverage of issues should be considered in additional protocols. The Convention provides a common framework for protecting human rights and human dignity in the developing fields of biology and medicine ([Council of Europe, 1996](#)).

Regarding the understanding and application of the term “private life”, attention is repeatedly drawn to its understanding under the ECPHR. Article 10 of the HRB Convention states that everyone has the right to privacy regarding their health information, and they have the right to know what information is collected about them. However, individuals' wishes to remain uninformed should be respected. In certain cases, legal restrictions may apply to protect the patient's interests.

The provision of the first part of this article is consistent with the provisions of Article 8 of the ECPHR, according to which everyone has the right to respect for their private life.

Researchers note that every person has the right to get acquainted with any information collected about their health. This provision applies to any medical information, including diagnosis, prognosis, or any fact related to their health ([Pelicioni et al., 2023](#); [Di Novi et al., 2024](#)). However, this right goes side by side with the “right not to know” information about the state of health. Patients may have reasons for not wanting to know about aspects of their health. Such desires should be respected ([Rees et al., 2023](#)).

With regard to the limitation of the right to health information, it is observed that the Convention on Human Rights contains rather vague and general provisions. First, these are exceptional cases. However, what are or could be such exceptional cases? Exceptional cases may involve situations in which there are good reasons to believe that providing medical information will not only be of no benefit but also cause serious harm to the patient. In this example, there is a connection with the patient's interests category.

Second, the main condition is the patient's interests ([Yunus et al., 2024](#)). Certain information about a person's health status may be of key importance to that person, even if that person wishes not to know such information. Knowing if a person is at risk for a disease can be crucial for taking preventive steps. This creates a conflict between the doctor's duty to inform the patient and the patient's right not to know. It is considered that the doctor should inform the patient, as such action serves the patient's best interests.

However, in the development of such situations, we note that when an individual is ill as their illness threatens others (e.g., in the case of infectious diseases), disclosing such information, in the interest of public safety, protecting public health, or safeguarding the rights and freedoms of others, precedes the individual's right to health information as the right not to be informed about their health status ([Krainova et al., 2024](#); [Sharmenova et al., 2024](#)).

Third, this restriction on the rights to health information should be established by law. However, in reference to Article 4 of the Convention on Human Rights, it should be noted that such restrictions on the right to health information may also be established through professional standards.

Restriction of the right to health information should be addressed in internal legislation, considering social and cultural characteristics and the perception of the “other” in a particular culture (Vinichenko et al., 2021; Isaev et al., 2023). However, in some cases, national legislation may allow doctors to conceal or disclose information cautiously (in case of therapeutic necessity) (Gafurova & Yusupova, 2022). National legislation’s task is to establish a fair balance between competing interests in cases where one person’s right not to be informed or to keep medical information concerning them secret conflicts with the legitimate interest of another person or group of persons interested in receiving such information (Zoń, 2017).

Specific provisions related to health information in the context of the right to respect for private life are reflected in soft law documents (Chico & Taylor, 2018). According to the general theoretical approach to lenient norms of international law, resolutions, recommendations, and other documents of international bodies and organizations can be attributed (Kocherov, 2023).

The Universal Declaration on Bioethics and Human Rights (UNESCO, 2005) emphasizes the right to privacy and confidentiality. It states that personal information should be kept private and only used for the purposes for which it was collected or consented to, in line with international human rights standards. This right ensures control over personal information, limits access to personal and medical data, and protects various aspects of a person’s private life from interference.

The Universal Declaration on the Human Genome and Human Rights (UNESCO, 1997) affirms the right to be informed or not about genetic analysis results and their implications; a similar provision is found in Article 10 of the International Declaration on Human Genetic Data (UNESCO, 2003). However, a clear line is drawn between two types of information: information that allows the identification of a person and information that does not allow the identification of a person or the obtaining of personal information.

### *Regulation of access to health information in the aspect of the right to privacy in the law enforcement practice of the ECHR*

The specifics of the European Court of Human Rights (ECHR) practice should be considered when defining and interpreting the right to respect for private life. Due to the principle of evolutionary (or, as it is sometimes called, dynamic) interpretation, the interpretation of the understanding of private life is changing. Positions expressed under the same conditions can be changed. However, for the sake of certainty, the ECHR, using the “reasonable expectation of confidentiality” test, identifies two main categories for protecting personal life: privacy (whether information can be kept secret from society) and personal choice (when it concerns the individual or their autonomy).

That is why the ECHR's understanding of the right to respect for private life depends on the specific circumstances of each case ([Stancescu-Cojocaru, 2023](#)).

The European Court of Human Rights (ECHR) has addressed cases where health information relates to the right to private life. In *I. v. Finland*, the court ruled that personal health data is part of an individual's private life ([European Court of Human Rights, 2008a](#)). The issue of access to medical records was discussed in *K.N. and Others v. Slovakia*, where the court found that while prohibiting copies of medical records aimed to protect privacy, the risk of misuse could be prevented in other ways ([European Court of Human Rights, 2009](#)). In *Z v. Finland*, the court emphasized that confidentiality of health information is a core principle in the legal systems of Convention countries. One needs to respect the patient's medical confidentiality and ensure their trust in the medical profession and medical services ([European Court of Human Rights, 1997](#)). In *L.L. v. France* ([European Court of Human Rights, 2002](#)), the spouse used her husband's medical records without consent during the divorce process. The decision in this case is a good example that illustrates the criterion of proportionality of disclosure of confidential health information. The ECHR ruled that Article 8 of the Convention (right to respect for private life) had been violated.

