

ORIGINAL ARTICLE

Lesson From Indonesia National Healthcare Security (BPJS Kesehatan): HIV/AIDS Patient Medical Data Protection Policies

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ABSTRACT

Introduction: There are many problems regarding the leakage of personal data in Indonesia, one of which is the leakage of medical data. Patient data is listed in a document called medical records. This paper discusses HIV/AIDS patient data privacy and public information disclosure. **Materials and methods:** This was dogmatic research which employed a statutory approach and a conceptual approach. **Results:** Regulations for medical data specifically regarding HIV/AIDS patient data in Indonesian laws and regulations are contained in Law Number 17 of 2023 which regulates health workers. Concerning the legal aspects of personal data protection, there must be special attention to HIV/AIDS patient data, privacy, and public information disclosure, especially the data protection. The data leakage case from the National Health Security (BPJS Health) which leaked hundreds of millions of data should be used as learning material for the government to increase data security, including data on medical colleagues for HIV/AIDS patients after it is established. **Discussion:** Data protection provisions regarding patient data are listed in the Personal Data Protection (PDP) Law. Medical records of HIV/AIDS patients are included in a specific data category in the PDP Law. The PDP Law has very strict regulations on the disclosure of specific data based on its management and processing. **Conclusion:** The author sees that there are limitations in the aspect of public information disclosure regulated in the Public Information Disclosure Act. Medical records are information that can be exempted from being disclosed to the public for certain reasons.

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INTRODUCTION

Technologies play a crucial role in the social order of the current digital era (1). The interaction patterns that were originally only identified as physical have now shifted (2) as people no longer need to come face-to-face to meet one another (3). This era is marked by various technological innovations, such as the emergence of the cloud computing industry.

Information and communication technologies act as a solution to facing the issue of social distancing. Technology users are demanded to provide electronic information in the form of personal data. This development certainly leads to the occurrence of issues, one of which is the leakage of personal data.

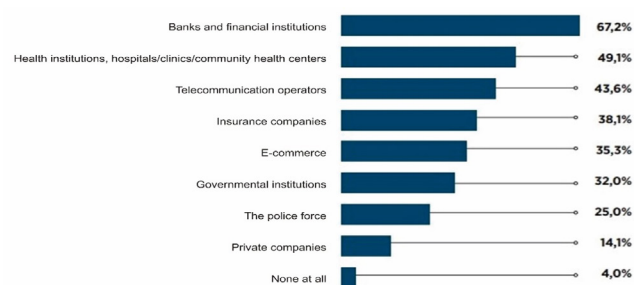


Figure 1: Institutions that Collect Personal Data.

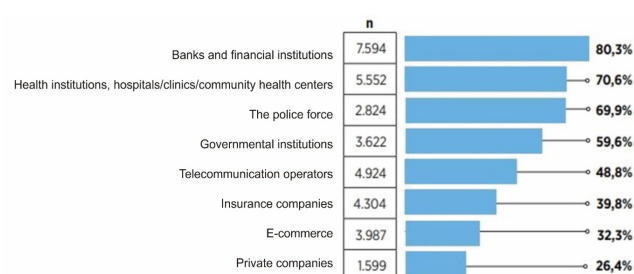


Figure 2: Institutions Trusted to Protect Personal Data.

According to the National Survey of 2021 conducted by the General Directory and Secretary of Information Application, health institutions are placed at the second rank in the category of institutions that collect personal data and institutions that are trusted to protect personal data even the most massive data leaked is from health related institution (The National Healthcare Security) (4). Trust in the data security of health institutions is not something strange because so far there has almost never been a leak of personal data at health institutions. The massive data leak from the National Healthcare Security by Social Health Insurance Administration Body (Badan Penyelenggara Jaminan Kesehatan Nasional, Abbreviated as BPJS Kesehatan) that occurred did have quite a big impact where the health institution which was previously ranked 1st in public trust in data security dropped to 2nd place.

