

DEVELOPING ELECTRONIC HEALTH DATA PRIVACY LEGAL FRAMEWORK FOR BANGLADESH

BY

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for the degree of Doctor of Philosophy in Law

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International Islamic University Malaysia

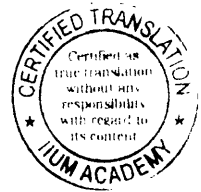
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ABSTRACT

Health data is considered one of the most sensitive forms of data that merits extra protection than any other forms of data. The increased adoption of eHealth system in the national healthcare framework has led the world to reassess the current protection mechanism and adopt a stringent regulatory framework to ensure adequate protection of eHealth data privacy. In Bangladesh, presently, there is no comprehensive data protection law, but there are few provisions scattered in different legislations that seek to ensure the protection of eHealth data privacy. The fact is that those provisions in the various legislations provide minimal protection. Therefore, it is high time for Bangladesh to reassess the present regulatory framework concerning data protection to streamline the current protection mechanism with the internationally recognised instrument. The present thesis thus investigates the current regulatory framework of Bangladesh concerning the protection of eHealth data privacy by analysing several statutes of particular relevance. The thesis also examines the current position of Bangladesh in realizing the benefits of the eHealth system. The study employs qualitative and doctrinal research methods, as well as comparative and analytical methods, are also used. The findings of the study is also supported by the semi-structured interviews from related stakeholders. The primary sources are taken from statutes and decided case laws of Bangladesh. Besides, foreign laws and case decision are also being referred to as a comparison. The study finds that in Bangladesh, the piecemeal protection provided by various provisions scattered in different legislation is not adequate. Further, in the absence of comprehensive legislation and co-regulation concerning data protection as well as sectoral specific law concerning eHealth data, make the current protection mechanism even weaker. Hence the legislators should consider addressing this lacuna by enacting a comprehensive data protection legislation with a separate provision ensuring extra protection for eHealth data.

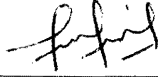
خلاصة البحث

تعتبر البيانات الصحية أحد أكثر أشكال البيانات حساسية والتي تستحق حماية إضافية أكثر من أي شكل آخر من أشكال البيانات. أدى الاعتماد المتزايد لنظام الصحة الإلكترونية في الإطار الوطني للرعاية الصحية إلى قيام العالم بإعادة تقييم آلية الحماية الحالية واعتماد إطار تنظيمي صارم لضمان الحماية الكافية لخصوصية بيانات الصحة الإلكترونية. في بنغلاديش، في الوقت الحالي، لا يوجد قانون شامل لحماية البيانات، ولكن هناك القليل من الأحكام المنتشرة في تشريعات مختلفة تسعى إلى ضمان حماية خصوصية بيانات الصحة الإلكترونية. والحقيقة هي أن تلك الأحكام في التشريعات المختلفة توفر الحد الأدنى من الحماية. لذلك، فقد حان الوقت لبنغلاديش لإعادة تقييم الإطار التنظيمي الحالي المتعلق بحماية البيانات لتبسيط آلية الحماية الحالية مع الأداة المعترف بها دولياً. وبالتالي، تبحث الأطروحة الحالية في الإطار التنظيمي الحالي لبنغلاديش فيما يتعلق بحماية خصوصية بيانات الصحة الإلكترونية من خلال تحليل العديد من القوانين ذات الأهمية الخاصة. تدرس الأطروحة أيضاً الوضع الحالي لبنغلاديش في إدراك فوائد نظام الصحة الإلكترونية. وتستخدم الدراسة طرق البحث النوعي والعقائدي، وكذلك الأساليب المقارنة والتحليلية. يتم دعم نتائج الدراسة أيضاً من خلال المقابلات شبه المنظمة من أصحاب المصلحة ذوي الصلة. المصادر الأولية مأخوذة من القوانين وقوانين القضايا المقررة في بنغلاديش. إلى جانب ذلك، تتم الإشارة أيضاً إلى القوانين الأجنبية وقرارات القضية على أنها مقارنة. توصلت الدراسة إلى أن الحماية الجزئية التي توفرها الأحكام المختلفة المنتشرة في تشريعات مختلفة في بنغلاديش ليست كافية. علاوة على ذلك، في ظل عدم وجود تشريعات شاملة وتنظيم مشترك فيما يتعلق بحماية البيانات فضلاً عن القانون القطاعي المحدد المتعلق ببيانات الصحة الإلكترونية، يجعل آلية الحماية الحالية أكثر ضعفاً. ومن ثم يجب على المشرعين النظر في معالجة هذه الثغرة من خلال سن تشريع شامل لحماية البيانات مع حكم منفصل يضمن حماية إضافية لبيانات الصحة الإلكترونية.



APPROVAL PAGE

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DECLARATION

I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at IIUM or other institutions.

