

Perception and Practices of Health Data Privacy Protection among Consumers: An Empirical Study in One of Indonesia's Major Cities

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ABSTRACT

Keywords: Perception, Practice, Protection, Health Data Privacy.

Online information exchange has become commonplace in today's digital era, especially in the health sector. However, this also raises concerns regarding personal data privacy, especially health data. This study analyses consumers' perceptions and practices of health data privacy protection. The empirical method is used in this research. The data collection techniques used were literature studies, direct observation, and interviews. After the data is obtained, it is analyzed through the stages of reduction, presentation of data, and conclusion. The results showed that consumers in Jakarta have a high level of perception of the importance of health data privacy; consumers understand that health data is sensitive information that needs to be protected. The law regarding the protection of consumer health data privacy in Indonesia is Law No. 27 of 2022 concerning Personal Data Protection. Practices in carrying out the personal data protection function by officers involve providing information and consultation to those in control of personal data to ensure compliance with the Personal Data Protection Law, monitoring to ensure that the rules applied by those in control of individual data are by the provisions of the applicable requirements, providing advice regarding the impact of personal data protection as well as monitoring the performance of individual data controllers and coordinating and taking action on issues related to activities in processing personal data.



Introduction

In today's digital era, online use and exchange of information have become commonplace, especially in the health sector. Information and communication technology development has made it possible for healthcare professionals and patients to

access and share medical information quickly and efficiently through online platforms. This allows for adopting a more effective and responsive healthcare system to the community's needs and facilitating collaboration between medical personnel in diagnosis, treatment, and disease management (Herryani & Njoto, 2022). However, along with the ease of access to information, various challenges related to health data privacy and security must be overcome with appropriate policies and technology.

The difficulty in dealing with consumer data leakage is due to security issues in the systems that allow unauthorized access to sensitive medical information. The need for more awareness about the importance of protecting personal data is a difficulty that must be faced, especially because various health histories are included in very specific and sensitive data categories. According to Director General Samuel, data owners and controllers must be aware of the need to protect data privacy. In addition, the management and implementation of personal data protection still need to be improved, which is becoming another challenge that needs to be resolved. The rapid development of wearable devices and health apps also introduces new challenges, given the involvement of personal data in the platform. Finally, balancing the public interest in accessing health information and protecting individual personal data is challenging. In addition, it is important to align the function of protecting individual data with medical ethics principles in the health sector.

In the spirit of the preamble to the 1945 Constitution of the Republic of Indonesia (1945 Constitution), the Government of Indonesia has a great need to protect the constitutional rights of citizens to improve overall welfare, contribute to educating the nation's life, and play a role in realizing a world order based on social justice as stated in the 5th precept and independence. In the development of innovation, this goal is translated to protect the privacy of every Indonesian individual during activities. Thus, the Government is responsible for ensuring that every step of technological innovation and development is carried out by paying attention to and respecting the privacy rights of citizens, thus creating a safe and fair environment for everyone to participate in social, economic, and cultural activities (Joestiawan, Dewa, & Mayasari, 2021).

Previous research (Indriani, 2017) shows that the development of e-commerce in Indonesia has made significant progress. The government, at least, has encouraged the birth of new startups with various programs, including the 1000 Technopreneur program and other initiatives. However, this success has yet to be achieved well because no law adequately protects it, especially regarding customer privacy rights. The relevant regulations are Law No. 11 of 2008 concerning ITE and Government Regulation No. 28 of 2012 concerning the Implementation of Electronic Systems and Transactions. With these two regulations, the Ministry of Communication and Information Technology can collect various data for e-commerce business owners with various profiling and report databases to protect against fraudulent actions by several irresponsible individuals.

Another study (Heryani & Njoto, 2022) found that adjudication and consensus processes can carry out data privacy breaches. Consumers can file a civil lawsuit regarding the provisions protecting victims of privacy violations under Indonesian laws,

such as the ITE Law and the Law on the Implementation of Electronic Systems and Transactions. This means that the legal process allows for a compensation claim. The demand for personal data violations is civil and has a wider scope. Therefore, a broader law for violating the right to privacy is also needed.