The cases of personal data abuse which bring loss to society happened in various parts of the Indonesian territory in the last few years . The greatest data leakage case is from National Healthcare Security (BPJS Kesehatan) with 279 million data (5). Besides that, there are several massive personal data leakage cases, including data leakage from *Bank Syariah Indonesia*/the Indonesian Sharia Bank (15 million) (6), citizen data from the General Election Commission (2.3 million personal data) (7), personal data from Tokopedia e-commerce (91 million personal data) (8), and Telkomsel, i.e., a cellular telecommunication company (8.9 million). Based on the survey, it was found that 28.7% of society feels they have become victims of personal data abuse. When related to an institution, there are times when society

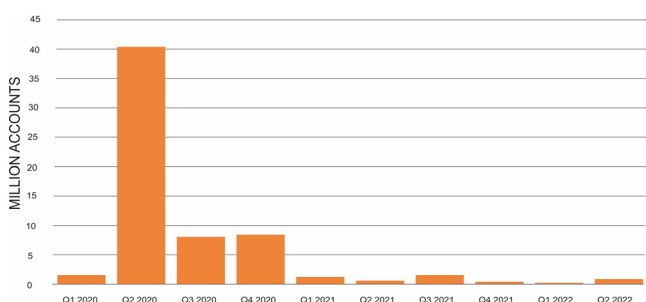


Figure 3: Cases of Personal Data Leakage in Indonesia.

shares personal data with those institutions. According to Surfshark, a cyber security business, 1.04 million accounts in Indonesia had user data leakage in the second quarter of 2022. The number of accounts experiencing data leakage in Indonesia has fluctuated from the first quarter of 2020. The peak occurred in the second quarter of 2020 when 39.6 million Indonesian accounts were compromised. The number of accounts with data leakage in Indonesia then fell to 669.4 thousand in the second quarter of 2021. Nonetheless, this figure rose again in the third quarter of 2021. The number of data leakage instances in Indonesia declined again between the end of 2021 and the first three months

of 2022. However, as shown in the graph above, it witnessed another sharp spike in the second quarter of 2022 (9).

In this research, the authors will discuss the protection of patients’ medical data. A case of data leakage related to health happened in 2021. The data leakage occurred at the *Badan Pengelola Jaminan Sosial Kesehatan* (Social Security Agency on Health, abbreviated as BPJS Kesehatan), where at least 279 million data were stolen, consisting of their ID Card numbers, phone numbers, and original address based on the ID Card. These data also included the records of their health conditions and diseases (10) . The Government ordered *Badan Siber dan Sandi Negara* (State Cyber and Code Agency, abbreviated as BSSN), the Ministry of Defense, and the Directorate of Cyber Crime to build a security system for the National Health Security’s data safety as well as capture the perpetrator.

In Indonesia, there has only been this one case of data leakage in the health sector, but it is very massive. According to the stipulations, a person’s medical records are confidential data that cannot be carelessly disclosed to the public except during legal or trial processes under *pro justicia* reasons (11), as stipulated in the Regulation of the Minister of Health No. 269/Menkes/Per/III/2008 (12).

The dilemma at the implementation level can be very strongly felt in the medical sector. The human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) is a sexually transmittable disease (13) which weakens the host’s immunity. This is different from AIDS, which is a disease that is caused by the degradation and weakening of a person’s immunity. In 2019, there were 50,282 cases of HIV/AIDS in Indonesia. According to the Association of Indonesian Children’s Doctors (*Ikatan Dokter Anak Indonesia/IDAI*), 1,188 children suffer from or are infected by HIV/AIDS (14). This condition has reached a concerning point as HIV can very quickly spread and it targets the immune system in the human body. Apart from that, no effective cure has been found (15).

Doctors’ professional code of ethics regulates the obligations of doctors to keep the secrets of patients. The results of the doctor’s examination are written in the patient’s medical records (16). Privacy is an important thing in the current era of information transparency. Alan Westin as quoted by Kusnadi and Wijaya, defined privacy as a claim made by an individual, a group, or an institution to independently determine when, how, as well as what information is desired to be disclosed through communication with other parties (17).

