

# Health Information Privacy Laws and Policies: Do We Need More Policies in the Arab World?

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## **Abstract.**

The privacy of patients' health information is an important aspect of the healthcare delivery. Within the health informatics community, there has been a debate about the role of health care policy in maintaining patients' privacy when using and sharing their health information by their clinicians. Some argue that stringent healthcare policies will empower the patients and improve the patient-clinician relationship. Others argue that having more health privacy policies will actually affect the patient-clinician relationship and will hinder the exchange of important information not to mention that it contradict with some of our cultural norms. These two arguments make valid points. Considering this debate, the purpose of this position paper is to provide an argument regarding the need for stringent healthcare policies. In this position paper, I argue that stringent healthcare policies are needed and will empower the patients and improve the patient-clinician relationship. Additionally, this paper continues the discussion that was raised by Almulhim's paper regarding the role of health policy in shaping health information technology uptake within healthcare.

**Keywords.** Health Information Privacy; Laws; Policies; Arab World.

## **Introduction**

There are different laws and policies that regulate the using and sharing of patients' health information around the world. For example, in the states, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule provides a federal protection regarding who and how your identifiable health information is handled. Some might say that the culture of each country plays an important role in the development of such regulations considering that since antiquity, various civilizations emerged and followed one another, each with different culture, tradition and rules. Others might think that the urgency of such development is the real reason for having these laws. Regardless, the need of having privacy policies has been for many an interesting subject for debate, especially in our Arab World. For example, a paper in 2012 discussed the role a health policy has in shaping the uptake of health information technology within healthcare. The paper refutes various claims to support its claim that "health policy must be developed prior to the implementation of health information technology within the Arab World"<sup>1</sup>. Accordingly, the experts in the Arab World have

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an argument whether we should have stringent health information privacy policies or is there no actual need for such laws and regulations within the region of the Arab World. Before examining these allegations, the definitions of the terms of the policy and privacy must be first be defined clearly. According to the World Health Organization (WHO), a health policy refers to the “decisions, plans, and actions that are undertaken to achieve specific health care goals within a society. An explicit health policy can achieve several things: it defines a vision for the future which in turn helps to establish targets and points of reference for the short and medium term. It outlines priorities and the expected roles of different groups; and it builds consensus and informs people”<sup>2</sup>. On the other hand, according to the HIPAA Privacy rule, privacy is defined as “an individual's interest in limiting who has access to personal health care information”<sup>3</sup>.

There has been a debate about the need to impose stronger privacy policies within the healthcare industry. Some argue that stringent healthcare policies will empower the patients and improve the patient-clinician relationship because it protect the patients and allow them to share more information with their clinicians. Others argue that having more health privacy policies will actually affect the patient- clinician relationship and will hinder the exchange of important information not to mention that it contradict with some of our cultural norms.

In this position paper, I argue that stringent healthcare policies are needed and will empower the patients and improve the patient-clinician relationship. Claims that both support and oppose this argument are presented. The paper also provides a conclusion that summarizes the main points of this argument.

### **1. Counter Claim Argument:**

Some in the Arab World argue that having more health privacy policies will actually affect the patient- clinician relationship and will hinder the exchange of important information not to mention that it contradict with some of our cultural norms. This argument has many valid points that support it.

First, what might seem ethically acceptable to be rendered as a private matter in the American or European culture may consider as censored or prohibited for the Arabian public and vice versa. Actually, a case like the one took place in 1992 in America, in which a court ruling was issued by San Francisco Superior Court judge considering that a parental or judicial consent for an unmarried teenage girl’s abortion was unconstitutional, may serve the cause of anti-privacy activist in our region. Led by the writer of the *Los Angeles Times*, Phillip Hager, a subsequent controversy was created around whether such law "violates a minor's right to privacy under the California Constitution." <sup>4</sup>. Considering the Arabic Culture in this regard, for such a sensitive issue as abortion for unmarried girl to be even considered as a private matter in the first place, is unthinkable. With the consequential ethical dilemmas and legal issues that may arise once health information privacy laws are issued and put into action within our Arab world, such cases can result in a considerable controversy.

