

## THE EUROPEAN STANDARD OF PROTECTION OF MEDICAL DATA

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**Abstract.** The aim of the study is to interpret the normative structure of the European standard for the protection of medical data as shaped in the case law and practice of the European Court of Human Rights. Adopting a dogmatic-legal approach, the author analyses the following cases: *Z v. Finland*, *I v. Finland*; *Mockutė v. Lithuania*; *P. and S. v. Poland*, *M.S. v. Sweden*; *Konovalova v. Russia*; *Frâncu v. Romania*; and *Y.G. v. Russia* in order to identify its elements. This analysis concludes that the standard for medical data limits the permissible extent of State Parties' interference with individuals' right to privacy concerning the collection, processing, and storage of their health information. It also designates the State Parties to the Convention as the entities responsible for both positive and negative obligations, while recognizing every individual as the rights holder.

**Keywords:** human rights law; case law of the European Court of Human Rights, medical data protection.

### 1. INTRODUCTORY REMARKS

Information concerning an individual's health constitutes one of the four primary categories of "personal data" that require protection in connection with the application of biology and medicine, as enumerated by the European Court of Human Rights. The other three categories are related to gender identity and sexual orientation, biometric data, and genetic data. In the case law of the European Court of Human Rights, the concept of "personal data" is interpreted in line with the definition given in the Council of Europe's Convention no. 108 on the Protection of Individuals with regard to the Automatic Processing of Personal Data, adopted on January 28, 1981. This definition covers any information relating to an identified or identifiable individual including both data that directly identifies a person and information that, when combined with other elements, could lead to their identification.

Health-related data constitute a core aspect of private life [Wnukiewicz-Kozłowska 2020; Mulder 2019] and their protection is crucial. As the Court

states in *I v. Finland*: “Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention. It is crucial not only to respect the sense of private life of a patient but also to preserve his or her confidence in the medical profession and in the health services in general. Without such protection, those in need of medical assistance may be deterred from revealing such information of a personal and intimate nature as may be necessary in order to receive appropriate treatment and, even, from seeking such assistance, thereby endangering their own health and, in the case of transmissible diseases, that of the community. The domestic law must therefore afford appropriate safeguards to prevent any such communication or disclosure of personal health data as may be inconsistent with the guarantees in Article 8 of the Convention.”<sup>1</sup>

The Court has assessed the standard ensuring such protection in various cases, including those concerning individuals infected with HIV, such as *Z v. Finland* and *I v. Finland*;<sup>2</sup> mental health conditions, as in *Mockutė v. Lithuania*;<sup>3</sup> women’s rights in the context of abortion, as in *P. and S. v. Poland*<sup>4</sup> and *M.S. v. Sweden*;<sup>5</sup> the right to privacy during childbirth, as in *Konovalova v. Russia*;<sup>6</sup> the refusal to grant a private hearing in cases concerning release from detention on health grounds, as in *Frâncu v. Romania*;<sup>7</sup> and the accessibility of medical databases, as in *Y.G. v. Russia*.<sup>8</sup> Their analysis aligns with this study’s objective: to determine the elements of the European standard for medical data protection and identify instances where it is violated. This analysis encompasses both the objective and subjective components of the standard in question. The objective component corresponds to its normative structure, which comprises three elements: the identification of the right-holder, the designation of the duty-bearer, and the definition of the object of protection [Drzewicki 1988, 155-78; Etzioni 2010, 187-97; Hunt 1996; Jasudowicz 2005, 105-28; Michalska 1976; Wronkowska 1973; Łasak 2013]. These elements find their legal foundation in the European Convention on Human Rights.<sup>9</sup> The subjective component of the standard pertains to the specific circumstances of the case under consideration. The examination of both components is situated within the dogmatic paradigm of public international law scholarship. The primary research method employed in this study is the logical-linguistic approach, developed through formal-logical

<sup>1</sup> *I v. Finland*, App no. 20511/03 ECtHR, Judgment of 17 July 2008.

<sup>2</sup> *Z v. Finland*, App no. 22009/93 ECtHR, Judgment of 25 February 1997.

<sup>3</sup> *Mockutė v. Lithuania*, App no. 66490/09 ECtHR, Judgment of 27 February 2018.

<sup>4</sup> *P. and S. v. Poland*, App no. 57375/08 ECtHR, Judgment of 30 October 2012.

<sup>5</sup> *M.S. v. Sweden*, App no. 74/1996/693/885 ECtHR, Judgment of 27 August 1997.

<sup>6</sup> *Konovalova v. Russia*, App no. 37873/04 ECtHR, Judgment of 9 October 2009.