Privacy is contrary to the phrase “information disclosure”. A dilemma arises when discussing these two matters. Concerning information disclosure, the Indonesian

government and the People's Representative Assembly issued Law No. 14 of 2008 on Public Information Transparency.

An interesting issue to be discussed concerns the relationship between public information transparency and the privacy aspect of data owners of HIV/AIDS patients. In this paper, the writer will profoundly analyze the rights of HIV/AIDS patients in the scope of personal data protection. In this research, the author will analyze (1) the regulations on the medical records of HIV/AIDS patients in the Indonesian legal regulations; (2) legal policies on data protection and the privacy of HIV/AIDS patients from the perspective of public information transparency; and (3) lessons from the data leakage case of the National Health Security (BPJS Kesehatan) HIV/AIDS patients in Indonesia.

MATERIALS AND METHODS

This research used the non-doctrinal method (18). The non-doctrinal research was chosen because the researcher observed that there was a contradiction between legal norms, the regulation on data privacy, and *the das sein* (law enforcement or implementation). In this research, the writer employed two approaches, namely the statute approach, the sociological approach (19) and the legal protection approach. This was because the researcher analyzed the object through the perspective of the law on public information disclosure and the law on data protection (15). Meanwhile, the legal protection approach was used because the aim of the data protection for HIV/AIDS patients is to protect them from the misuse of the data. The author will also analyze the issue of information disclosure and its link to medical workers' safety (21, 22). The researcher also employed the literary approach (23). The author used primary, secondary, and tertiary sources in this research. For the technique of data analysis, the author employed the descriptive qualitative technique of analysis (16).

RESULTS

Indonesian Regulations on Medical Data

Medical data contains a person's identity as well as all notes made by medical workers concerning that person. It may be used as valid evidence related to the *pro justitia* process in law enforcement (24). Some laws regulate medical records. First, it is Law No. 17 of 2023 on Health. It states that every health worker who provides individual health services must provide and create medical records of the health service recipients. According to this law, the confidentiality of medical records must be well-guarded, especially by health workers and directors of that health facility. Medical records are also regulated in the Governmental Regulation No. 46 of 2014 on the Health Information System (25). Article 17 letter b of the Governmental Regulation on the Health Information System regulates

data and information collection. The writer inventoried regulations on medical records regulated in Article 29 clause (1) of the Regulation of the Minister of Health No. 24 of 2022 on Medical Records. Medical Records are divided into two: (1) non-electronic medical records and (2) electronic medical records.

The Ministerial Regulation on Medical Records, the existence of medical records has four objectives. First, medical records' existence aims to increase the quality of health services. Second, it aims to provide legal certainty in organizing and managing medical records. Third, it is made to guarantee the existence of the safety, confidentiality, unity, and provision of medical records. Fourth, it aims to create a digital-based organization and processing of medical records with good integrity. Medical records are organized by an electronic system developed by the Ministry of Health.

Article 22 clause (3) of the Ministerial Regulation on Medical Records states that electronic system establishers are prohibited from opening, taking, manipulating, and damaging the data as well as undergoing activities on data usage and other activities that may bring harmful impacts to the health service facilities (26).

Further, the non-disclosure agreement is always equipped as an attachment in the case of cooperation agreement activities with health service facilities (27). It stipulates that the privacy aspect of an HIV/AIDS patient must be well-kept. The Ministerial Regulation on Medical Records of Article 26 clause (1) strictly regulates that the contents of medical records are owned by the patients. Its contents may be delivered to other parties such as family members under certain conditions, such as if the patient is underage or due to the order of judges.

Stipulations in Article 28 of the Ministerial Regulation on Medical Records determine that health service facilities must give access to all substantial contents of a patient's electronic medical records to the Ministry of Health (28). The state through the Ministry of Health can access this data to develop knowledge and technologies.

A request for the activity of disclosing medical records must always exist in a written and/or electronic form. Medical records can be opened with the patient's approval. Article 34 stipulates that first; it may be for health maintenance. Second, it may be carried out at the request of the concerned patient. Third, it may regard the interests of administrative activities. There are some cases where the patient is not equipped with proper legal knowledge. In such a case, the approval is in the hands of the closest family members, namely the husband or wife, adult child, biological parents, as well as biological siblings (29).

