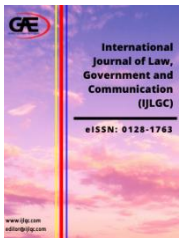
International Journal of Law, Government and Communication
EISSN : 0128-1763
IJLGC
Volume 7 Issue 30 (December 2022) PP. 33-41
DOI 10.35631/IJLGC.730004



INTERNATIONAL JOURNAL OF LAW, GOVERNMENT AND COMMUNICATION (IJLGC)
www.ijlgc.com

HEALTH DATA OWNERSHIP IN MALAYSIA PUBLIC AND PRIVATE HEALTHCARE: A LEGAL ANALYSIS OF HEALTH DATA PRIVACY IN THE AGE OF BIG DATA

Nazura Abdul Manap[1], Mohamad Rizal Abd Rahman[2], Siti Nur Farah Atiqah Salleh[3*]

[1] Faculty of Law, National University of Malaysia, Malaysia
Email: nazura@ukm.edu.my
[2] Faculty of Law, National University of Malaysia, Malaysia
Email: noryn@ukm.edu.my
[3] Ph.D Candidate, Faculty of Law, National University of Malaysia, Malaysia
Email: p97505@siswa.ukm.edu.my
[*] Corresponding Author

Article Info:

Article history:
Received date: 30.10.2022
Revised date: 07.11.2022
Accepted date: 15.11.2022
Published date: 31.12.2022

To cite this document:

Manap, N. A., Abd Rahman, M. R., & Salleh, S. N. F. A. (2022). Health Data Ownership In Malaysia Public And Private Healthcare: A Legal Analysis Of Health Data Privacy In The Age Of Big Data. *International Journal of Law, Government and Communication, 7* (30), 33-41.

DOI: 10.35631/IJLGC.730004.

Abstract:

Health data ownership in big data is a new legal issue. The problem stands between the public and private healthcare as the main proprietor of health data. In Malaysia, health data ownership is under government hospitals and private healthcare jurisdictions. Who owns the data will be responsible for safeguarding it, including its privacy. Various technical methods are applied to protect health data, such as aggregation and anonymization. The thing is, do these technical methods are still reliable to safeguard privacy in big data? In terms of legal protection, private healthcare is governed under Personal Data Protection Act 2010, while the same Act does not bind the government. With the advancement of big data, public and private healthcare are trying to extract values from health data by processing big data and its analytical outcomes. Considering that health data is sensitive due to its nature which contains personal information of individuals or patients, had raised an issue as to whether the proprietor could provide adequate legal protection of health data. Personal Data Protection Act 2010 is still applicable in giving protection for health data for private healthcare, but what are the laws governing health data privacy in public healthcare? This article aims to answer the questions by analyzing legal sources relevant to health data privacy in big data. We propose a regulatory guideline that follows the GDPR as a legal reference model to harmonize the public and private healthcare ownership of health data better to protect the privacy of individuals in big data.

Keywords:

Big Data, GDPR, Health Data, Health Data Ownership, Personal Data Protection Law 2010, Public-Private Healthcare.

International Journal of Law, Government and Communication
EISSN : 0128-1763
Volume 7 Issue 30 (December 2022) PP. 33-41
DOI 10.35631/IJLGC.730004

Introduction

The advancement of big data has led public and private healthcare to extract values from health data through big data technology. This effort has already taken its place in Malaysia's healthcare system. For example, the Malaysian Health Data Warehouse (MyHDW) 2017 was introduced and is currently an ongoing project under the Ministry of Health Malaysia (Ministry of Health, Malaysia, 2017). The purpose is to develop a centralized database for health data in Malaysia. Another technology implementing big data technology related to health is MySejahtera (Parliament Account Committee (PAC, 2021). It functioned to assist during the COVID-19 pandemic to facilitate contact tracing efforts.

