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JURIDICAL RECONSTRUCTING OF MEDICAL DATA PROTECTION IN MACHINE LEARNING TO FULFILL THE RIGHT TO HEALTH

Dyah Nur Sasanti[1], Megawati Barthos[2]
Borobudur University[1], Borobudur University[2]
Email : dyah_nsasanti@borobudur.ac.id[2], megawati_barthos@borobudur.ac.id[2]

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Abstract

The use of machine learning in the health sector has significantly changed the way medical personal data is managed and utilized. This technology improves the quality of health services, but at the same time poses a risk of violations of the right to health and the right to privacy due to algorithmic bias, lack of transparency, and weak data governance. This research aims to analyse the position of the right to health as a binding norm in the framework of medical personal data protection in Indonesia and to formulate an inclusive juridical reconstruction to mitigate risks. The research method used is normative juridical with a laws and conceptual approach, through the study of legal materials that collected by literature studies. The results of the study show that although the 1945 Constitution of Republic Indonesia, the Health Law, the PDP Law, and the ITE Law have provided a strong normative basis, there are still gaps due to the lack of specific regulations regarding algorithm audits, human rights impact assessments, and independent oversight. In conclusion, it is necessary to reconstruct regulations and strengthen supervisory institutions so that digital health innovations can apply in a fair, inclusive, and in line with the principles of non-discrimination. The author recommends to the Government to prepare regulations regarding the technical implementation of medical personal data protection, health service practitioners and digital health technology providers apply the principles of privacy by design and security by default, and encourage academics and legal researchers to develop studies about it.

Keywords: Human Rights; Machine Learning; Medical Personal Data; Protection of Personal Data; Right to Health;

A. INTRODUCTION

Human rights are universal, permanent, and sustainable, so the state is obliged to respect and protect them by ensuring that every citizen, without exception, obtains them equally in all aspects of life. The right to health is a human right that is constitutionally guaranteed in Article 28H paragraph (1) and Article 34 of the 1945 Constitution of the Republic of Indonesia, which is further regulated in the Law Number 39 of 1999 concerning Human Rights (Human Rights Law), Law Number 11 of 2005 concerning the Ratification of the International Covenant on Economic, Social and Cultural Rights (ICESCR Ratification), and Law Number 17 of 2023 concerning Health (Health Law). Health has a significant role in national development, therefore the right to health cannot be taken away (inalienable) and should be seen as a coercive norm (jus cogens), which includes not only access to quality medical services, but also a range of other factors that affect a person's physical and mental well-being (Dumako and Trisista 2024).

The development of human civilization today is characterized by disruption due to the advancement of digital technology that touches almost all aspects of life, including the health sector. This transformation brings us to an era where data is not just an administrative record, but a strategic asset that determines the quality of life and public safety. One of the most significant developments in the health sector is the use of artificial intelligence in the form of machine learning that digitizes health data to create a more efficient, accurate, and integrated service ecosystem, for example for telemedicine services, electronic medical records, and digital health applications.

The availability of massive and high-quality medical personal data as the main source for algorithmic learning in machine learning. Machine learning that processes medical personal big data into revolutionary instruments capable of improving the diagnosis of diseases, treatment methods tailored to each individual, chronic disease management, public health surveillance, development of new drugs, and overall medical research. Benefits of machine learning also felt by healthcare providers, researchers, and policymakers to make better decisions, improve the quality of care with reduced costs, and improve the quality and overall health outcomes (Iskandar, et al. 2024). But on the other hand, there is a possibility that the results of big data processing by machine learning is not representative, biased, inaccurate, ineffective, and cannot explain so that it will have implications for the autonomy of patient as the data subject (Librianty and Prawiroharjo 2023).

The right to health is no longer only interpreted as access to medical facilities, but also includes the protection of the confidentiality of information on patients' personal medical data. The confidentiality of medical personal data is also fundamentally a human right that is constitutionally guaranteed in Article 28G paragraph (1) of the 1945 Constitution of the Republic of Indonesia. In contrast to personal data in general, medical personal data is categorized as sensitive data with special characteristics because it is closely related to the most private aspects of a person's life, namely information about physical and mental conditions. Safe, fair, and inclusive management of medical personal data is a prerequisite for the realization of quality and equal health services. Conversely, failure to protect medical data can have a direct impact on the quality of diagnosis and treatment patients receive, potentially violating human rights. Historically, the protection of medical personal data secrecy has its roots in the Hippocratic Oath which emphasizes the ethical obligation of physicians to maintain patient confidentiality. This principle has been formalized through various regulations, especially the Health Law.

