

# **INTER-AMERICAN COURT OF HUMAN RIGHTS**

## ***MANUELA AND OTHERS V. EL SALVADOR***

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**WRITTEN SUBMISSIONS ON BEHALF OF  
THE INTERNATIONAL COMMISSION OF JURISTS**

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9 March 2021

## **Introduction**

1. Composed of 60 eminent judges and lawyers from all regions of the world, the International Commission of Jurists (ICJ) promotes and protects human rights through the Rule of Law, by using its unique legal expertise to develop and strengthen national and international justice systems. Established in 1952 and active on five continents, the ICJ aims to ensure the progressive development and effective implementation of international human rights and international humanitarian law; secure the realization of civil, cultural, economic, political and social rights; safeguard the separation of powers; and guarantee the independence of the judiciary and legal profession.
2. The ICJ is grateful to the Inter-American Court of Human Rights for the opportunity to submit the present third-party intervention and hopes that its submissions will be helpful to the Court in its ultimate determination of the present case.
3. In the present third-party intervention, the ICJ's submissions focus on:
  - a) the right to respect for private life in relation to information about one's health in the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine; and
  - b) The case-law of the European Court of Human Rights on the right to privacy of information about one's health.

### **The right to respect for private life in relation to information about one's health in the Council of Europe's Convention on Human Rights and Biomedicine**

4. The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine illustrates the importance in the Council of Europe of ensuring human rights in the context of health care.<sup>1</sup> The Convention on Human Rights and Biomedicine is the first legally-binding international instrument in the field of bioethics; it aims to provide an international legal framework to protect and ensure respect for human dignity, human rights and fundamental freedoms by codifying a number of principles and prohibitions with respect to health care, medical research, transplantation and genomics.<sup>2</sup>

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<sup>1</sup> See <https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164>, ETS No.164, Oviedo, 04/04/1997, entry into force 01/12/1999.

<sup>2</sup> See Explanatory Report, Convention on Human Rights and Biomedicine.

5. Article 1 of the Biomedicine Convention states that the instrument's object and purpose is safeguarding the dignity and identity of all human beings and guaranteeing to everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms in the context of the application of biology and medicine. To protect those interests, the Convention establishes a series of principles and prohibitions with respect to bioethics; medical research; consent; the rights to private life and information; organ transplantation; public debate etc.
6. In particular, the Convention guarantees several rights that are critical in the health care context, including the right to respect for private life in relation to information about one's health. Article 10 of the Biomedicine Convention, which is entitled "Private life and right to information", states, among other things, that: "Everyone has the right to respect for private life in relation to information about his or her health." As the Explanatory Report to the Convention notes, the first paragraph of Article 10 guarantees the right to privacy of information in the health care context. In so doing, Article 10 confirms the case-law of the European Court of Human Rights through which the Strasbourg Court has established that, pursuant to the right to respect for private and family life enshrined in Article 8 of the European Convention on Human Rights, people are entitled to respect for and protection of information about their health.<sup>3</sup>

### **The case-law of the European Court of Human Rights on the right to privacy of information about one's health**

7. Pursuant to Article 8 of the European Convention on Human Rights,

"the protection of personal data, not least 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 (art. 8). 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 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

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<sup>3</sup> Article 8 of the European Convention on Human Rights reads as follows "**Right to respect for private and family life**

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

to prevent any such communication or disclosure of personal health data as may be inconsistent with the guarantees in Article 8 of the Convention (art. 8) (see, *mutatis mutandis*, Articles 3 para. 2 (c), 5, 6 and 9 of the Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data, European Treaty Series no. 108, Strasbourg, 1981).<sup>4</sup>