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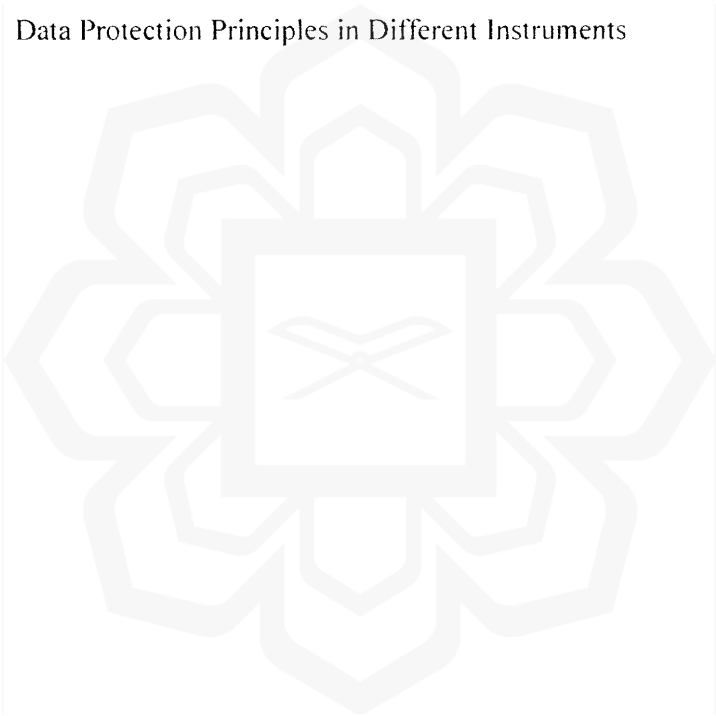
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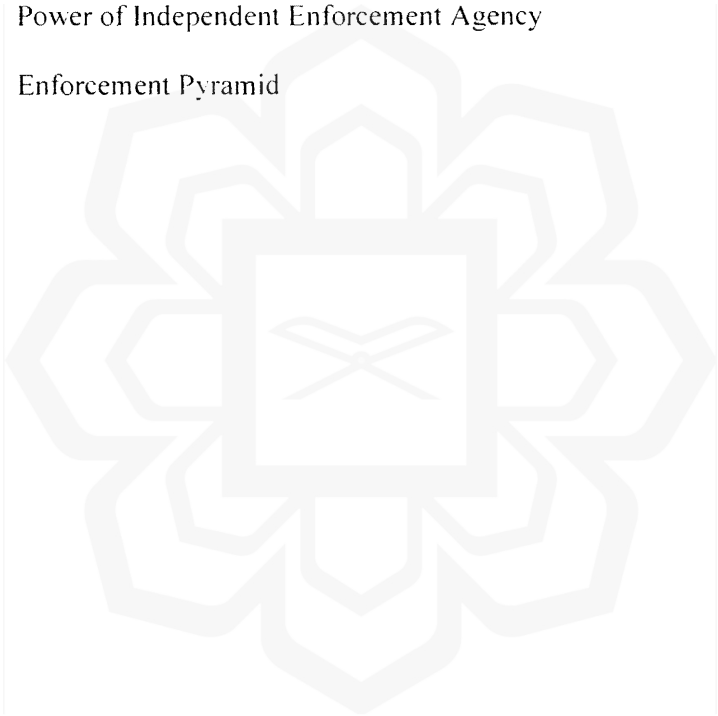
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Health Insurance Portability and Accountability Act (HIPPA) 1996

Privacy Act 1974

CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

Development in information and telecommunication system is evident in every sector of our modern life. The present health services have been witnessing the same heat with the advancement of the concept of electronic health system widely known as eHealth. Presently, the healthcare system is much more efficient, cost-effective, and capable of facilitating health services to rural and remote communities instantaneously, which anyone hardly ever thinks of before. Now medical checkup for patients, prescribing medicine, even medical surgery is possible with the blessing of eHealth through the internet. In addition to that, with the advent of the Electronic Health Records (EHRs) system, the records of every patient are now kept electronically. The effect of eHealth service in flourishing the health industry has also been progressed noticeably in developing countries lately.

Health records are confidential and private information. This information is also regarded as sensitive as the disclosure of health information could have harmed the individual myriad of ways, either mentally or financially. EHealth tools and services have already demonstrated its effectiveness in providing health services in more efficient ways, which is helpful for health professionals and healthcare authorities. The paradigm shift in healthcare service is evident with the advent of mobile health services, wearable devices, the internet of things (IoT), big data, and artificial intelligence (AI). Although easy access and availability of health data or patients' information anytime

and from anywhere are regarded as one of the significant advantages of the eHealth system, such conveniences also pose significant threats for health professionals, health consumers, lawyers, and policymakers. The privacy of health data has emerged as a significant threat to the development of e-health. The vast amount of information and technical data related to healthcare services demand a robust and strict policy protecting patients' health data and privacy. eHealth technologies entail a variety of ethical and legal problems.

Bangladesh has made considerable development in the eHealth sector. The present government has given special attention to rendering health services to all citizens as part of the government's promise to build digital Bangladesh. Although the history of eHealth in Bangladesh can be traced back to 1980, it has not achieved the desired result it should have been made in considering development made in other countries. However, the Ministry of Health and Family Welfare has continuously developed a comprehensive eHealth system. It has already established a Management Information System (MIS) under the Directorate General of Health service. In addition to that, a platform for maintaining lifetime electronic health records of all citizens has already been established and successfully deployed in two hospitals.