<sup>7</sup> *Frâncu v. Romania*, App no. 69356/13 ECtHR, Judgment of 13 October 2020.

<sup>8</sup> *Y.G. v. Russia*, App no. 8647/12 ECtHR, Judgment of 30 August 2022.

<sup>9</sup> Convention for the Protection of Human Rights and Fundamental Freedoms, ETS No. 005.

and linguistic analysis [Wróblewski 1973; Izdebski 2021, 25-38]. The formal-logical analysis of the case-law of the European Court of Human Rights is complemented by a functional analysis, which is particularly suited to exploring the relationship between law – as the source of the objective component of the identified standards – and the socio-cultural context, which informs their subjective dimension [Borucka-Arctowa 1982, 49-70].

## 2. THE EUROPEAN STANDARD OF PROTECTION OF MEDICAL DATA IN THE CASE-LAW OF THE EUROPEAN COURT OF HUMAN RIGHTS

In *Z v. Finland*,<sup>10</sup> the Court held that the disclosure of sensitive health information constituted a violation of Article 8 of the Convention. The case concerned a woman whose HIV-positive status was revealed in an appellate court ruling from December 10, 1993, which upheld her ex-husband's conviction for rape and attempted murder. Despite an order that the case files remain confidential for ten years, the ruling was published in the media, exposing her personal health information. After unsuccessful attempts to extend the confidentiality period, the applicant turned to the European Court of Human Rights, arguing that her rights under Articles 8 and 13 of the Convention had been violated. The Court found that the appellate court's disclosure of her medical data was unjustified. Moreover, it concluded that the ten-year confidentiality period was insufficient to protect her interests, as making her health data public even after that period could lead to further violations of her rights under the Convention.

In the case of *I v. Finland*<sup>11</sup>, the European Court of Human Rights found a violation of Article 8 of the European Convention on Human Rights due to the failure of national authorities to ensure an adequate level of protection against unauthorized access to the medical records of a nurse diagnosed with HIV [Råman 2008]. While employed at the Eye Diseases Clinic, the applicant was also a patient at the Infectious Diseases Clinic – both situated within the same hospital – where she received her HIV diagnosis. Suspecting that hospital staff had accessed her medical records without authorization through an unsecured registry, the applicant requested an investigation to identify those responsible. However, due to the absence of access logs, it was impossible to establish who had accessed the records. She subsequently initiated civil proceedings against the authority responsible for maintaining the medical records registry, seeking compensation for material and non-material damages resulting from the failure to safeguard her personal health

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<sup>10</sup> *Z v. Finland*, App no. 22009/93 ECtHR, Judgment of 25 February 1997.

<sup>11</sup> *I v. Finland*, App no. 20511/03 ECtHR, Judgment of 17 July 2008.

data. The national courts, however, dismissed her claim, citing an absence of sufficient factual evidence. The applicant then brought her case before the European Court of Human Rights, asserting that the lack of safeguards constituted a violation of Article 8. The applicant was unable to pursue her rights effectively through the civil action initiated, as she could not establish a causal link between the deficiencies in access security rules and the dissemination of information regarding her medical condition. Shortcomings in the hospital's record-keeping, overlooked at the time, imposed undue burden of proof on the applicant. It is evident that had the hospital exercised greater control over access to medical records – by restricting access to healthcare professionals directly involved in her treatment or by maintaining a register of all individuals who accessed the records – the applicant would not have been placed at a disadvantage before the domestic courts. What is decisive is that the hospital's record-keeping system was clearly not in compliance with the legal requirements set forth in Article 26 of the Personal Files Act, a fact to which the domestic courts failed to attribute due weight.

In *Mockutė v. Lithuania*,<sup>12</sup> the Court examined interference in private life involving the public disclosure of sensitive information in a documentary about the alleged links between the Ojas Meditation Centre in Vilnius and the Osho sect. The programme featured interviews with the applicant's mother, sister, and physician, which – when combined with the disclosed data – enabled her to be identified, despite a pseudonym being used. Prior to the documentary airing, the applicant had undergone psychiatric treatment following multiple hospitalizations between 1992 and 2002. During this period, she obtained a law degree, completed postgraduate studies in the United States, and worked in both the private and public sectors, including a role at the Ministry of Economy in Vilnius. Following a series of personal hardships – including a car accident, a job transition, and her father's cancer diagnosis – she experienced a psychological crisis that led to her involuntary hospitalization at Vilnius Psychiatric Hospital. It was during this hospitalization that her case was featured in the documentary.

