

Privacy of Personal Health Information as a Patients' Right in Sri Lanka

Upeksha Madukulpani Sapukotana[#]

Legal Draftsman's Department, Sri Lanka

[#] Corresponding author; <upekshasapukotana@yahoo.com>

Abstract - Health information privacy refers to the right of a patient to expect that their personal health information remains private and shared with others to the extent in order to provide proper health care.

Personal health information, whether written, oral or electronic in its form needs to be accessed by large number of parties such as doctors, nurses, administrative staff of a hospital pharmacists and even third parties such as insurance companies. Unauthorised access as well as authorised persons misusing such information has become a major issue in relation to the privacy of personal health information.

This research addresses the problem whether the legal system of Sri Lanka has adequately responded to the challenge of protecting health information privacy as a patient right in Sri Lanka. Data collection was done through a comprehensive survey of available literature on the subject. For comparative purposes, legal developments in India were taken into account.

It was found out that Sri Lanka has no proper legal mechanism to protect privacy of personal health information and it is recommended that a proper legal framework be introduced based on the legal developments that have been taken place at the international level and in other domestic jurisdictions.

Keywords— Privacy, Personal Health Information, Legal Protection

I. INTRODUCTION

Privacy of personal health information derives from the broader concept of right to privacy. Privacy has been recognised as a deeply felt yet elusive concept to define as it is generally experienced on a personal basis (Gostin, 1995). Gavison (1980) states that It is an "interest of the human personality that protects the inviolate personality, the individual's independence, dignity, and integrity". The historical roots of the right to privacy stems from the philosophical thinking of Aristotle where he made a distinction between the public sphere of political activity and the private sphere associated with family and domestic life (Glancy, 1979).

Modern approach to right to privacy is found in the article written by Warren and Brandies in the Harvard Law Review in 1890 where they introduced right to privacy as "the right to be left alone". In such circumstances privacy can be considered as another name for personal autonomy and as Justice Brandeis held in his dissenting opinion in the case of *Olmstead v. United States* (1928) 277 U.S. 438,478, privacy is "the most comprehensive of rights, and the right most valued by civilized men".

Privacy, as a concept has its different limbs which include;

1. information privacy, which involves control and handling of personal data;
2. bodily privacy, which concerns the protection of people's physical selves against invasive procedures
3. privacy of communications, which covers individuals' interests in communicating among themselves using various forms of communications; and
4. territorial privacy, which involves setting limits or boundaries on intrusion into a specific space (Domingo, 1999)

Among the aforesaid limbs, Information privacy is very important as it involves the ability of a person to control and protect one's personal information (Glancy 1979). Amidst of the types of information that needs best legal protection, health information privacy is at a leading position due to its sensitive and confidential nature.

Health information can be broadly defined as all records that contain information that describes a person's prior, current or future health status, including aetiology, diagnosis, prognosis or treatment or methods of reimbursement for health services. (Gostin et al. 1993). A

Health information privacy refers to the right of a patient to expect that their health information remains private and shared with others to the extent in order to provide proper health care (Nass et al, 2009). Vaz (2007) is of the view that patient's privacy encourages patients to seek information and assist to understand and evaluate their options, so that they can make the most informed medical decisions.

The fiduciary relationship between the doctor and patient which is embedded in the Hippocratic Oath of the medical practitioners is the oldest form of legal protection to protect health information privacy. The importance of privacy of personally identifiable health information has been felt all over the world due to the increasing vulnerability of such information. Personal health information, whether written, oral or electronic in its form needs to be accessed by large number of parties such as doctors, nurses, administrative staff of a hospital (for billing purposes), pharmacists and even third parties such as insurance companies. Unauthorised access as well as authorised persons misusing such information has become a major issue in relation to the privacy of personal health information.

Breaches of health information privacy can lead to serious consequences for the patient, including disclosure of traumatizing health information being released to the public, identity theft, an increased risk of discrimination and marginalisation, or even damage to the patient's reputation and employment status (Dunkel, 2001). Further, the damage which privacy breaches bring upon a health care institution is almost as serious as the institution's reputation for confidentiality which is a cornerstone of effective treatment can also be undermined. Accordingly this study seeks to address the problem whether the legal system of Sri Lanka has adequately responded to the challenge of protecting health information privacy as a patient right in Sri Lanka. Data collection was done through a comprehensive survey of literature and for comparative purposes, legal developments in India were taken into account.

II. WHY PRIVACY OF HEALTH INFORMATION NEEDS LEGAL PROTECTION?

Every country around the world has some form of value for the notion of privacy especially health information privacy and its need of protection largely depend on the culture and society of each country (Westin 2007) and (Milberg *et al.* 1995). Most of the western countries in the such as United States and member states of the European Union gives higher value to the notion of privacy (Milberg *et al.* 1995). Several studies such as Tam (2001), Kitiyadisai (2005) and Kennedy, Doyle and Lui (2009), Asian countries face huge obstacles in enacting the law for privacy and data protection due to the inevitable influence of culture, social customs and values, economies and government policy. Samsuri, Ismail and Ahmad (2013) suggests that with the development of the information technology and the need to introduce legal

safeguards for data protection, the concern for privacy is rapidly increasing in Asian countries. This includes the need to protect health information as well.