The presence of machine learning creates a new legal relationship involving third parties, namely technology developers and platform providers, who are not directly bound by the medical code of conduct. The process of extracting and processing medical personal data by machine learning is very likely to blur the line between the interests of technological innovation and the right to patient privacy. Medical personal data, which was once considered a sacred medical secret, is now transformed into an information commodity that is vulnerable to exploitation. This raises juridical challenges related to the protection of a person's privacy, which is now expressed in the form of digital data. Unauthorized management of medical personal data has the potential to have serious consequences, both for the subject of the data and for the institution that stores the data.

People tend not to understand the importance of maintaining the privacy and security of their personal medical data (Meher, Sidi and Risdawati 2023), however, the state is still obliged to actively enforce regulations regarding the security system for the protection of medical personal data from unauthorized access, through the personal data protection authority institution (Aqilah, Waryenti and Susanti 2024). The protection of medical personal data regulated in the Human Rights Law and the Health Law, more specifically regulated in Law of the Republic of Indonesia Number 19 of 2016 concerning Amendments to Law Number 11 of 2008 concerning Information and Electronic Transactions (ITE Law), and Law Number 27 of 2022 concerning Personal Data Protection (PDP Law). The promulgation of the ITE Law and the PDP Law actually raises its own beliefs in an effort to strengthen data sovereignty, because it explicitly places medical data as specific personal data whose processing requires a strong legal basis and very strict safeguards. However, at the level of development implementation machine learning, creates tension between the interests of human rights protection and the interests of technological innovation for efficiency. In addition, there is also a dilemma between the principle of goal limitation and data minimization, where the nature of the algorithm machine learning requiring big data often collides with legal principles that require data to be used only for specific, limited purposes. Unfortunately, currently there are no laws and regulations that specifically regulates the use of medical personal data in relation to the use of machine learning, and the risk of algorithmic bias also its implications for the right to health.

Studies on medical personal data protection in the context of machine learning have generally focused on issues of data privacy, cybersecurity, and compliance with personal data protection regulations. A number of studies only emphasize the importance of consent mechanisms, data anonymization, and data governance in the health sector. This shows that there is still a lack of understanding of the protection of medical personal data as an integral part of the fulfillment of fundamental and binding human rights, especially in the context of the risk of bias and algorithmic discrimination. Based on this description, it is important to study normative juridical regarding the protection of medical personal data in order to mitigate the risk of using machine learning in the framework of fulfilling human rights to health.

B. METHODOLOGY

Legal research is a process to seek scientific truth about law by using methodical, systematic and logical scientific methods to solve legal problems or find the truth (answer) of legal events that occur both theoretically and practically (Widiarty 2024). This research is an analytical descriptive research that aims to make a systematic, factual, and accurate description of the facts, natures, and relationships between the phenomena being studied. The normative juridical method is the main approach in dogmatic legal research, known as the pure legal approach or the internal approach using dogmatic legal optics (Susanto 2015). The author conducted research with a legislative approach (statute approach) which examines all laws, namely regarding their conformity and consistency by studying ratio legist and the ontological basis of a law (Susanto 2015). The legal materials used are primary, secondary and tertiary legal materials, which are collected through literature studies.

C. RESULTS OF RESEARCH AND DISCUSSION

1. The Position of the Right to Health as a Compelling Norm in the Regulation of Medical Personal Data Protection against Machine Learning Disruption in Indonesia

International Covenant on Economic, Social and Cultural Rights (ICESCR) regulates the right to health as part of economic, social, and cultural rights. Initially, the right to health was not directly included in the category non-derogable rights, but in its development in certain aspects the right to health is strictly considered to have the character of non-derogable because it relates to the right to life of a person and the prohibition of torture. The right to health is related to the right to life of a person so its fulfillment should not be diminished (Rahman 2025). Protection of the right to health becomes state’s core obligations to protect and these obligations cannot be suspended, especially in emergency conditions, which include the provision of access to health services and medicines.

The presence of the PDP Law, the ITE Law, and the Health Law in the framework of Indonesian law has integrated the protection of medical personal data which is specific data that requires special treatment as part of the right to health that must be maintained, while providing public interest-based restrictions. The principle of confidentiality is the central principle and the principle of public interest is the basis for the legitimacy of its limitations. Even if individual rights are important, the state may restrict these rights for the benefit of the general public. The state balances between the protection of personal rights and public needs, so that the law must accommodate public welfare, such as health research or disease prevention, as long as it is carried out in a limited manner and regulated by law by prioritizing the principles of justice and proportionality. The confidentiality of medical personal data can only be waived in certain public interest situations, such as outbreak management, law enforcement, limited education/research, and health financing interests, as affirmed in Article 4 paragraph (2) of the Health Law. Medical personal data controllers are also subject to the obligation to maintain the confidentiality of the data processed, meaning that healthcare providers are obliged to ensure the security of systems and internal policies so that patient data is not misused.

