

E-HEALTH PERSONAL DATA PRIVACY: A COMPARATIVE STUDY OF MALAYSIAN AND AUSTRALIAN LAWS

BY

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INTERNATIONAL ISLAMIC UNIVERSITY MALAYSIA

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BY

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A thesis submitted in fulfilment of the requirement for the degree of Master of Comparative Laws

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ABSTRACT

Health data, which is one of the most sensitive data, requires adequate protection to ensure overwhelming participation of the people in e-health. The thesis analyses the Malaysian Constitution and relevant legislation on the e-health data privacy and their adequacy. They are Telemedicine Act 1997, the Medical Act 1971, the Communications and Multimedia Act 1998, the Digital Signature Act 1997, the Computer Crimes Act 1997 and the Insurance Act 1996. The common law has also been analysed to see whether the constitutional and legislative gaps can be filled with the common law. The discussion of the laws of Australia on e-health data privacy is an attempt of comparison with Malaysian laws and where necessary, to suggest improvement and amendments into Malaysian law. The Islamic law on right to privacy is also discussed to address the position of right to data privacy in Islam and to recommend it in formulating laws on e-health data privacy. The study reveals the need for a liberal interpretation of Articles 5 and 8 of the Federal Constitution. Though there are statutory provisions on privacy, only a limited e-health data privacy protection is available. Certain common law principles allow some level of protection even though it may be difficult to prove violation of privacy under them. The draft Bills on personal data protection specify special protection for sensitive data that includes e-health data. As the implementation of this Bill is delayed, the current legislative framework is not seen to be adequate in Malaysia to protect the e-health data privacy. The passing of new legislation is imperative and the Australian laws can be of good resource to look into.

ملخص البحث

APPROVAL PAGE

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To all those who seek avenues to information privacy.

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Income Tax Assessment Act 1936

Telecommunication Act 1991

National Health Act 1953

UNITED KINGDOM

Access to Health Records Act 1990 Access to Medical Reports Act 1988

Data Protection Act 1998

LIST OF ABBREVIATIONS

AC Appeal Cases

ALJ Australian Law Journal
All E R All England Report
ALR Australian Law Report
Ch. Chancery Report
Cth Commonwealth

CLJ California Law Journal
CLJ Current Law Journal
CLR Calcutta Law Reports

CLR Commonwealth Law Report

CTLR Computer and Telecommunications Law Review

F.Supp Federal Supplement

FMSR Federal Malay States Report

Harv. L.R. Harvard Law Review
Lloyd's Rep. Lloyd's List Law Report
MLJ Malayan Law Journal
NSW New South Wales
P.B.U.H. Peace Be Upon Him
R.A.U. RadhiyAllah Unh / Unha
S.W.T. Subhanahu Wa Ta'ala

QB Queen's Bench

US United States Supplement Court Reporter

CHAPTER ONE

INTRODUCTION

1.0 INTRODUCTION

Advanced technological developments in information and communication technologies have enabled the health industry to carry out medical check up for public and get their prescriptions from relevant doctors or medical practitioners via Internet. In the process, all relevant information about the patient are stored in the computer system of the medical practitioner and other related parties for record and reference purposes. However, storing such information in the computer is not at all secured due to the availability of technology that may circumvent or access the said information. This could be a threat to the privacy of the patient. Regulatory compliance and liability issues arising from the use of information technologies and possibility of privacy violation in health care industry should be given important consideration as the evolution and progression of e-health industry is dependent upon and influenced by the rapidly changing advances in law.

The Multimedia Super Corridor (MSC) is the physical evidence of the vast investments made by the Government in Malaysia to propel the transition to an ICT (Information and Communication Technology)-enabled economy. The incorporation of e-health as one of the MSC flagships by the government shows that it is gearing all sectors including the health sector to achieve development by 2020. In order to regulate the e-health flagship, the government has introduced the Telemedicine Act 1997. However, the 1997 Act is still undergoing the process of revision as it only provides provisions of infrastructure for e-health programme.

An inevitable transition of ICT based industries is a common phenomenon in many developed nations. Having realised this phenomenon, countries like the US, the UK and Australia have taken bold steps towards improving and enhancing the health sector by ensuring adequate protection for the patients' records. For example, Australia through the National Health Information Management Advisory Council's Health Online: A Health Information Action Plan for Australia¹ provides strategy for information management and the use of online technology within the health sector. It also addresses the issue of protection of patient's records against abuses. As Malaysia strives towards being a developed nation, there is indeed a need to analyse the facts and evaluate the following questions:

- Are privacy issues the main barriers to the adoption and implementation of e-health program in the country?
- 2. What is the availability of legal protection of the right to e-health data privacy?
- 3. What is the available legal framework for protecting e-health data in Australia that can provide important lessons to Malaysia?
- 4. What is the *Sharī* ah perspective on right to privacy?