Further, the disclosure of medical records without the approval of the patient can be carried out under certain

interests as regulated in the Ministerial Regulation on Medical Records. First, if it concerns the request of the law enforcing apparatus in the *pro justitia* process. Second, if it concerns the enforcement of ethics or discipline from stakeholders. Third, if it concerns the activity of medical audit. Fourth, if it concerns extraordinary activities such as an epidemic. Fifth, if it concerns activities in education and research. Sixth, if it is to protect the individuals or the general society from the dangers of other people's health threats.

Article 35 clause (2) of the Ministerial Regulation on Medical Records explains that even though the Medical Records are disclosed, the identity of those patients is still confidential (30). However, the patient's identity can be disclosed to the authorized institution based on a certain interest. First, if it concerns the handling of extraordinary activities such as an epidemic of infectious disease or the condition of a public health emergency. Second, it may be carried out if it concerns efforts to protect individuals or the general society from the dangers of other people's health threats (31).

DISCUSSION

The Legal Policies on Data Protection and Privacy of HIV/AIDS Patients in the Perspective of Public Information Transparency

Privacy is precious for individuals. Zelman Cowan explained that a person without privacy is a person without dignity (32). Privacy and the legal liability towards personal data bring about challenges for related parties such as the government, law enforcers, and industrial actors. This challenge is even more felt in the strengthening of the digital era.

In the global scope, privacy has two perspectives, namely the subjective approach and the objective approach. The subjective approach is adopted by the United States and it perceives that privacy is an aspect of freedom or liberty (33). This is different from the perspective of countries in Europe which perceive privacy as dignity. In the case of privacy as freedom, privacy accepts the existence of differences and it considers that there are social norms that can be ignored. It perceives that a person has the right to determine something based on his/her thoughts. On the contrary, privacy as dignity shows that a person prioritizes cooperation. People who embrace this perspective respect and accept the implementation of social norms and they feel that they are connected to one another as a unit of communal society that interacts based on the similarity of norms.

Referring to Indonesia, the clauses in the constitution do not explicitly state the right to privacy. The clause of the Republic of Indonesia's 1945 Constitution Article 28G clause (1) states that "Every person has the right for protection on themselves, their families, their dignity, their honour, and the wealth under their power, as well

as having the right over a sense of security and protection from the threats of fear to do or to not do things that are part of their right." Referring to that article, there are no explicit phrases that state protecting a person's privacy. The existing *clausula* is the phrase on the protection over an individual person.

The protection of an individual person can be defined as holistic protection for a person when that person communicates and interacts. The object of privacy encompasses privacy over information, physical condition, communication, and territory, as implied from the "the right for protection on themselves". Thus, this phrase can be deemed as a manifestation and a translation of privacy (34). The Indonesian constitution does not directly define the meaning of privacy. The protection of privacy and data, especially medical data is regulated in Law No. 27 of 2022 that has been enacted. The Law on Personal Data Protection (the PDP Law) is a law which specially regulates stipulations of a person's personal data. Philosophically, this law must provide protection to guarantee that people's rights are fulfilled. Apart from that, every individual must obtain adequate acknowledgement and respect (35).

The PDP Law regulates two types of personal data, namely specific personal data and general personal data. General personal data includes full name, identity, gender, citizenship status, religious identities, marital status, and identifying data (36). Meanwhile, specific personal data is regulated in Article 4 clause (2) which states that there are some specific data that are part of specific personal data. Specific data includes health information, biometric data, genetic data, child data, financial data, as well as other data stipulated in the legal regulations. The writer perceives that medical record data, both electronic and non-electronic are categorized as health data. Therefore, it is categorized as specific personal data.