Implementing these two technologies has shown that Malaysia realized the necessity to maximize the potential of the latest technology in healthcare. The one thing that is lacking; does the privacy of these data could be protected under the law with the advancement of such technology in data processing and analytics. The implementation of this technology has caused a public outcry over the issues of data privacy (Ideas, 2022) and the readiness of the Malaysia Personal Data Protection Law 2010.

The Malaysia healthcare system has been known as a dual-tiered system, a government-led and private-sector healthcare (Judith Healy, 2013). The Ministry of Health, Malaysia organises and manages public healthcare through a civil service organisation and a centralised administration(Judith Healy, 2013). The Ministry of Health is responsible for the planning and governance of the vast majority of health services offered by the public sector, despite the fact that it currently has very little influence over the private sector.

In terms of privacy context, Malaysia has no specific law governing health data privacy. However, there are medical-related laws that protect the confidentiality of patient information. The Medical Law Act 1971, which relates to the registration and practice of medical practitioners, is applicable in private and public healthcare (Jahn Kassim, 2007). There is also code created by Malaysian Medical Council, such as Confidentiality Codes 2011.

Health data ownership is very much related to the context of health data privacy because institutions often think that they own the patient data because they are the ones who collected it. But in reality, these institutions are just "data custodians." The patient is the owner of the information, and consent from the patient is typically required in order to access and make use of the information outside of the clinical institute (Jamuar et al., 2019). Moreover, ownership conjures up images of possessions and financial gain (Cartwright Smith et al., 2016). When someone owns a piece of property, they have the freedom to use it however they like. The owner has several options, including altering, destroying, selling, donating, and allowing others to use it under their terms (Cartwright Smith et al., 2016)

In some circumstances, the law may grant specific ownership rights over a portion or the entirety of a health record. Still, in other situations, several parties may use the information without specific ownership rights, including the subject of the data. Stakeholders at the state and federal levels struggle with these issues as more applications for health information are created, mobility is increased thanks to technological advancements, and ownership and accessibility of health information gain importance. However, the answer to the ownership question is still ambiguous (Cartwright Smith et al., 2016). Therefore, this paper seeks to legally analyze the issue of health ownership at the level of public and private healthcare in

International Journal of Law, Government and Communication
EISSN : 0128-1763
Volume 7 Issue 30 (December 2022) PP. 33-41
DOI 10.35631/IJLGC.730004

Malaysia within the context of data privacy to come out with possible legal solutions to improve the protection of health data privacy in big data.

Health Data Ownership in Malaysia

Public and private healthcare plays a vital role as the proprietor of health data, including protecting the privacy of health data in managing such data for better usage. The healthcare sector is looking forward to stepping up the digital health landscape in Malaysia and is open to new ways of extracting health data to be utilized using new technology (Koh, 2020).

The public and private healthcare in Malaysia possess the ownership of medical records. In public healthcare, the ownership power could be traced in the government circular "Guidelines for Handling and Management of Patient Medical Records for Hospitals and Medical Institutions 2010". It is clearly stated, in the guideline, that the hospital, in its physical form, owns the medical report, but the patient's own the information (Ministry of Health Malaysia, 2010). However, it is understood that the meaning of medical report refers to the extended definition of health data because the information elements within the report amount to the importance of health data.

On the other hand, private healthcare extracted the same power to own the medical record from the Guideline on Medical Records and Medical Reports 2006. All rights pertaining to the ownership of a patient's medical record are held jointly by the medical practitioner, the healthcare institution, and the healthcare services (Malaysia Medical Council, 2007). It is essential to recognize the confidential nature of Medical Records. Even if the practitioner, healthcare facilities, and services all have ownership rights, they are not allowed to release any information from the patient's medical records to a third party without the patient's agreement or the permission of the patient's next of kin (Malaysia Medical Council, 2007).