8. The European Court of Human Rights found as much in the case of **Z. v. Finland**, which arose from and concerned the disclosure of the applicant's HIV-positive status in the context of criminal proceedings against her husband. In that case, the Court held that the disclosure of the applicant's identity and of her medical condition, that is, her HIV-positive status, in the text of a domestic court's judgment made available to the media in the absence of any cogent reasons militating for such a disclosure of confidential medical information about her, had amounted to a violation of her right to respect for her private and family life under Article 8 of the Convention.
9. In its 2006 judgment in the case of **Panteleyenko v. Ukraine**, which arose from and concerned the applicant's complaint about the disclosure at a court hearing of confidential information about his mental state and psychiatric treatment, the European Court of Human Rights found that obtaining from a psychiatric hospital confidential information about the applicant's mental state and relevant medical treatment and disclosing it at a public hearing had violated the applicant's right to respect for his private life guaranteed by Article 8 of the Convention.
10. The case of **Armonas v. Lithuania and Biriuk v. Lithuania** arose from and concerned the 2001 publication by Lithuania's biggest daily newspaper of an article on its front page concerning 'an AIDS threat in a remote part of Lithuania'. In its judgment in the case, the European Court of Human Rights reiterated that it was crucial that domestic law safeguarded patient confidentiality and discouraged any disclosures of personal data, especially bearing in mind the negative impact of such disclosures on the willingness of others to take voluntary tests for HIV and seek appropriate treatment. The Court went on to find a violation of Article of 8 and expressed particular concern at the fact that, according to the newspaper, the information about the applicants' illness had been confirmed by medical staff.
11. In the case of **P. and S. v. Poland** too, the European Court of Human Rights reiterated its holdings in *Z. v. Finland* on the fundamental importance of the protection of medical data to people's enjoyment of their "right to respect for their private and family life as

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<sup>4</sup> See, *Z v. Finland*, no. 22009/93, 25 February 1997, para. 95. See, also, Guide on Article 8 of the European Convention on Human Rights, Right to respect for private and family life, home and correspondence, Updated on 31 August 2020, para. 197, p. 48.

guaranteed by Article 8 of the Convention”,<sup>5</sup> as well as on the fact that respect for “the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention. The disclosure of such data may dramatically affect an individual’s private and family life, as well as his or her social and employment situation, by exposing that person to opprobrium and the risk of ostracism [...] Respecting the confidentiality of health data is crucial not only for the protection of a patient’s privacy but also for the maintenance of that person’s 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 seeking appropriate treatment, thereby endangering their own health”.<sup>6</sup>

12. The case arose from and concerned, among other things, the disclosure to the public of personal and medical data about a teenage girl, who had become pregnant as a result of rape and who wished to have an abortion. The Court found, among other things, that “the fact that the issue of the availability of legal abortion in Poland is a subject of heated debate does not confer on the State a margin of appreciation so wide as to absolve the medical staff from their uncontested professional obligations regarding medical secrecy”,<sup>7</sup> and that the disclosure of information about the teenager’s unwanted pregnancy could not “be regarded as compatible either with the Convention standards as to the State’s obligation to secure respect for one’s private or family life, or with the obligations of the medical staff to respect patients’ rights laid down by Polish law. It did not therefore pursue a legitimate aim. That of itself is sufficient to ground a breach of Article 8 of the Convention.”<sup>8</sup>
13. Furthermore, the Court held that the teenage girl “was entitled to respect for her privacy regarding her sexual life, whatever concerns or interest her predicament generated in the local community. The national law expressly recognised the rights of patients to have their medical data protected, and imposed on health professionals an obligation to abstain from disclosing information about their patients’ conditions [...] Yet, despite this obligation, the Lublin hospital made information concerning the present case available to the press.”<sup>9</sup>
14. In light of the above-mentioned findings, the Court went on to hold that the authorities’ disclosure of personal and medical information in the case had constituted a violation of Article 8 of the Convention.
15. Once again, in the case of **Y.Y. v. Russia**,<sup>10</sup> the European Court of Human Rights reiterated that:

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<sup>5</sup> *P. and S. v. Poland*, 57375/08, 30/10/2012, para. 128.