According to the PDP Law, Explanation Letter A and Article 4, specific personal data means that these data have great impacts and influences on the owner of that data (37). Discriminative actions and great losses may occur in case these specific personal data are leaked. Then, health data and information based on the stipulation in the Explanation Letter A and Article 4 clause (2) of the PDP Law are records and information of individuals concerning physical health, mental health, as well as the health services they obtained. Therefore, the writer perceives that electronic and non-electronic medical records are categorized into health data.

Law No. 36 of 2009 57 clause (2) contains stipulations on conditions where the confidentiality of a person's health status does not apply due to the following causes: First, based on the order of a law. Second, the court ordered its disclosure. Third, there is approval from the patient to disclose the confidential health condition. Fourth, there

is an urgency based on the interests of society. Fifth, there is an interest of that person. The writer sees that the stipulations of that article contain certain requirements in case one desires to disclose the health condition of a patient. This is relevant to the medical records of HIV/AIDS patients. Based on this article, medical records can be opened under certain conditions.

From the aspect of the legal stipulations on the transparency of public information, public information transparency has a very close relationship with the definition of information. Information is further regulated in Law No. 14 of 2008 on the Public Information Transparency. This law stipulates that information is an explanation in the forms of declarations, ideas, and symbols that have valuable meanings, and definitions, as well as containing messages that can be fully presented in the form of data and facts. It can be seen, heard, and read (38). All of this can be presented in a package and format according to the development of the era and technologies, both electronic and non-electronic.

Information that can be disclosed and published to the public is public information. Thus, it is not random or special information that is not consumable to the public. The Law on Public Information Transparency defines public information as information that is made, stored, managed, delivered, as well as received by a public agency related to the state establishment or establishments of other public agencies based on the law that is related to public interests. Based on the above definition, it can be understood that such information that is processed by public agencies and information related to the public will be limited.

A national database of medical records is crucially needed by doctors and medical staff, especially for deadly and infectious diseases such as HIV/AIDS. A database of patient medical records is needed so that doctors and medical staff can find out early whether the patient they are treating has an infectious and deadly disease such as HIV/AIDS or not. It is also to ensure the use of special health protocols in treating patients with such diseases. The database must be on a national scale so that wherever a patient goes for a check-up or undergoes a medical procedure, it can instantly be known by doctors and medical staff. This gives doctors and medical staff the time to prepare health protocols for their safety.

Access to patient medical data is also accompanied by strict legal sanctions if a doctor or medical officer leaks medical data, considering that patients also have the right to protect their personal data. Experience in the pandemic era shows that the absence of a national medical record database has brought a disaster. Many doctors and medical staff have died because patients did not act honestly when they had contracted an infectious disease. The deaths of doctors and medical staff were

due to infection and could have been prevented if health protocol procedures had been carried out.

Medical record data of HIV/AIDS patients are certainly not information that is managed by a public agency. Medical records managed by the Ministry of Health also do not include and comprise the identity of the medical record data owner. Apart from that, diseases caused by HIV is not a disease like Covid-19 that can quickly spread through the air. HIV can only spread to other people through several means, such as through sexual intercourse with a person infected with HIV/AIDS, through injection needles previously used by a person infected with HIV/AIDS, etc. This opinion of the writer is certainly supported by a legal basis. The legal basis included in the stipulation of Article 17 of the Law on Public Information Transparency gives a substance that when public agencies are allowed to open access to every pleader to receive public information under the following conditions:

First, public information can be disclosed and given to the pleader to prevent the inhibition of the enforcement process. Such information must at least have contents to ease the investigation and indictment process in a suspected criminal case, it can uncover the identity of informants, plaintiffs, witnesses, as well as victims that have information on a criminal case. The uncovering of data owned by criminal intelligence and all plans are related to the prevention and handling of all forms of transnational crimes.

Then, such information can be disclosed if it is related to the safety and life of law-enforcing actors and medical workers as well as their families. It may be disclosed if its confidentiality endangers the condition of the facilities and infrastructure owned by the apparatus. The condition when the public information is opened by the pleader will bring the impact of disturbances towards the interests of the protection of intellectual rights as well as protection from unhealthy business competition. Third, information can be disclosed if there is a condition where if the information is not disclosed, it will endanger safety and security. The disclosure of HIV/AIDS patients' health status concerns the safety and the life of law enforcement apparatus or health workers and their families (service providers). The confidentiality of HIV patients' medical records may endanger the conditions of the facilities and infrastructure of the concerned apparatus. If medical workers who treat the patient know of his/her health condition, it will be easier for the health workers to protect themselves.