Medical records are also the intellectual property of the physician who created them and morally and ethically belongs to both the physician and the patient (Malaysia Medical Council, 2007). The medical practitioner records the patient's personal information (Malaysia Medical Council, 2007). It is predicated on the notion that the notes are created since the patient sought the consultation voluntarily. Information obtained by the practitioner from a third party (often a relative) about the patient is not considered part of the patient's information because it may have been disclosed under strict confidentiality guidelines (Malaysia Medical Council, 2007). This information may be vital to the patient's care. The practitioner may be required to disclose such information when providing the patient with a Medical Report. In the light of the third-party informant's instructions on secrecy, the practitioner should not reveal the information's source (Malaysia Medical Council, 2007).

The medical record guidelines were last visited in 2007, and their application is still ongoing. From here, it is understood that these guidelines extracted some legal power from public and private healthcare regarding the ownership of health data in Malaysia. The concept of confidentiality raises a duty of confidence when a person receives confidential information in circumstances where they know or have accepted that the information is personal. They should not disclose the information to a third party (Tharini & Low, 2021). Since the concept of health data privacy is very much related to individuals' protection of their personal information, confidentiality per se is not sufficient to curb the issue of health data ownership and big data.

International Journal of Law, Government and Communication
EISSN : 0128-1763
Volume 7 Issue 30 (December 2022) PP. 33-41
DOI 10.35631/IJLGC.730004

Conflict Between Public and Private Healthcare Data Ownership, Data Privacy, And Big Data

Public and private healthcare own the power not only to maximize the potential of health data in big data but also owns the responsibility to protect the privacy of the data. These institutions are the data custodians (Jamuar et al., 2019). According to Allen et al. (2019), data custodian act on behalf of institutions to allow the release of individuals' health information and are accountable for ensuring that data release complies with legal and regulatory constraints.

Big data has massive potential for improving public and private healthcare. Its infrastructure, intelligent analytical tools, and advanced computational approaches that could conceptualise, theorise, and model big data with the grounded theory method need to be established, understood, and made available by both data analysts and domain researcher so that they can, among other things, facilitate knowledge discovery and make it actionable and operational for better life science solutions (Nohudin et al., 2021). Thus, few studies and research regarding big data and its application in healthcare have been put to the test, such as using text analytics for cancer patients, text mining for children's vaccination, machine learning for patient waiting time, and image mining for the detection of diseases (Nohuddin et al., 2021).

Big data has also become a valuable database in many countries, where the information it produces can be used to prevent and control disease (Nohuddin et al., 2021). Malaysia has started to focus on big data, and some initiatives share patient records and medical expertise between public and private hospitals and clinics (Nohuddin et al., 2021). With the advent of big data, the healthcare sector in Malaysia realized that it could be harnessed and benefit the citizens.

Healthcare in Malaysia is transitioning into digitalization. It is in line with the fourth industrial revolution (4IR) policy on the national level that encourages the implementation of 4IR technology into every sector in Malaysia (EPU, 2020). Unfortunately, the preparation we put on technological advancement is not equivalent to data protection for health data.

The reliability of health data is the essentials elements of big data in healthcare. However, the health data system in Malaysia in public and private healthcare is not integrated (Fatt & Ramadas, 2018). Public healthcare collects health data in silos within their respective healthcare centres and is governed and controlled by the administrative departments of hospitals or clinics. No specific law regulates the protection of health data, specifically concerning privacy in public healthcare. Private healthcare also collects health data but is governed by the Personal Data Protection Act 2010.

Individuals have always been the primary source of health data. They contribute to the data collected by public and private healthcare. The argument as to the relevancy of protecting the privacy of health data signifies a need to give protection to individuals. Safeguarding health data is equal to protecting a person. This responsibility supposes to lie on the shoulder of both healthcare providers.

To date, there is no specific law regarding privacy in Malaysia. However, Malaysia has gone through quite a journey to position privacy rights in Malaysia. Therefore, privacy rights in Malaysia could be found scattered under various Acts ("Beyond Data Protection," 2013). Public healthcare does not provide a specific privacy law to cater to health data privacy.