<sup>6</sup> *Ibid.*

<sup>7</sup> *Ibid.*, para. 133.

<sup>8</sup> *Ibid.*

<sup>9</sup> *Ibid.*, para. 134.

<sup>10</sup> *Y.Y. v. Russia*, 40378/06, judgment of 23 February 2016.

- a) personal information about health patients pertains to their private life;
- b) the protection of medical information is of fundamental importance to people's enjoyment of their right to respect for private and family life as guaranteed by Article 8 of the Convention;
- c) respecting the confidentiality of health information is a vital principle in the legal systems of all the Contracting Parties to the Convention, and it is crucial not only to respect health patients' sense of privacy but also to preserve their 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.

16. The case arose from and concerned the applicant's complaint that the St Petersburg Committee for Healthcare had collected and examined her medical records and those of her children and forwarded its report containing the results of its examination to the Ministry of Healthcare without her consent. With respect to this, the Court found that the disclosure of medical data to public bodies without the applicant's consent had constituted a violation of Article 8 of the Convention.

17. In its 2018 judgment in the case of *Mockute v. Lithuania*, which arose from and concerned the applicant's complaint that a publicly run hospital had revealed highly personal and sensitive, confidential information about her private life to journalists and to her mother, the European Court of Human Rights confirmed, among other things, that the right to respect for private life as guaranteed by Article 8 of the Convention provides specific protection for personal data, including protection of personal health records. In its judgment in the case, the Court went on to find that:

- a) the hospital had unlawfully shared private information -- including about the applicant's sexual life, her diagnosis of acute psychosis and references to her treatment -- without her consent;
- b) those disclosures, as well as those made to the applicant's mother, had amounted to an interference with her right to privacy; and
- c) the disclosures had constituted a failure on the part of the hospital as a State agent to abide by international legal obligations and domestic health and data protection laws.

18. In light of the above-mentioned findings, the Court concluded that there had therefore been a violation of Article 8.

## CONCLUSIONS

19. Both the Convention on Human Rights and Biomedicine and the case-law of the European Court of Human Rights under Article 8 of the European Convention on Human Rights establish that the right to private life, in turn, guarantees the right to respect for and protection of information about one's health, such as personal and medical data, including relating to an abortion, to one's sexual life and references to one's health treatment. Disclosure of information about people's health will engage Article 8 and constitute an interference with their right to respect for private life under that provision unless the individuals concerned have unequivocally waived their right to respect for private life with regard to that information.<sup>11</sup>
20. The case-law of the European Court of Human Rights under Article 8 of the European Convention on Human Rights has further established that Contracting Parties to the Convention must ensure that their domestic law provides effective and adequate safeguards against abuse, and to prevent disclosure of personal health information.<sup>12</sup>
21. In the first place, any interference with the right to respect for private life under Article 8 must be "in accordance with the law", have a legal basis and be foreseeable. Furthermore, under Article 8, interferences with the right to respect for and protection of information about one's health, such as those caused by disclosures of medical information, including relating to an abortion, will be incompatible with Article 8 unless they are justified by an overriding requirement in the public interest,<sup>13</sup> or when they are in the interest of the person concerned or in the interest of the safety of medical staff.<sup>14</sup> Protecting the confidentiality of information about one's health will therefore weigh heavily in determining whether the interference, i.e. the disclosure, was proportionate to the legitimate aim pursued. Finally, the disclosure will have to be "necessary in a democratic society" and proportionate to the legitimate aim pursued if it is to be consistent with Article 8 of the Convention.

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<sup>11</sup> *M.S. v. SWEDEN*, 20837/92, 27 August 1997, paras 32-33.

<sup>12</sup> *Z v. Finland*, para. 95; *Mockute v. Lithuania*, paras 93-94.

<sup>13</sup> *Z v. Finland*, para. 96.

<sup>14</sup> *Y. v. Turkey*, 648/10, 17 February 2015, paras 77-78.