Second, for some, there have not been security breaches or privacy violations as much as there have been in the western societies, so as a result, no need for the Arab world to duplicate their own tailored version of security and privacy laws such as HIPAA (Health and Insurance Portability and Accountability Act of 1996) and therefore, the current laws are considered protective enough.

Third, some people think that more privacy law will endanger the freedom of speech in general, and restrict and complicate, in particular, the communication of health information among healthcare providers which can eventually have side effects on the patient health. Would not that discourage physician and put them in fear of being sued for violation of privacy laws whenever they want to consult with another physician especially in times of emergencies? And therefore, would backfire on the patient whom we want to protect in the first place?

Finally, the concept of patient private health information is, to some extent, blurred and unclear in the Arab world. Additionally, in our Arab world, the concept of privacy is more focused on the physical part of the idea of privacy. A shift in thinking of the way we address and manage the health information privacy, in particular, need to be made in order to increase the health care providers' awareness of the seriousness this matter has on a person's entire life.

The arguments claiming that having more health privacy policies will actually affect the patient-clinician relationship and will hinder the exchange of important information not to mention that it contradict with some of our cultural norms are valid. However, there are numerous arguments that can refute them. Take the first point for example, which argues that having stronger health privacy policies can contradict with our cultural norms. Even in the States and Europe, there still disagreement about what is acceptable as a privacy right and what is not. This is supported by the constitutional controversy that was created after the court ruling that was issued in the story above. That does not mean that we shouldn't have a modified version of such law as HIPAA privacy rule that consider such cultural sensitivities.

Regarding the second point, which posits that there have not been security breaches or privacy violations as much as there have been in the western societies and therefore, there is no need for stringent policies in this regard. The answer to this claim might be that there has not been as many violations of privacy reported due to the fact that there is no such law that criminalize and punish those guilty of violating the patients' rights of privacy. This fact could also have discouraged those concerned with similar cases to go to the court of law.

The third point which argues that more privacy law will endanger the freedom of speech in general, and restrict and complicate, in particular, the communication of health information among healthcare providers which can eventually have side effects on the patient health is also flawed. When the patient knows that whatever he said to his/her clinician is fully protected, this will empower him/her to share more information and will, in turn, reflect on the outcome of the treatment. This also can serve the movement of patient rights in particular and the human rights in the Arab

world in general. Regulation that rule how clinicians use and share information can take the emergency cases into consideration.

And last, the fourth point that claims that the concept of patient private health information is, to some extent, blurred and unclear in the Arab world can also be refuted. This very situation can be taken advantage of by adjusting the HIPAA privacy rules for all of the patients, employers and government to be suitable for each Arabic country's individual needs and requirements.

## **2. Our argument:**

I believe that stringent healthcare policies are needed and will empower the patients and improve the patient-clinician relationship. Mostly, in the hospital or in any other organization, in order to ensure that any desirable action will be followed by everyone, a clear detailed policy in this regard needs to be issued. This paper presents two main points that indicate the need for stronger health privacy policies and actions that are needed within the Arab World accordingly.

*2.1 Point I: the absence of patient privacy laws and policies in some of the Arab world, particularly the KSA, should be rectified by establishing strong privacy policies and ensure that they are being followed.*

A consultative preparatory meeting for a Follow-up International Conference on Financing for Development was held by the United Nations Economic and Social Commission for Western Asia (ESCWA), on 2008 in Doha, Qatar. In which one of the speakers, Dr. Nibal Idlebi a member of the United Nations Economic and Social Commission for Western Asia, addressed the topic of "Cyber Legislation in the ESCWA Region: Security Issues." <sup>5,6</sup>.