Accordingly, ensuring legal protection for personal health information is very important for the following reasons:-

A. Ensuring confidence in the healthcare system.

It is difficult to think of an area more private than an individual's health or medical information. Assurance of privacy of health information is pivotal in prompting patient's confidence in the health care system. In spite of such confidence, patients would be reluctant to reveal all health information especially which are very sensitive in nature such as information in relation to sex life, mental health etc.

B. Sensitive nature of personal health information.

Health information has been identified as a type of sensitive data in many legislation around the world such as Section 2(e) Data protection Act of UK 1998, Section 6 - Privacy Act of Australia 1988, section 11 - Personal Data Act No. 523 of Finland, section 7 - The Act on Processing of Personal Data Act No. 429 of 2000 of Denmark, section 9 - Federal Data Protection Act of 2003 of Germany, section 4 - Personal Data Protection Act No. 709 of 2010 of Malaysia.

C. Concerns about human dignity.

Health information privacy goes hand in hand with the concerns about human dignity due to the intimate nature of health information (Roback and Shelton,1995), Applebaum, 2002), Accordingly disclosure of certain personal health information can cause embarrassment and damage to reputation and social status of a person and may lead to social stigma and marginalisation in certain cases such as HIV patients.

D. Promoting better communication between patient and physician and decision making.

Ensuring privacy facilitates better communication between physician and patient, which is a factor crucial for quality of care and help to enhance patient's autonomy preventing embarrassment and discrimination (Gostin *et al* 1993).

Studies reveal that privacy is a decisive factor in people's decisions whether to seek or forgo treatment, particularly in relation to sensitive health issues such as psychiatric problems and sexually transmitted diseases. (Gostin, 1995), (Dunkel, 2001) and (Appari, and Johnson, 2011)

E. Facilitate health research

Additionally, when people have less confidence in the level of protection for their personal health information in the healthcare system, they will engage in privacy protective behaviours or would possibly divulge incomplete or inaccurate information. This would on one hand, affect proper treatment of that individual as well as would give incomplete or inaccurate data for subsequent health research and statistical purposes which would on the other hand affect facilitation of public health purposes.

F. Economic value of personal health information

Most importantly personal health information has an economic value in the present marketing world. Personal health information obtained by a healthcare service provider, it would reveal the health condition, the kind of drugs taken and possible need for health insurance plans. Such information can be used for marketing purposes by health related business ventures like health insurers, pharmaceutical companies, hospitals, online medical sites.

III. LEGAL PROTECTION AT THE INTERNATIONAL LEVEL

The need to protect privacy of personal health information has been recognised in the following international legal instruments which protect right to privacy which includes health information privacy:-

A. Universal Declaration of Human Rights – 1948

Under Article 12 recognises right to privacy in following terms:

“No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation.”

B. International Covenant on Civil and Political Rights 1966

Article 17 of the Convention recognises this right as “No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.”

Apart from them the following international legal instruments on personal data protection are also important:-

- I. Organization for Economic Cooperation and Development’s (OECD) Guidelines on the Protection of Privacy and Trans border Flows of Personal Data 1980;

European Union Council Directive 95/46/EC entitled “Directive on the Protection of Individuals with regard to the Processing of Personal Data and the Free Movement of Such Data 1995;

United Nations General Assembly guidelines for the Regulation of Computerized Personal Data files 1990 ;and

Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data 1981 also deals with the issue of personal data protection.

Additionally International Covenant on Economic, Social and Cultural Rights of 1966 is important as it explicitly sets out a right to health under Article 12. Such right can be interpreted to contain the right of privacy of medical data.

Apart from that the Council of Europe Recommendation No. R (97) 5 on the protection of medical data of 1997 and the World Health Organization Declaration on the Promotion of Patients’ Rights of 1994 which speaks of ensuring quality, safety and ethical standards and respect for the principles of confidentiality of information, privacy, equity and equality of health information is also important.

Absorbing these legal developments, many countries around the world have introduced laws to protect information privacy. Certain countries have adopted specific laws on health information privacy, due to its importance such as Health Insurance Portability and Accountability Act of 1996 and Health Information Technology for Economic and Clinical Health Act of 2009 of the United States, Personal Information Protection and Electronic Documents Act of 1999 of Canada, Personally Controlled Electronic Health Records Act of 2012 of Australia, Health Information Privacy Code of 1994 of New Zealand.

V. PRIVACY OF PERSONAL HEALTH INFORMATION IN INDIA

India shares many social, cultural and legal common characteristic with Sri Lanka and is a common law country as well. India is in the process of absorbing e-health into their health care system while in the process of implementing legal measure to protect health information privacy through its general data protection regime, following the EU model. India recognizes health information as a type of sensitive data and has a growing body of judicial decisions on the subject. Accordingly

India was taken as the comparative jurisdiction for the purpose of this study.