The novelty of this research comes from the research object, namely the perception and practice of health data privacy protection among consumers, which has never been studied before. This research contributes to a further understanding of the perception and practices of health data privacy protection in the beauty clinic sector in Jakarta. Its theoretical implications include the development of theories and frameworks that can be used to analyze health data privacy issues in the context of beauty clinics. This study explores consumers' perceptions and practices of health data privacy protection.

Method

Empirical legal methods are used in this study. Empirical legal research is a type of research involving law, with the data used being primary data obtained directly. Empirical research prioritizes facts obtained directly based on observation results (Lodang, Dima, & Kian, 2024). The data collection technique is carried out by literature study, observation, and direct interviews. The case study is based on a beauty clinic in Jakarta. After the data is obtained, it is analyzed through the reduction stages, data presentation, and conclusion.

Results and Discussion

The importance of health data privacy is closely related to the human rights of individuals to maintain the confidentiality of their medical information. Health data often includes highly sensitive information, such as disease history, medical test results, and mental health conditions. Protecting the privacy of health data is important because it helps maintain trust between patients and healthcare providers. Patients may become reluctant to share important information about their health without adequate privacy, which can hinder proper diagnosis and effective treatment. Additionally, with more healthcare adopting digital technologies, such as electronic medical records, it is important to ensure that healthcare data remains safe from the threat of hacking and misuse.

Health data protection also has a broader impact in the context of public health and medical research. Health data collected from populations can provide valuable insights into health trends, diseases that are spreading, and responses to medical interventions. However, to take advantage of this potential information, it is important to maintain health data privacy. By securing the confidentiality of health data, we can encourage greater participation in medical research and public health programs without sacrificing individual trust or privacy. This helps ensure that healthcare innovation is supported by strong ethics and integrity, strengthening the foundation for progress in healthcare.

Consumers see consent as a form of privacy protection. The crucial role of consent is to demonstrate the value of consumers in maintaining the policies provided and the

skills in selecting the data to be used. Everything done illegally, such as deleting data and transparency, is related to data sharing. While there is no protection without permission, it is just as important as consent. This shows that the combination of consent and additional permissionless protections can increase consumer benefits and encourage them to be more willing to share data (Gupta et al., 2023). Data is personal data that must be guaranteed confidentiality if it relates to an individual because it can identify the individual as the owner of the data (Medlimo, Septania, Hapsari, Zuleika, & Agustin, 2022).

In the constitution of the State of Indonesia, it has been stipulated that all citizens have the right to individual protection, which is one of the constitutional rights. This is stated in Article 28G paragraph (1) of the 1945 Constitution of the Republic of Indonesia (1945 Constitution). The article states that every individual has the right to personal protection, feel safe, and be protected from the threat of fear (Ravlindo & Gunadi, 2021). Protecting personal data rights is the same as protecting the right to freedom of speech. So, the right to privacy also guarantees protection against various threats of fear of doing or not doing because it is included in human rights.

Some of the reasons the right to privacy needs to be protected are: first, to foster a network between one individual and another, an individual does not have to open his entire personal life to the point that the individual can maintain his position in a certain position. Two, individuals need time to be alone at some point, so privacy is sometimes necessary. Third, privacy is a right to oneself and has nothing to do with others. However, this right will only be recovered if the individual shares various private things with the general public. Fourth, privacy includes the right of individuals to build internal relationships such as fostering marriage, family, and close individuals who can know about these private matters. Fifth, privacy must be protected by law because the losses obtained are difficult to assess (Kusnadi, 2021).

According to the Regulation of the Minister of Communication and Information Technology Number 20 of 2016 concerning the Protection of Personal Data in Electronic Systems, it is explained that personal data has a special meaning of information about important individuals, so it is necessary to protect and give confidential data protection. The types of personal data are divided into two: general and special. General personal data includes information such as name, date of birth, occupation, and other personal information. The personal data includes disease history, education, financial information, race/ethnicity, sexual preferences, political views, family information, crime data, and others (Karu & Febriansyah, 2024). Privacy is an individual freedom. Privacy is in every individual, and it is important to respect it (Yel & Nasution, 2022). The importance of protecting human rights and privacy is found in:

1. Universal Declaration of Human Rights, 1948;
2. Law No. 12 of 2005 concerning the Ratification of the International Covenant on Civil and Political Rights;
3. Law No. 36 of 2009 concerning Health regulates the confidentiality of patients' conditions;