On an international scale, various standards have placed health as a basic right that requires strict protection of medical personal data. Committee of Economic, Social and Cultural Rights interpret that healthcare facilities and services must respect medical ethics and design systems that guarantee the confidentiality of patient data. The protection of health data is not just a technical policy, but an international human rights obligation. In addition, digital health global strategy by World Health Organization (WHO) classifies medical personal data as very sensitive and requires high security standards, so WHO encourages member countries to build inclusive and ethical digital health strategies, as well as medical personal data infrastructures that pay attention to security, privacy, and interoperability. WHO recommends the implementation of privacy by design in order for digital innovation to strengthen the principle of confidentiality (EOLAS 2021).

The European Union, through its General Data Protection Regulation (GDPR) more explicitly regulates the prohibition of the processing of medical, genetic, or biometric personal data without a specific legal basis, such as the explicit consent of the data subject or public health interests, so that clinical recommendations based on artificial intelligence, in this case machine learning, must include human control or patient consent. Data protection authorities are actively issuing specific guidelines for health and artificial intelligence, including the obligation to conduct data protection impact assessments and limit foreign data transfers. Germany requires an ethical process and explicit consent for medical data research, while the United Kingdom engages an ethics committee for the evaluation of artificial intelligence technology on patients. Singapore and South Korea issued specific policies for telemedicine and medical personal data during the pandemic, including encryption standards and data subject consent.

Unfortunately, in Indonesia there are still systemic weaknesses in digital health data governance (Nadiroh and Wiraguna 2025). Normatively (law in books), although Indonesian law has established the right to health as a constitutional right that is binding and compulsory, it also includes the protection of the confidentiality of medical personal data, which in principle imitates some international provisions and practices, but the implementation stage and scope are still minimal and not detailed. At the level of practice (law in action), there are still real gaps and inconsistencies, both in the public and private sectors, which provide digital health services. In the public sector, the digitalization of health systems such as electronic medical records and national health service applications is more oriented towards policy efficiency and data integration, while aspects of protecting medical personal data have not been fully accompanied by adequate security and oversight standards. Laws and regulations that The regulation is very general and has not applied specific personal data protection principles indicating that there is no maximum protection so that there is still medical personal data that can be easily accessed by other parties without any agreement with the data subject concerned (Rosadi 2016). In the private sector, the gap between law in books and law in action seems more complex, where by law machine learning providers are obliged to comply with the principle of protecting medical personal data, but in practice the consent of data subjects is often formalistic and not accompanied by adequate transparency regarding the purpose of data processing and how algorithms work.

The gap between law in book and law in action is further widened by the lack of specific regulations on mitigating the risk of algorithmic bias in digital health services. Indonesia does not yet have provisions that specifically regulate algorithm audit obligations, human-in-the-loop, as well as human rights impact assessment in the use of machine learning. As a result, in practice, algorithm-based medical recommendations or decisions have the potential to discriminate against vulnerable groups, which is substantively contrary to the principle of non-discrimination as the core of the right to health (Aqilah, Waryenti and Susanti 2024). This condition has implications for the potential legal responsibility of the state and digital health service providers. The state can be seen as negligent in fulfilling its constitutional obligations if it fails to provide effective supervision and law enforcement, while service providers could potentially be subject to administrative sanctions or civil lawsuits for the breach of medical personal data. Therefore, it is necessary to improve implementing regulations, strengthen independent institutions that carry out supervision of medical personal data protection, and integrate a human rights-based approach so that the right to health does not stop at the normative level, but is implemented in real life in the practice of digital health services.

2. Juridical Reconstruction of Inclusive Protection of Medical Personal Data to Mitigate the Risk of Algorithmic Bias as a Form of Fulfillment of Human Rights for Health

The main legal problem in the use of machine learning in the health sector lies in the lack of a ready-made Indonesian legal framework to ensure that the processing of medical personal data takes place in a fair, inclusive, and discrimination-free manner. In fact, according to progressive legal theory, whenever there is a problem in and with the law, it is the law that needs to be reviewed, corrected, and reconstructed, citizens cannot be forced to enter in the problematic legal scheme (Aulia 2018). Progressive legal theory views law as not static, but as an instrument of substantive justice which demands that regulations accommodate all changes that occur, in this context the normative reconstruction of medical personal data needs to follow the dynamics of social and technological developments. The law must not stop at normative certainty, but must be able to respond to social realities and the risk of algorithmic bias as a novelty. The law must also be a tool of social empowerment that quickly adjusts without abandoning the value of justice. The inequality of digital access and the risk of bias in algorithm-based systems make the law required to be more adaptive, inclusive, and humanitarian-friendly so that no one is left behind in this transformation process (Nugroho and Bijaksana 2025).