International Journal of Law, Government and Communication
EISSN : 0128-1763
Volume 7 Issue 30 (December 2022) PP. 33-41
DOI 10.35631/IJLGC.730004

Privacy protection is a concept that ensures sensitive personal information is not utilized in ways that create socially unacceptable harm (Waterman & Bruening, 2014). This concept is reflected in the introduction of the Personal Data Protection Act in 2010, where Malaysia took a sectoral approach to data protection. To control the collection, use, and dissemination of personal data in specific sectors, such as healthcare, legislation, rules, regulations, guidelines, and codes of practice have been produced. However, they only address a subset of the data protection challenges ("Beyond Data Protection," 2013). Khaw Lake Tee correctly points out that personal data protection is insufficient if it is only available through piecemeal legislation ("Beyond Data Protection," 2013). It is argued that comprehensive regulation covering all areas of personal data protection is required. It was emphasized that personal data protection law is not a law governing broad privacy or information freedom. It does not restrict the collection, storage, processing, or use of personal data; instead, it requires the data used to follow the personal data protection principles and other data protection legislation rules.

However, in the context of the said law, the applicability is limited to private healthcare because section 3 of the Act states that the Act shall not apply to Federal and State government, including public healthcare. The Federal Government means the Government of Malaysia, including the Prime Minister's Office, Departments, and all Ministries (Alibeigi & Munir, 2021). The state Government is the government of a state which includes organizations (Alibeigi & Munir, 2021). Moreover, the scope of data user under the Act is still limited only to anyone processes personal data either alone, cooperatively or in common with other people (Section 4, PDPA).

Khazanah Research Institute report, in which the central theme relates to Electronic Health Records, is related to the research of this paper, specifically on data ownership. It mentioned that when it comes to data ownership, legislation must be focused on empowering patients, who should profit the most from the construction of EHRs in the first place (Ilyana Syafiqah Mukhriz Mudaris, 2021). The ownership of health data by the public and private healthcare in Malaysia is very limited and inadequate in providing privacy protection in big data with the limitation of available laws. Therefore, a legal suggestion should be proposed to assist in facing this issue.

The General Data Protection Regulation Approach as Model Reference for Malaysia

General Data Protection Regulation (GDPR) comes into effect in 2018 to be implemented at the European Union (EU) level. The EU claimed GDPR was designed to "harmonize" data privacy laws across all its member countries and provide more excellent protection and rights to individuals (Burgess, 2020). In dealing with private and public healthcare data ownership in Malaysia, the EU obviously does not encounter the same issue. Even though there are no similarities in that particular context, Malaysia's data protection law was developed and modelled by the EU Data Protection Directive (a previous version of GDPR). The only difference is that the EU has tried to improve the legal protection for data privacy while Malaysia chose to develop the technology before the law. The related legal situation or approach in EU will be addressed and supported by the research conducted by a few researchers will be addressed below.

The GDPR does not explicitly highlight the aspect of data ownership. Still, it does prepare a legal regulation in positioning data subject's rights, defining personal and sensitive personal

International Journal of Law, Government and Communication
EISSN : 0128-1763
Volume 7 Issue 30 (December 2022) PP. 33-41
DOI 10.35631/IJLGC.730004

data to enable member states of the European Union to face the issue of health data ownership. Liddell (2021) stated that GDPR covers the meaning processing of personal data, which suits the big data context, whether the data are in electronic or computerized records or on paper. Article 4 of GDPR defines personal data as any information relating to an identified or identifiable natural person (data subject). Since how the data may become identifiable are broad (e.g., by including names, identification numbers, location data, online identifiers, or one of several unique characteristics in a data set). The GDPR applies in practice to information that can be assigned to a particular person (Liddell et al., 2021).