Indian Constitution does not have an explicit right to privacy. However, Article 21 of the Constitution of India 1950 states that:

“No person shall be deprived of his life or personal liberty except according to procedure established by law”.

This constitutional provision was adopted to recognize the right to privacy in India in the case of *Kharak Singh v. State of UP (1963 AIR 1295)* where the Supreme Court held that

“It is true our Constitution does not expressly declare a right to privacy as a fundamental right, but the said right is an essential ingredient of personal liberty.”

This was confirmed in a number of judgment such as *Govind v. State of Madhya Pradesh(1975) AIR 1378*, *Naz Foundation v. Govt. of NCT of Delhi160 Delhi Law Times 277*, and *Rayala M. Bhuvneswari v. Nagaphomender Rayala(2008) AIR AP 98*.

India does not have a general statute that specifically deals with health information privacy but the concept is recognized in several health related legislation including Epidemic Diseases Act 1897, Mental Health Act 1987, Pre-Natal Diagnostic Techniques (Regulation and Prevention of Misuse) Act 1994 and Medical Termination of Pregnancy Act 1971

Also the Medical Council of India's Code of Ethics Regulations, 2002 provides for the professional standards for medical practice in relation to Patient Confidentiality. Accordingly, Physicians are obliged to protect the confidentiality of patient's health information unless the law requires their revelation, or if there is a serious and identified risk to a specific person and/or community

Indian Information Technology Act, 2001 provides legal protection for handling sensitive personal information which includes information on physical, physiological and mental health condition and medical records. This protection has been strengthened through the Information Technology (Reasonable security practices and procedures and sensitive personal data or information) Rules, 2011 issued under section 43A of the above Act. Rue 3 lists out the sensitive personal data to include

- I. physical, physiological and mental health condition;
- II. sexual orientation;

- III. medical records and history; and
- IV. Biometric information;

Additionally, the right to privacy in relation to health information has been considered in a number of cases in India including *Mr. "X" vs. Hospital "Z" (1998) Appeal (civil) 4641*, *Neera Mathur v. Life Insurance Corporation of India (1992) AIR 392*, *Selvi & Ors vs State Of Karnataka. (2004) Criminal Appeal No. 1267*, *Raghunath Raheja vs. Maharashtra Medical Council, (1996) AIR Bom 198*, *Surjit Singh Thind. V. KawaReproductive Autonomy (2003) AIRP H 353*, and *Parthasarathi vs. Government of Andhra (2000) (1) ALD 199*. Courts have followed a case by case approach in these issues and in certain cases disclosure of personal health information have been held as humiliating and embarrassing, recognising the privacy aspect of such information and on the other hand in some cases disclosure of such information has been justified for the interest of the public such as disease prevention.

Indian Data Protection Bill still remains at the draft stage and it also recognizes health information including physical and mental health and medical history, biometric, bodily or genetic information as a sensitive type of information of which privacy needs to be protected (Hinailias 2014)

V. SRI LANKAN EXPERIANCE

Sri Lanka does not have an expressed right to privacy in the Constitution of 1978. No specific or general legislation exist at the moment in relation to data protection or protection of health information privacy.

Some protection can be traced through the remedies available in Law Delict such as an action against invasion of privacy under *actio injuriarum*. Also protection can be ensured through contractual liability. Hospitals especially private hospitals have their own privacy policies on a case by case basis and no legal compulsion or any guideline issued by the ministry of health or the Private Health Services Regulatory Council on this subject.

National Health Development Plan (2013-2017) initiated by the Ministry of Health recognizes that healthcare is an information intense field, relevant, accurate and timely information is the key for evidence-based management in healthcare. Also the National Strategy and Implementation Guidelines for Health Information Management seek to protect Data/Information Security, Client Privacy, Confidentiality and Medical Ethics.

V. CONCLUSION

Healthcare is an extremely information intensive industry. Healthcare personnel must acquire, process, store, retrieve and transfer clinical, administrative and financial health information. Misuse of information, disclosure of confidential information and risk of privacy Violations caused by unauthorized access as well as authorized persons misusing such information is a threat felt all over the world. Therefore it is obvious that any patient would have a reasonable expectation about the privacy of their persona health information,

VI. RECOMMENDATIONS.

In this context it is highly recommended that Sri Lanka introduce a proper law in relation to the protection of health information privacy based on fair information practices. The protection for privacy of personal health information should be ensures while providing room for disclosure of such data with prior consent being obtained or through de-identification, for special purposes such as public health, disease prevention and health research purposes. Also it is important to have an independent body to monitor the compliance of the provisions of the Act by healthcare service providers.

Apart from this Ministry of Health and the Private health Services Regulatory Council must issue a comprehensive guideline on ensuring privacy of health information by healthcare service providers and such service providers must be encouraged to have self regulatory measures through appreciating them by giving awards, giving necessary technical and legal assistance and other forms of encouragement.

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