Apart from that, telemedicine services with advanced telemedicine peripherals such as tele stethoscope, tele ECG, tele microscope, tele glucometer, Geographic Information System (GIS) for disease surveillance, and Pregnancy Care Advice through SMS had been introduced. Furthermore, Medical Biotechnology (MBT) program was introduced as part of the Health Information System (HIS) and eHealth operational plan. Although current government initiatives for the development of eHealth are worthy to praise, the associated risks that come with implementing these technologies should be

considered. One of the significant concerns with the electronic healthcare system is the privacy and security of health data.

The internet has brought radical changes in the economic, social, health, and political life of people, but it is always considered a grave threat to privacy. The issue of privacy and data protection is not new in the modern world. The privacy concern has been in existence since the evolution of human beings, but the gravity of such concern is different in the present time than previous. Technological evolution and its rapid advancement accelerated such concern to a level where people now live in a state of confusion about whether they have any privacy. Information or data always has its importance for the smooth functioning of States and the welfare of the citizenry, and the rapid informational explosion can be traced back to 1970. The gradual rise of information technology and computational power sow the seed of fear of privacy in individuals, leading to adopting protective measures and standards to safeguard personal information and privacy. In the view of Rosemary Jay,

while data protection instruments, at both international and national level, were probably the earliest legislative responses to the information age, since then the field of information law has matured. There is host of European legislation either in force or in preparation dealing with what can broadly be described as information law issues; numerous UK statutes cover or include information provisions and the courts are increasingly called on to decide cases concern information.¹

While technology has proved useful for every aspect of our lives, the need for trust, confidence, and security remains a pivotal issue. People regularly give away their information while availing of health services and buying online, but they have little idea what the companies do with their information. On the other hand, with the increasing sophistication of websites that collect data or information through cookies, spyware that

¹ Rosemary Jay, *Data protection: Law and Practice*, (London: Sweet & Maxwell, 4th edn., 2003), 1.

collect data on users, and smartphones that records one's movements, the amount of personal data being collected has reached a level where it is pointless to stop collection instead of addressing the regulation of how the collected information is used.²

The unprecedented development in the area of information and technology has hurled the question of whether there is any privacy or not. In the opinion of Wei, "the problem of privacy is twofold- does the law recognise a substantive right of privacy or a right to respect for a private or personal fact? If the law does provide a legal right, is the law confer adequate but proportional remedies...?"³ Even if the law provides the right to privacy, would it be possible to provide absolute privacy? In considering the present development of information technology such as the rise of smart cities, the internet of things, big data, AI, predictive analytics, among other things, there is no absolute privacy, not even in the jungle. That does not mean that there is no need to have a legal framework or certain kinds of check and balance in society. Considering the rapid growth in the technological arena, sometimes it is unreasonable to expect that the law will keep pace with every challenge posed by technology. However, it is not unreasonable to expect minimum legal protection regarding the protection of citizens' personal data and privacy.

Moving to Bangladesh's present legal infrastructure, there is currently neither a specific statute to deal with health data privacy nor any comprehensive data protection law. There are some provisions scattered in different legislations addressing the issue of data privacy. The Constitution of Bangladesh recognises the right to privacy, but that is limited to home and correspondence. Apart from that, the Digital Security Act (DSA)

² Simon Chesterman, *Data Protection Law in Singapore: Privacy and Sovereignty in an Interconnected World*, edited by Simon Chesterman. (Singapore: Academy Publishing, 1st edn., 2014). 2.

³ George Wei, "Effectively protecting private facts: Privacy and confidentiality". *Singapore Academy of Law Journal*, vol. 24, no. 1 (2012): 223.

2018, Information and Communication Technology (ICT) Act 2007, Right to Information (RTI) Act 2009, and Bangladesh Bank Order 1972 and its related regulations provide provisions ensuring to protect the interest of privacy of the citizenry. These legislations are not designed to ensure personal data privacy. For example, the DSA deals with cyber-related crimes, though a single provision affords protection against illegal and unauthorized use of personally identifiable information without permission. Further, the ICT Act was enacted to recognise e-commerce transactions and electronic records. Bangladesh Bank Order ensures the privacy of financial data, and the RTI Act imposes restrictions on public authorities not to disclose confidential information regarding any individual, which may offend his privacy.

Apart from that, more than twenty statutes are in force in the health sector, but none of the statutes explicitly provide any provision regarding health data privacy. In the opinion of Chesterman, “across Asia, the absence of European-style rights protection meant that an approach similar to the US model taken, with piecemeal legislation or episode court intervention or, as in many jurisdictions the matter was either left to the market or essentially ignored.”⁴ It can be said that the policymakers or the government of Bangladesh are hardly paying any heed to the importance of ensuring the data privacy of the citizenry.

It is high time for Bangladesh to review the present legal framework regarding the protection of eHealth data, privacy, and security, keeping in mind the considerable amount of initiatives taken to develop the eHealth system. The existing legal protection offered by the scattered legislations is in no way comprehensive enough to afford the

⁴ Chesterman, 20.