After the broadcast, the applicant published an open letter on the Ojas Meditation Centre's website in response to the programme. She subsequently initiated civil proceedings, alleging that Vilnius Psychiatric Hospital had unlawfully deprived her of liberty, violated her right to private life and freedom of religion, infringed upon her bodily integrity, denied her adequate information regarding her diagnosis, treatment, and prognosis, and failed to provide appropriate medical care. The first-instance court ruled in her favour, finding that her detention had been unlawful and that her rights to private life and freedom of religion had been violated. However, the appellate court overturned this decision.

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<sup>12</sup> *Mockutė v. Lithuania*, App no. 66490/09 ECtHR, Judgment of 27 February 2018.

The applicant then brought her case before the European Court of Human Rights, alleging that the disclosure of her personal data by a physician at Vilnius Psychiatric Hospital constituted a violation of Article 8, and that the restrictions imposed on her meditation practices amounted to a violation of Article 9. The Court ruled in her favour, concurring with the findings of the first-instance court. It held that the disclosure of the applicant's private medical data violated her right to respect for private life under Article 8 and that the interference with her religious practices was unjustified, thus constituting a violation of Article 9.

In *P. and S. v. Poland*<sup>13</sup> the European Court of Human Rights addressed multiple violations experienced by a minor and her mother in their efforts to access the right to a legal abortion following a rape. Despite meeting the statutory requirements for abortion under Polish law, the applicants encountered systemic obstruction from medical professionals in Lublin and Warsaw. The head of the hospital in Lublin not only refused to perform the procedure but also, without the applicant's consent, arranged for her to meet with a Catholic priest, K.P., in an attempt to dissuade her from terminating the pregnancy. Seeking medical assistance in Warsaw, the applicants were subjected to further interference. While awaiting the procedure, P. received text messages from K.P. and unidentified individuals informing her that prayers were being offered on her behalf. The priest, accompanied by an anti-abortion activist, visited her at the hospital, while an unidentified woman sought to pressure her into continuing the pregnancy. These events led the applicants to leave the hospital. However, anti-abortion activists obstructed their departure by blocking their access to a taxi and notifying the police. Following police intervention, P. was placed in a juvenile shelter, where she was denied access to her mobile phone and again visited by K.P. She was subsequently transferred back to the hospital in Lublin, while the Lublin Family and Juvenile Court initiated proceedings to revoke S's parental rights. These proceedings were later discontinued due to lack of legal grounds. Intervention by the Ministry of Health ultimately facilitated the applicant's transfer to a hospital in Gdańsk, where the abortion was performed. However, the Catholic Information Agency obtained and disseminated details of the procedure online. The case had already attracted national attention due to the actions of Jana Bożego Hospital, subjecting P. to harassment by medical professionals, clergy, journalists, and anti-abortion activists. The unauthorized disclosure of her personal data was facilitated by institutions entrusted with assisting her in exercising her legal right to abortion following a rape. Several criminal proceedings ensued: 1) against P. for allegedly engaging in unlawful sexual activity with a minor under 15; b) against P's parents and members of the

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<sup>13</sup> *P. and S. v. Poland*, App no. 57375/08 ECtHR, Judgment of 30 October 2012.

Federation for Women and Family Planning for allegedly coercing her into an abortion; c) against individuals who pressured P. to continue the pregnancy; d) against police officers for detaining P. pursuant to the order for her placement in a juvenile shelter; e) against those responsible for the unauthorized disclosure of her confidential information.

All proceedings were ultimately discontinued, prompting the applicants to file a complaint before the European Court of Human Rights, alleging violations of Articles 8, 5, and 6 of the Convention.

The Court found a violation of Article 8, highlighting the discrepancy between the theoretical right to a legal abortion under Polish law and the systemic barriers impeding its practical enforcement. It further condemned the unauthorized disclosure of the applicant's medical information, underscoring the legal protections for patient confidentiality under Polish law and the explicit prohibition of healthcare professionals divulging such information.

With respect to Article 5(1), the Court ruled that P's detention was unlawful, as its primary purpose was to separate her from her parents – particularly S. – and obstruct access to abortion rather than to ensure educational supervision, as required under Article 5(1(d)) of the Convention.

Finally, the Court found a violation of Article 3, emphasizing that the applicant's young age, vulnerability, and personal circumstances were not adequately considered. The suffering she endured as a minor rape victim seeking a legal abortion underlined the State's failure to fulfil its positive obligations under the Convention.