Additionally, the GDPR provided for a clearer definition of what constitute data controller under Article 4 as natural person or legal person, public authority, agency and other body which, alone or jointly with others, determines the purposes and means of the processing of personal data. Data controller is very much similar to the data user, in PDPA context. If comparison was to be made with the PDPA in defining data user in terms of the extend of who constitute data user, it can be seen there is a need to broaden the definition. The PDPA is developed based on the model of EU previous regulation, the amendment as to this important term has not taken place yet.

The GDPR emphasized cardinal principles that data controllers must observe when processing personal data (Liddell et al., 2021). According to Liddell (2021), These include, amongst other things, the principles of accuracy, transparency, integrity, confidentiality, and security. Notably, these related principles protect interests similar to, but not the same as, a person's right to privacy and autonomy with their information.

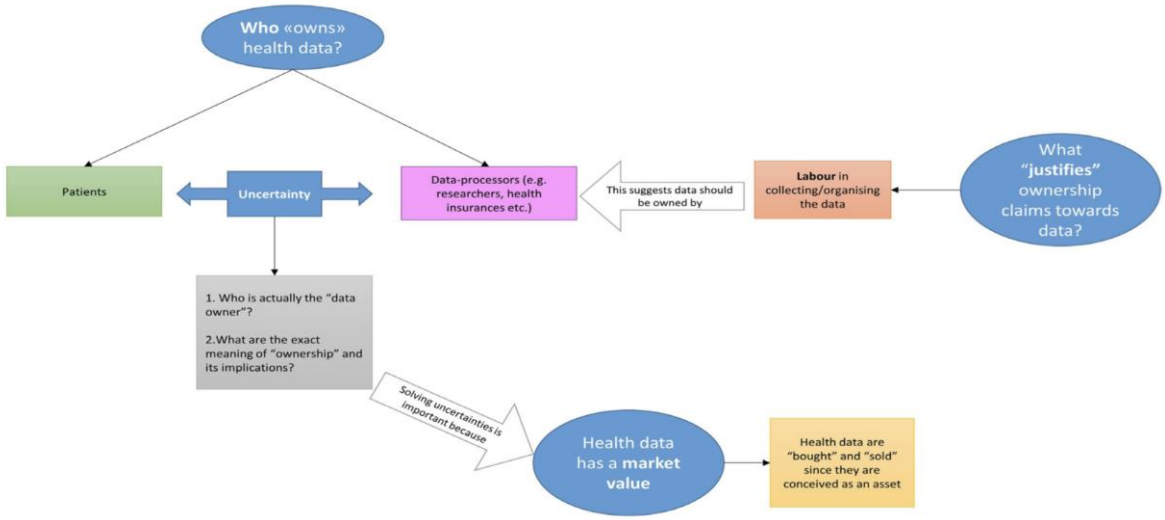


Figure 1: Representation Of The Themes Related To Health Data Ownership (Martani et al., 2021).

Figure 1 shows Martani et al. (2021) research findings conducted in Switzerland to observe the impact of GDPR on the issue of health data ownership. They found that the term data processors is used broadly to refer to all the institutions and people who collect and/or manage data for a specific purpose, as opposed to data subjects," who are the people (usual patients) from whom the data comes. The GDPR suggests that there can be a difference between the

International Journal of Law, Government and Communication
EISSN : 0128-1763
Volume 7 Issue 30 (December 2022) PP. 33-41
DOI 10.35631/IJLGC.730004

institutions or people who do the processing and those who decide the purposes and means of the processing (art.4 (7) GDPR). These people are called data controllers.

According to Martani et al. (2021), the GDPR changed the rules for handling data in the European Union. The GDPR attempted to clarify the roles and rights of both the people whose information is being collected (data subjects, art. 4 (1) GDPR) and the people in charge of collecting that information (data controllers and data processors, art. 4 (7), (8) GDPR.