In her presentation, Idlebi discussed where we stand as Arab countries, from Data Protection & Privacy (DP&P) laws & regulations. She revealed that as of February, 2008; countries like Bahrain, Jordan, Iraq, Kuwait, Oman, Palestine, Saudi Arabia, Syria, and Yemen were classified as countries that do not have any rule regulating Data Protection & Privacy. Furthermore, other countries were found to have articles on DP&P such as Egypt (Telecom Law), Lebanon (draft of e-commerce law), and Qatar (Telecom Law 2006 Decree 34). Lastly, only the United Arab Emirates (UAE) was left alone to be described as the only country within the Arab world that has a specific rule for DP&P, (Data protection Law 2007, UAE). Those were the facts presented by someone who may not be considered as an expert in health information privacy, nevertheless, experts such as Joan Antokol do agree with what Dr. Idlebi said.

At the same year of 2008, in the eighth annual conference of Public Responsibility In Medicine & Research (PRIM&R), which is an organization that describes its mission as being dedicated to advance the highest ethical standards in the conduct of research, a report discussing the 'International Privacy And Data Protection Laws' was compiled by Joan Antokol from the law firm of Baker & Daniels LLP. Back up with her particular expertise in a number of aspects of privacy and security, including

medical and clinical research, addressing and preventing security breaches, transferring personal information between countries, and with the help of the reports of ESCWA, Joan discussed the level and measures of privacy and data protection around the world, including our Arab world. She came up with a similar finding to the previous Nibal Idlebi presentation.

However, in the case of Tunisia, Antokol expressed her admiration for the Tunisians Data Protection Act regardless of her certain reservations in which she said that “The extensive new law [it contains 105 articles, compared to 34 for the European Union (EU) directive] establishes a series of new standards on privacy and data protection and establishes a National Data Protection Commission to ensure their enforcement. Like the EU's Data Protection directive, the Act establishes in its first article that Tunisian citizens have a framework right to privacy and protection of their personal data.”<sup>7</sup>.

Nevertheless, Antokol questioned the motives behind these laws in which she said “Tunisia is the first nation in Africa to enact a specific privacy and data protection law based on the European Union's data protection directive (Directive 95/46/EC of the European Parliament). Unlike the EU directive, the new Data Protection Act (No. 2004-63, July 27, 2004) permits the government to engage in surveillance on its citizens and to restrict press freedom.”<sup>7</sup>. She goes further in elaborating that by adding, “The Act strictly limits the use, diffusion, or transfer of personal data by journalists, media companies, and non-governmental organizations, permitting high fines and up to five years jail time for violations, so the government could use the Act to stifle journalistic activity, rather than to protect personal liberties. Some suggest that the prior consent powers given to the Data Protection Commission may be used to block scientific research.”<sup>7</sup>.

Subsequently, Antokol came to a result that in order for these privacy laws to have a real and sincere effect on the society is tightly connected to the ways that those laws are practiced and firmly applied regardless of their presence or absence, nor the standards such laws follow, when she says, “So, the fact that Tunisia has passed privacy and data protection legislation similar to the EU data protection does not necessarily mean that Tunisia is next in line for approval as providing adequate protection for personally identifiable data, and it may not even mean that Tunisians will soon have meaningful privacy protections. In fact, the Act may merely illustrate that the effectiveness of privacy laws depends upon the way that those laws are enforced.”<sup>7</sup>.

Finally, in the end of her report, Antokol concluded that [“in the arab region in general, and in the ESCWA region, in particular, there is still an absence of specific and adequate laws protecting data processing and privacy rights. While some articles exist in national laws, these relate mainly to civil status, statistics or storing banking information. Data protection legislation is still lacking in many countries of the ESCWA region. In Tunisia, by contrast, chapter 6 of the e-commerce and e-transactions law includes provisions to protect personal data.” source: “models for cyber legislation in ESCWA member countries”]<sup>7</sup>.