In *M.S. v. Sweden*,<sup>14</sup> the European Court of Human Rights examined the conditions under which medical data may be lawfully processed between public institutions for the purposes of legal proceedings. The applicant, M.S., had suffered from spondylolisthesis since the age of fourteen. Following a workplace accident that resulted in a spinal injury and rendered her incapable of resuming her profession, she applied for compensation under occupational accident insurance regulations. Upon reviewing copies of her case file, requested by her legal representative, she discovered that her medical records – including information regarding a prior abortion – had been transferred by the hospital where she had received treatment to the competent insurance authority without her prior consent.

After an unsuccessful outcome in the compensation proceedings, the applicant lodged a complaint with the Court, alleging violations of Articles 6(1), 8, and 13 of the Convention. However, the Court dismissed her claims, ruling that Article 6(1) was inapplicable and that no violations of Articles 8 or 13 had occurred. In its reasoning concerning the transmission of medical data, the Court underscored that: in deciding whether to accept the applicant's

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<sup>14</sup> *M.S. v. Sweden*, App no. 74/1996/693/885 ECtHR, Judgment of 27 August 1997.

compensation claim, the authority had a legitimate need to compare the information provided by the applicant with the data held by the clinic. In the absence of objective information from an independent source, it would have been difficult to establish the validity of the claim. Accordingly, the transfer of medical data between public institutions in this case was deemed a justified example of the processing of medical information for the purposes of ongoing legal proceedings.

In *Konovalova v. Russia*,<sup>15</sup> the Court analysed the provision of medical services in the presence of medical students through the lens of Article 8 of the Convention. On April 23, 1999, the applicant was admitted to the gynaecology department of the S.M. Kirov Military Medical Academy Hospital due to labour contractions. Upon arrival, she was provided with a brochure informing patients that their hospitalization was linked to the educational process of medical students. Following several days of monitoring and treatment, the applicant gave birth to her daughter on April 25, 1999. The newborn was subsequently transferred to the neonatal ward due to mild symptoms of oxygen deprivation. The delivery was attended by fourth-year medical students, who had been briefed on the course of treatment and the applicant's medical condition.

On August 10, 1999, the claimant filed a complaint against the hospital, alleging that the planned participation of medical students in the delivery had resulted in a delay in the birth. In response, the hospital asserted that the presence of students had no impact on the medical staff's conduct and that the treatment met applicable medical standards.

A year later, on July 27, 2000, the applicant initiated civil proceedings against the hospital before the Vyborg District Court of Saint Petersburg, seeking compensation for non-pecuniary damage. On November 22, 2003, the court dismissed her claim, and this decision was upheld on appeal on May 24, 2004. After exhausting domestic remedies, the applicant filed a complaint with the European Court of Human Rights on August 2, 2004, alleging violations of Articles 8 and 3 of the Convention.

The applicant's first allegation pertained to the presence of medical students during childbirth without her informed consent. The second allegation concerned the alleged deliberate postponement of the delivery to coincide with scheduled academic training hours. In its judgment, the Court upheld the first claim, concluding that the applicant's inability to exercise autonomy over the presence of students during such a highly personal medical procedure constituted a violation of her right to private life under Article 8 of the Convention. Conversely, the Court found no evidentiary basis for the second claim and accordingly dismissed it as unsubstantiated.

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<sup>15</sup> *Konovalova v. Russia*, App no. 37873/04 ECtHR, Judgment of 9 October 2009.

In *Frâncu v. Romania*,<sup>16</sup> the European Court of Human Rights held that the denial of a private hearing in connection with the applicant's motion for release from pretrial detention on medical grounds constituted a violation of the right to respect for private life under Article 8 of the European Convention on Human Rights [Goffin 2021]. The applicant had been placed in pretrial detention following allegations of irregularities in the public procurement process. In appealing the detention order, he sought release on health grounds and requested that the hearing be conducted in camera. He argued that the public disclosure of his medical information would constitute an unwarranted intrusion upon his right to private life and that the presence of the media and public could further compromise the presumption of innocence. The Court of Appeal denied the request for a closed hearing, reasoning that the applicant's case did not fall within the exceptions recognized under Romanian law. It affirmed the pretrial detention order, a decision that was subsequently the subject of satirical media coverage. The European Court of Human Rights found that this decision violated Article 8 of the Convention, explaining with respect to the asserted public interest in a corruption case involving an elected official, the Court determined that, even assuming the applicant's public status could be considered in evaluating the proportionality of his request for a private hearing, it was evident that the Court of Appeal failed to conduct an individualized proportionality assessment. Furthermore, the disclosure of the applicant's medical records bore no relevance to the substantive merits of the allegations against him.