Protecting personal data, including medical information, is essential for exercising the right to private and family life under Article 8 of the ECPHR. Respect for health confidentiality is a key principle in all Convention member states' legal systems. National laws should include safeguards to prevent the transfer or disclosure of personal health data that could violate the protections outlined in Article 8 of the Convention (*Z v. Finland*). Respecting the patient's medical confidentiality and maintaining their trust in the medical profession and medical services is extremely important.

The right to privacy and other considerations also apply when it comes to protecting the confidentiality of human immunodeficiency virus (HIV) information because of the possible negative consequences. For this reason, people may lose the desire to discover their diagnosis and receive medical care, neglecting preventive measures. Therefore, the interest in the confidentiality of such information will be more important in determining whether the interference with the exercise of this right was consistent with the intended purpose. Article 8 of the Convention states that such interference cannot be considered unless justified by specific, more important public interests. Given the sensitive nature of HIV status, any government actions that require disclosure or provision of such information without the patient's consent should be carefully scrutinized by the court. In cases like *Biriuk v. Lithuania* ([European Court of Human Rights, 2008b](#)) and *Armoniene v. Lithuania* ([European Court of Human Rights, 2008c](#)), the court examined a situation where, in January 2001, Lithuania's largest daily newspaper published a front-page article about a supposed AIDS threat in a remote area of the country. The medical staff of the AIDS center and the hospital confirmed that the applicants were HIV-positive. The first applicant, who had two illegitimate children with the second applicant, was described as having a "promiscuous sex life". The newspaper also noted that "residents of the surrounding villages are afraid that their men will bring home a deadly virus". The applicants appealed to the courts, which recognized the violation of their right to confidentiality and awarded them compensation of 10 thousand lats. The applicants

complained to the ECHR under Article 8 that, despite the national courts' recognition of their rights under Article 8, the compensation awarded to them was too low.

The court noted that the Lithuanian courts had awarded the applicants compensation for moral damage. However, the main question was whether the award of 10,000 lats, which the newspaper had to pay, was proportional to the damage it caused the applicants. The court recognized that financial standards based on the state's economic condition must be considered when determining the measures necessary to fulfill the state's obligations under Article 8. The court also noted that the Council of Europe member states may regulate issues of compensation for moral damage differently. However, in the case of the outrageous abuse of freedom of the press, as in this statement, the court recognized that strict legal restrictions on the award of compensation by courts for moral damage by distributors of information about private life (maximum 10 thousand lat under the law) did not provide the applicants with the protection they could have expected under Article 8 of the ECHR, in violation of this provision.

Any interference with a person's rights under Article 8 of the Convention can only be justified if it is "according to the law," serves a legitimate goal, and is "necessary in a democratic society" (Zhumagulov et al., 2017; European Court of Human Rights, 2021).

The phrase "according to the law" means the measure must be based on national legislation and align with the rule of law, as stated in the Convention's preamble and central to Article 8's purpose. Thus, the "law" (which is an autonomous concept under the Convention) must be sufficiently accessible and predictable, that is, formulated clearly enough to provide a person with the opportunity, if necessary through appropriate consultation, to regulate their behavior (S. and Marper v. the United Kingdom (European Court of Human Rights, 2008d)). The requirement of predictability also means providing individuals with an appropriate indication of the circumstances and conditions under which public authorities have the right to take measures affecting their rights under the Convention.

Article 8's main goal, as interpreted by the ECHR, is to protect individuals from arbitrary state interference in their rights. Besides this negative duty, the state has positive obligations to ensure respect for private and family life, including in personal relationships (Sheremeteva et al., 2024). The state's responsibility varies depending on the aspect of private life involved. While the state has discretion in choosing how to protect private life from individual actions (Polovchenko, 2022), effective criminal laws and their enforcement are needed to protect fundamental values and privacy.

## CONCLUSIONS

Based on the analysis of international legal documents, the following conclusions can be drawn. It is recognized that defining the right to privacy remains one of the most complex tasks. The scope of what is typically included within the concept of private life continues to evolve alongside changes in social structures. International law provides only universal and general provisions regarding the right to respect for private life. A provision on health information can be found in the recommendation documents of international governmental and non-governmental organizations. International legal

means, primarily the provisions of strict norms of international law, cannot adequately respond to social changes. The implementation and enforcement of international law norms regarding health information are mainly carried out in advisory documents.

It is assumed that the legal and ethical implications of protecting personal health data require a dual approach: one based on binding legal norms and the other on soft law instruments that offer adaptable guidance in response to emerging biotechnological and digital challenges. The analysis shows that the evolving jurisprudence of the ECHR plays a pivotal role in defining the contours of private life, gradually incorporating the right to health information and its protection as essential to ensuring dignity and autonomy.

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### CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

### CONTRIBUTION AND CREDIT

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