1.1 STATEMENT OF PROBLEM

Privacy concern has been a growing major issue globally. The advancement of technology has given numerous opportunities to various people to breach personal data privacy of e-health consumers. Various studies have shown that concern over violation of privacy is increasing. Initiatives taken by various international governments to protect privacy of netizens highlight the significance of having

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¹ Health Online, "A Health Information Action Plane for Australia,"

<www.health.gov.au/healthonline/her_rep.htm> (accessed 13 December, 2005).

adequate protection for the protection of netizens and the issue has become a subject of academic and practical interest. In Malaysia, there are no express provisions under the constitution to protect the right to privacy. However, it is argued that Articles 5 and 8 may be of help in protecting right to privacy. The existing legislation and the common law only provide patchy protection to individual's right to privacy. Malaysian government has proposed "Personal Data Protection Bill" to address the issue of data privacy. However, the Bill is under much scrutiny and scepticism on its effectiveness. There are numerous limitations under the Bill. These limitations would allow the disclosure of personal data without the consent of data subject. Further, Telemedicine Act 1997 provides for regulation of infrastructure for a programme of telemedicine rather than e-health care programme and related privacy regulation. The Act is now being reconsidered for redrafting. However, Australia provides various legislative frameworks or the protection of e-health data privacy. Similarly, Islam recognises various rights of private life which have been affirmed by the Qur'an and Sunnah. Islam considers private life as the integral part of human rights. Even if one is sure of someone's improper behavior by inference, he has no right to 'develop' information that would become evidence. We have to give that person the benefit of doubt, which becomes his right to privacy. The current study of e- health personal data privacy protection in Malaysia is intended to analyse the legislative framework of e-health data in Malaysia in the light of the relevant Australian legislation. The study also focuses on Islamic perspective on the issue. Thus the research focuses on the following research problems:

There is an urgent need to understand the emergence of legal problems
that threaten e-health privacy of patients and the importance of reforming
the existing laws. Malaysia is currently undergoing a rapid economic

growth and has taken various measures to boost e-commerce activities which inevitably have tremendous impact on domestic transactions and consumer-related issues.

- A study covering issues of e-health personal data privacy protection in Malaysia is imperative and beneficial to the national legislative body. There have been initiatives to pass new laws while amending existing laws to address various issues on cyber law.
- A study of content and comparative analysis will contribute to the advancement of knowledge in the area of e-health personal data privacy as there is a dearth of legal literature on the subject matter particularly in Malaysia.

For these reasons, a critical study on the issue of e-health personal data privacy protection would make a substantial contribution to the existing pool of knowledge.

1.2 HYPOTHESIS

- Technologies are used for more efficient health delivery and data are kept electronically. This might be used to breach the e-health data privacy of individuals.
- 2. Individuals are concerned about violation of their e-health data privacy.
- Article 5 and 8 of the Federal Constitution of Malaysia may provide protection for one's right to privacy including e-health data privacy.
- 4. The available legislation like Medical Act 1971, Telemedicine Act 1997, Computer Crimes Act 1997, Digital Signature Act 1997, Communication and Multimedia Act 1998 and common law are not adequate to address the breach of privacy right.

- 5. Relevant legislation in Australia addresses e-health data privacy and can be of guide to Malaysia to follow.
- 6. Islamic law ensures protection of privacy of individuals.

1.3 LITERATURE REVIEW

Joan Dzenowagis² in his paper shows that the technological development in health sector brought new relationships between consumers and providers and consumers and suppliers. He also states that a dual challenge for legal and regulatory framework had been brought by this new development: "growth" vs "protection".

He stresses that there is a need for common regulatory and standards relate to:

- information gathering, storage and exchange;
- reliable, secure, effective networks; and
- evaluation of impact on consumer.

He identifies privacy and confidentiality will be one of the major issues in ehealth sector.

A survey by Louis Harris³ reveals that privacy concern in e-health initiatives is real. It confirms the perception of a lack of sufficient safeguard for medical records. 25% respondent reported that they believed their medical record had been improperly disclosed, and 34% of the health care professionals believed that the records are given to unauthorized persons "somewhat often". In Malaysia too, the privacy concern is said to be a cause hindering the adoption of ICT based health program. A recent survey revealed that the assurance of privacy protection was the most important factor

² Joan Dzenowagis, *Protecting eHealth Consumers Regulatory & Normative Issues*, (USA: World Health Organization, 2000), 3.