In its judgment in *Y.G. v. Russia*,<sup>17</sup> the Court addressed the unlawful dissemination of medical data for commercial purposes. The applicant's personal data Goffin – including his full name, date and place of birth, nationality, residential address, a note regarding a prior criminal conviction, and information regarding his HIV and hepatitis C status – were recorded in a registry that was subsequently sold as part of the database of the Moscow Department of Internal Affairs at the Savelovsky Center.

The applicant submitted a request to the Information Center of the Moscow Department of Internal Affairs, seeking clarification as to why his health-related information had been included in this database. Upon receiving a response stating that the registry did not belong to the Department, he filed a complaint with the Investigative Committee of the Russian Federation, alleging violations of his right to privacy and abuse of power, asserting that state officials must have been responsible for disclosing the data to third parties. The case was referred to the prosecutor's office, which declined to initiate an investigation. The applicant then resubmitted his complaint to the

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<sup>16</sup> *Frâncu v. Romania*, App no. 69356/13 ECtHR, Judgment of 13 October 2020.

<sup>17</sup> *Y.G. v. Russia*, App no. 8647/12 ECtHR, Judgment of 30 August 2022.

Investigative Committee, which concluded that his submission did not contain sufficient information to establish that an offence had been committed. This position was ultimately upheld by the Moscow Court. The existence of the database at the Savelovsky Center was also the subject of press reports and a separate inquiry conducted by the Ministry of Internal Affairs.

Before the European Court of Human Rights, the applicant alleged violations of Articles 8 and 13 of the Convention, contending that the State authorities had unlawfully collected, stored and processed his health data, failed to ensure the confidentiality of his medical information, and neglected to conduct an effective investigation into its disclosure. The Court upheld the applicant's claim concerning the violation of Article 8, finding that the domestic authorities had failed in their positive obligation to ensure an adequate level of protection for the right to respect for private life. The decisive factor in establishing the violation was that state authorities had not prevented the unlawful dissemination of the applicant's health data, nor had they clarified the circumstances of the breach.

As the Court emphasized: "The protection of personal data, particularly medical data, is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 of the Convention. Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention. It is crucial not only to respect the sense of privacy of a person but also to preserve his or her confidence in the medical profession and in the health services in general. The domestic law must afford appropriate safeguards to prevent any such communication or disclosure of personal health data as may be inconsistent with the guarantees in Article 8 of the Convention. The need for such safeguards is all the greater where the protection of personal data undergoing automatic processing is concerned."

### 3. FINAL REMARKS

The standard for the protection of medical data has been developed in the Court's jurisprudence, notably in *Z v. Finland* and *I v. Finland*, which concerned individuals living with HIV; *Mockutė v. Lithuania*, which addressed the disclosure of mental health data; *P. and S. v. Poland* and *M.S. v. Sweden*, which pertained to the rights of women who had undergone an abortion; *Konovalova v. Russia*, concerning privacy rights during childbirth; *Frâncu v. Romania*, regarding the refusal to hold a private hearing in proceedings related to a request for release from detention on health grounds; and *Y.G. v. Russia*, which involved the unlawful disclosure of medical database records. While the subjective element of this standard is determined by the above-mentioned factual situations of the cases analysed, its objective element is determined by Article

8 of the European Convention on Human Rights. The standard for the protection of medical data delineates the permissible extent of State Parties' interference in the right to respect for private life concerning the collection, processing, and storage of individuals' health information, and designates the State Parties to the Convention as the entities responsible for both positive and negative obligations, while recognizing every individual as the rights holder. In assessing whether these limits have been exceeded, the Court considers whether the interference in question is lawful, pursues a legitimate aim, and is necessary in a democratic society. Accordingly, the Court examines compliance with the principles of minimizing the quantity of collected and recorded data, ensuring the accuracy and timely updating of such data, restricting data retention to the period strictly necessary for achieving the intended purpose, processing data in accordance with the purpose for which they were collected, and maintaining transparency in data processing procedures. The Court found violations of the standard for the protection of medical data in circumstances where: a) information concerning an individual's HIV status was disclosed in an appellate court ruling, b) the authorities failed to ensure an adequate level of protection against unauthorized access to the medical records of a nurse living with HIV, c) mental health data were disclosed in a television documentary in a manner that allowed the applicant to be identified, d) public service employees breached their obligation to protect medical data by disclosing information concerning a minor rape victim and her mother, e) the applicant's right to respect for private life was infringed by the presence of medical students during childbirth without her consent, f) a request for a private hearing in proceedings concerning release from detention on health grounds was denied, g) the authorities failed to discharge their positive obligation to ensure an adequate level of protection of the right to respect for private life by preventing the unlawful disclosure of the applicant's health data and by failing to clarify the circumstances of such a breach.

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