Based on the GDPR approach, it is proposed that Malaysia should develop a regulatory guideline specifically on the definition, as we are still lacking. The regulatory guideline will be explained below:

Guideline on health data ownership in Malaysia for the protection of health data privacy		
Part 1	Executive Summary and Objectives	Applicable to the healthcare organisations dealing with health data.
Part 2	Definition	• Health Data • Ownership/ Custodian • Data Subject • Data Processor Big Data
Part 3	Principles (follow the GDPR)	• Accuracy • Transparency • Confidentiality • Principles under GDPR (similar to PDPA 2010)
Part 4	Rights (follow the GDPR)	• Data Subjects • Data Controller
Part 5	Limitation of the regulation	To what extend does this regulation will be apply.
Part 6	Conclusion	

Figure 2:Example Of Regulatory Guideline

The above guideline is a rough version to show how the suggestion could be put into the picture, inspired by the GDPR. The column in red is the essential section, executive summary and objective and definition. The executive summary will clarify the purpose and objective to be

International Journal of Law, Government and Communication
EISSN : 0128-1763
IJLGC
Volume 7 Issue 30 (December 2022) PP. 33-41
DOI 10.35631/IJLGC.730004

achieved. The next part which is definition will be explaining and defining the context and limits of the key terms under the guideline. The main focus of these guideline is to enable a working definition relating to health data ownership that will fit in the realm of health data privacy in big data. The general framework will be the point of beginning to develop a comprehensive framework for health data privacy in big data within public and private healthcare in Malaysia.

Conclusion

The concept of health data ownership is essential because it implies a level of control over the use of health data and places responsibilities on the owner to protect the privacy of health data. There are numerous feasible answers to the ownership issue with health information. Allowing everyone to be the owner of their data, even if it is under the custodian of healthcare, is possible. The concept of ownership is not meaningless even in a highly regulated environment because of the numerous rights associated with health information. It is unknown whether this is still the current government's viewpoint, but it is concerning because privacy concerns must be included in the system's design, not as an afterthought. It could be explicitly controlled as privacy protection or as limitations on the harm produced. Acknowledging that Malaysia still needs to improve its legal data protection law to enable a functional ownership-privacy environment at the healthcare level is essential to balance the big data technology application and privacy protection. It is crucial to apprise that health data ownership in the EU is still an ongoing issue, and solutions are yet to be sought. However, these could be taken to form regulatory guideline in Malaysia that follows the GDPR as a legal reference model.

Acknowledgment

The authors would like to acknowledge the financial support from the Ministry of Higher Education, Malaysia. This research is funded under the Fundamental Research Grant Scheme FRGS / 1 / 2020 / SSO/ UKM/01/2.

References

Allen, J., Adams, C., & Flack, F. (2019, January 18). The role of data custodians in establishing and maintaining social licence for health research. *Bioethics*, *33*(4), 502–510. https://doi.org/10.1111/bioe.12549

Alibeigi, A., & Munir, A. B. (2021, February 22). Malaysian Personal Data Protection Act, a Mysterious Application. *University of Bologna Law Review*, *5*(2), 362–374. https://bolognalawreview.unibo.it/article/view/12441

Beyond Data Protection. (2013). In N. Ismail & E. L. Y. Cieh (Eds.), *Strategic Case Studies and Practical Guidances* (1st ed.). Springer.

Burgess, M. (2020, March 24). What is GDPR? The summary guide to GDPR compliance in the UK. *Wired*. Retrieved October 1, 2022, from https://www.wired.co.uk/article/what-is-gdpr-uk-eu-legislation-compliance-summary-fines-2018

Cartwright Smith, L., Gray, E., & Thorpe, J. H. (2016, season-04). Health Information Ownership: Legal Theories and Policy Implications. *Vanderbilt Journal of Entertainment & Technology Law*, *19*(2), 207–241.