³ Harris Interactive, Survey on Medical Privacy (pdf), (New York: Louis Harris & Associates, 2004), http://www.harrisinteractive.com/news/newsletters/healthnews/HI_HealthCareNews2004Vol4_Iss13. pdf>

encouraging e- activities. 99.66% of the respondents felt that assurance against abuse of personal data was pertinent. Majority of the respondents felt that the web sites must ensure the security during transfer of sensitive data.⁴

Malaysian users are also concerned about their privacy. A survey conducted by Taylor Nelson Sofres Interactive showed that the percentage of Internet users dropped from 25% of the population in 2000 to 21% in 2002. Among the existing Internet users, only 3% to 5% users were online shoppers. Out of which 38% felt that doing shopping offline provided adequate security including privacy protection.⁵

Noor Raihan et al., finds that consumer concern over security and privacy is intertwined. The anxiety about their personal data or confidential information getting into the wrong hands or even the hands of the Government is a major obstacle to more people going online. Although misuse of personal data has not been prevalent or highlighted in the local press, many users are constantly reminded of the possibilities by the vast number of spam received. The most popular reason given by the respondents for their reluctance to fill online registration forms at web sites is that information is not provided on how the data is going to be used (62%), and that they do not trust the entity or company collecting the data (60%). There is an innate knowledge that personal data is being used and "sold" by Internet companies, and that consumers are more careful about releasing their financial information such as credit card number. Their fear of their data being misused is compounded by the fear that unscrupulous parties can gain access to their data by hacking the Internet companies they have transacted with. It is said that the public concern over privacy protection should be given serious consideration so that the Malaysian vision of being a global

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⁴ Hurriyah-el-Islamy, "Protection of Online Privacy & Its Impact on E-commerce," http://www.cljlaw.com (accessed 13 January, 2005), 4.

Taylor Nelson Sofres Interactive, *Global E-Commerce Report*, (USA: Taylor Nelson Sofres Interactive, 2002), 2.

ICT and multimedia hub and promotion of e-commerce as stated in the Eighth Malaysian Plan can be materialised. ⁶

Many developed nations like the US, the UK and Australia had realized the importance of improving and enhancing the health sector in this ICT era and have given special consideration for the protection of e-health privacy. For example, Australia through the National Health Information Management Advisory Council's Health Online: A Health Information Action Plane for Australia⁷ provides a strategy for information management and the use of online technology within the health sector. One key component of Health Online is the plan for national electronic health records. Under this, it is proposed that health related information about an individual will be collected in a standard electronic format at the point of care. The information will take the form of health summaries rather than all the notes a health care provider may choose to keep after consultation. Consumers would have access to their own records.

According to Privacy International, Malaysia lacks comprehensive legislative framework to provide protection for e-health data. Jawahitha and Mazahir state that although there is an absence of specific provision on the issue of right to privacy in the Malaysian Federal Constitution, Articles 5(1) and 8(1)¹⁰ may recognise such a right if these provisions are to be interpreted broadly and liberally in accordance with the

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⁶ Noor Raihan, Elena, & Jawahitha, "Security and Privacy Issues as Barriers to E-Commerce Growth: A Consumer Perspective," *Proceedings the 2003 International Business Information Management Conference* (Cairo: IBIMA, 16-18, December 2003), 114.

⁷ Health Online, "A Health Information Action Plane for Australia,"

<www.health.gov.au/healthonline/her_rep.htm> 1 (accessed 13 December, 2005).

⁸ Ibid.

⁹ Privacy International, Survey: Malaysia,

http://www.privacyinternational.org/survey/phr2003/countries/malaysia.htm (accessed 17 December, 2005).

Article 5(1) reads that "no person shall be deprived of his life or personal liberty save in accordance with law" and Article 8(1) states that "all persons are equal before law and entitled to the equal protection of the law."

particular needs of the developing society. They also point out that the expression 'life' appearing in Article 5(1) does not refer to mere human existence. It incorporates all those facts that are an integral part of life itself and more matters, which go to form the quality of life. As such the right to privacy which is considered as important to have a decent and quality life may be easily included in the expression of "life". In the event if right to privacy is recognised under Article 5(1) as one of the fundamental liberties, then the netizens will have better protection of their right to privacy in case where there is a decision that adversely affected the guaranteed fundamental liberty. When such a decision is taken, Article 8(1) will ensure that right to access to justice is ensured. This provision will ensure that procedural and substantive fairness have been adopted. ¹¹

According to Privacy International, the legislation, which have implication to privacy, include Computer Crimes Act 1997, Digital Signature Act 1997, Communication and Multimedia Act 1998, Penal Code, Official Secrets Act 1972, National Land Code 1965, the Consumer Protection Act 1999, and the Banking and the Financial Institutions Act 1989. The Computer Crimes Act imposes criminal punishment to those who access, modify, communicate or use computer programs or files or documents without authority. The General Consumer Code 2003, issued by the Malaysian Communications and Multimedia Commission, a statutory body established in accordance with the provisions of Communications and Multimedia Act 1998, also addresses the issue of privacy and provides certain remedies against its violation.

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¹¹ Jawahitha & Mazahir. "Protection of e-consumer Privacy in Malaysia," *International Conference on Intelligent Agents, Web Technologies, and Internet Commerce,* (Gold Coast: IEEE, 2004): 12-14.

¹² Privacy International, *Survey: Malaysia*, http://www.privacyinternational.org/survey/phr2003/countries/malaysia.htm (accessed 17 December, 2005), 2.