Inclusive protection of medical personal data must be understood as a legal instrument to ensure that the use of machine learning truly functions as a means of improving the quality of health services, not as a new source of injustice. To mitigate the problems that currently occur, juridical reconstruction is needed to rely on the principle of non-discrimination, the precautionary principle, and the principle of proportional public interest. The principle of public interest can be the basis for justifying the large-scale use of medical personal data for technological innovation, but it must be strictly limited so as not to compromise individual rights. The principle of proportionality demands that any use of medical personal data for machine learning be accompanied by a guarantee that the resulting public benefits are not achieved at the expense of vulnerable groups or minorities.

Juridical reconstruction can be carried out, among others, through amendments to the PDP Law, the ITE Law, and the Health Law which add explicit regulations regarding the obligation of data protection impact assessment and algorithmic impact assessment, specifically for the processing of medical personal data based on machine learning, for example by requiring privacy by design and security by default in electronic medical record systems. This is in accordance with the principle of prudence and proportionality that has been affirmed in Article 16 and Article 39 of the PDP Law, as well as in line with international practice, so that it should be further developed through ministerial regulations or independent personal data authority regulations. Furthermore, juridical reconstruction can also be carried out through the addition of provisions in ministerial regulations or government regulations that require digital health service providers to publish algorithmic policies and ensure public participation in testing systems using machine learning as a tangible manifestation of artificial intelligence. This publication aims to uphold the principles of transparency, accountability, and the right to information, as well as strengthen social control over algorithm-based medical decision-making. In the long term, these efforts will bring digital healthcare practices closer to the principle of substantive justice in a responsive legal framework that favors the rights of data subjects as legal subjects that are fully protected by the constitution and laws.

Juridical reconstruction also requires strengthening the role of the state through the establishment and strengthening of an independent personal data protection supervisory institution that is authorized to carry out substantive supervision of algorithmic justice in the digital health service system, both in public and private health service facilities. Without effective oversight, legal norms have the potential to become symbolic and lose their binding force. This can be done through a data protection authority that has the authority to review the algorithm system based on the principle of non-discrimination as stipulated in Article 28I paragraph (2) of the 1945 Constitution and the principle of public interest protection in Article 15 of the PDP Law. The authority should also be given the authority to issue technical guidance on data standardization and model inclusivity in the development of digital health algorithms.

D. CONCLUSION

Based on this research, it can be concluded that the right to health in the context of the use of machine learning in the health sector in Indonesia has been normatively placed as a constitutional right that is binding and coercive, including the protection of medical personal data as an integral part of the fulfillment of human rights, but its implementation still faces a serious gap between law in books and law in action. The result of this research show that although the national regulatory framework through the 1945 Constitution, the Health Law, the PDP Law, and the ITE Law have provided a legal basis for the protection of medical personal data, these regulations have not specifically and operationally accommodated the risk of algorithmic bias, lack of transparency, and potential discrimination in the use of machine learning, so that the purpose of the study to assess the effectiveness of human rights protection for health has not been fully achieved. Theoretically, this study emphasizes the importance of a progressive and human rights-based legal approach in responding to technological disruption, by placing the protection of medical personal data not just a technical issue of privacy, but as a prerequisite for substantive justice and non-discrimination. Meanwhile practically, this research has implications for the urgency of regulatory reconstruction through the obligation of data protection impact assessment, algorithmic impact assessment, and strengthening the role of independent supervisory authorities so that digital health innovation runs in balance with the protection of patient rights. The contribution of this research lies in expanding the discourse on health law and data protection by integrating the issue of algorithmic bias as a real human rights risk, even though it still has limitations because it is normative-descriptive and has not empirically examined the practice of implementing machine learning in certain health facilities.

E. RECOMMENDATION

The author suggests to the Government to prepare more technical and operational implementing regulations from the PDP Law, ITE Law, and Health Law, especially related to algorithm transparency standards, human-in-the-loop mechanisms, and strengthening personal data protection supervisory institutions that are independent and authorized to conduct substantive audits on the digital health system. Healthcare practitioners and digital health technology providers are advised to actively apply the principles of privacy by design and security by default in the entire medical personal data management cycle, including by conducting data protection impact assessments and algorithmic impact assessments before and during the use of machine learning, to minimize the risk of data leakage, algorithmic bias, and violation of data subject rights. Academics and legal researchers are expected to use the results of this research as the basis for the development of interdisciplinary studies between law, ethics, and technology, both in the form of curriculum, advanced research, and policy texts, so that the discourse on the protection of medical personal data does not stop at the normative level, but is able to provide applicable guidance that supports machine learning innovation that is fair, inclusive, and in line with the fulfillment of the right to health as a human right.

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