EPU. (2020). National 4IR Policy. In Economic Planning Unit. Economic Planning Unit, Prime Minister Department. Retrieved August 31, 2022, from https://www.epu.gov.my/sites/default/files/2021-07/National-4IR-Policy.pdf

International Journal of Law, Government and Communication
EISSN : 0128-1763
Volume 7 Issue 30 (December 2022) PP. 33-41
DOI 10.35631/IJLGC.730004

Fatt, Q. K., & Ramadas, A. (2018). The Usefulness and Challenges of Big Data in Healthcare. *Journal of Healthcare Communications*, *3*(2). https://doi.org/10.4172/2472-1654.100131

Ideas. (2022, April 27). Ideas: MySejahtera episode poses questions about data privacy. *The Edge Markets*. Retrieved August 30, 2022, from https://www.theedgemarkets.com/article/ideas-mysejahtera-episode-poses-questions-about-data-privacy

Ilyana Syafiqah Mukhriz Mudaris. (2021, August). Electronic Health Records: Planning the Foundation for Digital Healthcare in Malaysia. In *Khazanah Research Institute* (No. 05/21). Khazanah Research Institute.

Jahn Kassim, P. N. (2007). *Law and Ethics Relating to Medical Profession* (1st ed.). International Law Books Services.

Jamuar, S. S., Moody, A. R., Karnes, J. H., Varga, O., Hedensted, S., Spreafico, R., Hafler, D. A., & McKinney, E. F. (2019, March 1). From Big Data to Precision Medicine. *Frontiers in Medicine*, *6*, 34. https://doi.org/10.3389/fmed.2019.00034

Judith Healy (Ed.). (2013). *Malaysia Health System Review* (978 92 9061 584 2). Asia Pacific Observatory on Health Systems and Policies.

Koh, D. (2020, July 1). An overview of Malaysia's digital health landscape. *Healthcare IT News*. Retrieved September 10, 2022, from https://www.healthcareitnews.com/news/asia/overview-malaysia-s-digital-health-landscape.

Liddell, K., Simon, D. A., & Lucassen, A. (2021, July). Patient data ownership: who owns your health? *Journal of Law and the Biosciences*, *8*(2). https://doi.org/10.1093/jlb/lsab023

Malaysia Medical Council. (2007, January). Guidelines of the Malaysian Medical Council 002/2006: Medical Records and Medical Reports. In *mmc.gov*. Retrieved May 5, 2022, from https://mmc.gov.my/wp-content/uploads/2019/11/Medical-RecordsMedical-Reports.pdf

Martani, A., Geneviève, L. D., Elger, B., & Wangmo, T. (2021, April). "It's not something you can take in your hands". Swiss experts' perspectives on health data ownership: an interview-based study. *BMJ Open*, *11*(4), e045717. https://doi.org/10.1136/bmjopen-2020-045717

Ministry of Health Malaysia. (2010, June). *Government Circular Guidelines for Handling and Management of Patient Medical Records for Hospitals and Medical Institutions 2010* (MOH/PAK/199.10 (GU)). Unit for Health Management Services.

Ministry of Health, Malaysia. (2017). *Malaysian Health Data Warehouse (MyHDW) 2015-2016 Start Up: Initiation*(MOH/S/RAN/115.17 (BK)). Health Informatics Centre, Planning Divison, MOH.

Nohuddin, P. N. E., Zainol, Z., & Baharin, H. (2021). *Smart Healthcare in Big Data Revolution* (1st ed.). UKM Press.

Parliament Account Committee (PAC). (2021, December 12). Laporan Jawatakuasa Kira-Kira Wang Negara (PAC): Report of Public Accounts Committee. In *Parlimen Malaysia* (DR.18/2022). Parlimen Malaysia. Retrieved September 30, 2022, from https://www.parlimen.gov.my/pac/review/docs-241-294.pdf

Tharini, R., & Low, J. (2021). *Medical law and ethics in Malaysia* (1st ed.). Lexis Nexis.

Waterman, K. K., & Bruening, P. J. (2014). Big Data analytics: risks and responsibilities. *International Data Privacy Law*, *4*(2), 89–95.