Lessons from the data leakage case of National Health Security (BPJS Kesehatan) HIV/AIDS patients in Indonesia

Indonesia faces the same challenges. Apart from the issue of suboptimum health service system (39) and the case of BPJS Health data leakage, it is important to take a

quick step in providing legal certainty in guarding patient data such as their medical statuses through an inter-sectoral cooperation. The inter-sectoral cooperation may include the State Cyber and Code Agency (BSSN), the Cybercrime section of the Republic of Indonesia's Police Force, the Ministry of Defense's Center of Cyber Defense, the Coordinating Ministry in the Political, Legal, and Security Sector, as well as the Coordinating Ministry in the Section of Human Development and Culture. Another special effort is carried out by arranging a technique to handle a constructive protection, that may be described in the Figure below:

A constructive cyber security system has a great role in providing legal protection and certainty for doctors, medical workers, and patients of harmful and communicable diseases such as HIV/AIDS. The personal data protection system should not be compromised. Doctors and medical patients should be able to access the medical record database under emergency reasons for the safety of patients, if it is known from the start that they have communicable and deadly diseases. This is to ease the job of doctors and medical workers in carrying out medical actions with special procedures, even though their condition is bound by a confidentiality code of ethics against patient data and they may be penalized for leaking patients' personal data.

Apart from that, cyber security of medical record data must be maintained. For instance, there should be a routine checking of the data traffic and transaction to prevent data leakage as what has happened in BPJS Kesehatan and other institutions. Medical data must be made by considering data safety to prevent further cases of data leakage. It must be noted that running the cyber security system is a highly intentional process.

Health workers also have an interest in this as their lives are at stake. Health workers such as doctors, nurses, midwives, and anesthesiologists will use certain health protocols if they know that a patient suffers from HIV/AIDS (40), especially when injecting the patient, helping her give birth, or when treating her. Another interest is before a wedding is organized. The bride-to-be and groom-to-be have the right over health information (whether or not the spouse-to-be is infected by HIV/AIDS) considering that they are at great risk. People planning to get married have the right to know the condition of their spouse-to-be (as HIV/AIDS patients may be dishonest) as they are at great risk if they marry a person with HIV/AIDS.

Based on the explanation above, the writer suggests that the disclosure of information to the public may become an exception in the case of medical record data of people with HIV. This concerns aspects that are closely related to physical and non-physical health treatments. Thus, it is clear that the Law on Public Information Transparency determines exceptions on the limited

disclosure of medical record information of HIV/AIDS patients to protect the lives and health of the parties that are at risk.

CONCLUSION

The Indonesian stipulations on medical data, especially concerning the data on HIV/AIDS are regulated in Law No. 36 of 2014 on Health Workers; the Governmental Regulation No. 46 of 2014 on the Health Information System; and derivative regulations in Minister of Health Regulation Number 24 of 2022 which further regulate medical records. The confidentiality of the medical records of HIV/AIDS patients must be well-kept and written in a document, namely a pact of integrity that is often known as the Non-Disclosure Agreement. This pact of integrity will always be attached to activities of a cooperation agreement with health service facilities where HIV/AIDS patients stay and are treated. Stipulations on data protection on patients' data are regulated in the Law on Personal Data Protection. The writer sees that there are limitations in the aspect of public information transparency regulated in the Law on Public Information Transparency. Medical records are information that can be excepted to not be disclosed to the public for certain reasons. This is clearly written in the stipulations of Article 17 of the Law on Public Information Transparency with the exception of data disclosure to the public. However, this law has not taken the side of the interests of the safety of medical workers and other parties that are at high risk and whose lives are threatened if they do not obtain information on the HIV/AIDS suffered by the patients.

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