4. Law No. 10 of 1998 concerning Banking regulates personal data regarding depositors and depositors.

Government Regulation Number 71 of 2019 concerning the Implementation of Electronic Systems and Transactions Article 1 Number 29 states that personal data is a specific individual profile that can be identified with other information conventionally or electronically (Meher, Sidi, & Risdawati, 2023). Then, the Draft Ministerial Regulation on Personal Data Protection, which was passed based on Government Regulation Number 82 of 2012, along with the Draft Law on Personal Data Protection, is the government's effort to respond to public needs related to consumer privacy protection (Indriyani et al., 2017).

Personal data from the beauty clinic is included in the health data. Health data provides sensitive and specific information such as health test results, disease conditions, and other information that requires special protection. Protecting patients' data as consumers is important because individual data concerns all information in it. This is regulated in Law No. 29 of 2004 concerning Medical Practice. Then, Law No. 36 of 2009 concerning Health, and Law No. 44 of 2009 concerning Hospitals. In the digital realm, personal data protection is protected by Law No. 19 of 2016 concerning Amendments to Law No. 11 of 2008 concerning Electronic Information and Transactions (Faiqy, Damargara, Alhidayah, & Maulana, 2022).

The confidentiality of patient information is related to Law No. 14 of 2008 concerning Public Information Disclosure. The law that protects the confidentiality of personal data is contained in Article 29 g of the 1945 Constitution, which states that every individual has the right to defend themselves, their closest people, or their property, as well as a sense of security from various actions (Simamora, 2022).

Article 5 paragraph (1) of the Regulation of the Minister of Health of the Republic of Indonesia Number 269/MENKES/PER/III/2008 mandates that doctors or dentists who practice must provide medical record facilities as one of the health services offered. Furthermore, Article 6 of the Regulation of the Minister of Health of the Republic of Indonesia Number 269/MENKES/PER/III/2008 concerning Medical Records stipulates that certain doctors, dentists, and health workers have responsibility for the records and documents made in the medical records. The health worker responsible for the medical records and documents is known as a medical recorder. Medical recorders are included in the medical, technical health workers category as regulated in paragraph (1) letter j of Law Number 36 of 2014 concerning Health Workers (Ramadhani, Alwiya, & Afwa, 2021).

In the world of health, there are medical records. A medical record is one of the facilities in health services that contains patient information as a consumer. Medical records contain important things, so their confidentiality needs to be maintained by all parties in the implementation of health services. Medical records are required for review in implementing health practices or legal aspects (Novita & Lubis, 2022).

The perception of consumers or patients of beauty clinics in Jakarta towards the confidentiality of personal data is quite good because awareness of the importance of

personal information privacy has increased in this digital era. Many beauty clinics have introduced clear privacy and data security policies to consumers, and they often provide transparent explanations of how personal data will be used and protected. However, while awareness of the importance of privacy has increased, the implementation of appropriate data protection has only sometimes been adequate. Many beauty clinics may still face challenges in implementing strict data security standards and ensuring that consumers' personal information is guaranteed safe from cyber threats or internal abuse.

Further efforts are needed on the part of beauty clinics to improve their compliance with data privacy regulations and to increase transparency to consumers about how their data will be managed. In addition, continuous education about consumer rights related to data privacy is also key. Beauty clinics need to ensure that their staff is well-trained in managing and protecting consumers' data and are prepared for data security challenges that may arise in the future. Thus, with the joint efforts between beauty clinics and consumers, the security level and data privacy awareness can be significantly improved.

Conclusion

Consumers in Jakarta are highly aware of the importance of health data privacy, realizing that health information is a sensitive matter that must be properly protected. In Indonesia, regulations governing the protection of consumer health data privacy are listed in Law No. 27 of 2022 concerning Personal Data Protection. In practice, officers protecting personal data involve several steps, such as providing information and consultation to personal data controllers or personal data processors to ensure compliance with applicable laws. Furthermore, they also monitor the implementation of rules by personal data controllers or personal data processors to ensure compliance with applicable legal provisions. In addition, they advise on the impact of personal data protection and supervise the performance of personal data controllers and processors. Finally, they are responsible for coordinating and mediating in resolving issues related to activities in processing personal data.

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