Based on the aforementioned, the fact that there are no clear health information privacy laws in the region should be seen as an opportunity to come up with such laws

that can serve as a common ground for all Arab countries involved. A room should be left for each country to add any additional specifications they may think are necessary, and to benefit from the UAE's experience as a living example for the rest of the countries.

Furthermore, HIPAA laws, for example, can be taken and modified in a way that suits our culture and religion that respect and value the human life above anything else, and view the right of secrecy for every human being not to mention a patient, as a sacred obligation a healthcare provider committed himself to once he took the oath of the profession.

## *2.2 Point II: Clearly define and differentiate between the concept of privacy and confidentiality.*

In a healthcare environment, we should differentiate between the concept of privacy “the individual’s right to limit access to the patient’s health care information” and confidentiality “the expectation that information shared with a health care provider during the course of treatment will be used only for its intended purpose and not disclosed otherwise. Confidentiality relies on trust.”<sup>3</sup>, and how these two are interconnected to one another. Equally important, a patient might trust his healthcare giver to maintain the confidentiality of his information, yet, he may become reluctant to share some important information with him because he/she does not fully trust the healthcare system itself. This can be clearly seen through the results of studies conducted in USA, which indicated that “patients do not fully trust that their private health care information is being kept confidential. Only a third of the adults surveyed in a California HealthCare Foundation national poll (1999) said that they trusted their health plans and government programs to maintain confidentiality all or most of the time. In the same poll, one in six said they had done something out of ordinary to keep medical information confidential. The Health Privacy Project (1999) reports that one in five American adults believes that a health care provider, insurance plan, government agency, or employer has improperly disclosed personal medical information. Half of these individuals also reported that the disclosure resulted in embarrassment or harm. This lack of trust exists in spite of state and federal laws and regulations designed to protect patient privacy and confidentiality and in spite of the ethical tenets under which health care providers work”<sup>3</sup>.

This cannot be lightly taken, especially if we know that the patient is not fully qualified to assess the urgency and importance of the hidden information as his/her physician or nurse is, which may result in a real threat to the patient’s life. A simple example of that is if, for an instant, a person is visiting the Emergency room and due to the fact that he/she does not fully ensure of the privacy of his/her information, he will not tell the doctor about all the medication that he has, because of embarrassment. That could include for example a psychiatric drugs, such as Prozac that is used for depression along with other disorders, which can contradict with the Aspirin if given together and may increase the risk of bleeding which might be fatal for patients with underlying cause. Adverse drug reactions are considered as the fourth to the sixth leading cause of death in the United States according to a 1998 article in the Journal of the American Medical Association <sup>8</sup>. This issue is one of a high importance because as a recent study mentioned that improved usage of information and communication

technology (ICT) was viewed by the physicians as the only realistic strategy for improving information access and sharing among the medical professionals at a Kenyan hospital<sup>9</sup>. Therefore, once automation of healthcare kicks in the developing countries, such important information will not be available if the patient did not fully trust the system enough to disclose important information to the care provider in the first place which can result in a serious consequence.

Additionally, when a patient seeks medical care, meets his healthcare provider and provide him with the necessary information so that the physician can do his job and make sure that this patient is well taken care of, patient expects that these intimate information is protected by some sort of a code or laws and regulations. In some cases, due to embarrassment or shame, such information is being kept hidden from the immediate family or closest friends. However, we cannot say that such secrecy is the case in our Arab world. One shocking fact is revealed in the paper of Nabil A. Alrajeh "HIPAA Based Healthcare Information Security Qualitative Assessment Application of Information Security for Saudi Hospitals"<sup>10</sup>.

In this paper, Alrajeh outlines the procedures undertaken to measure the security systems of two major Saudi healthcare institutions using a HIPAA based qualitative assessment approach against the world's best practice in the area of securing healthcare information. Additionally, the findings of the proposed HIPAA based Qualitative assessment were presented as well as recommendations suggested to fill the gap identified in the former two Saudi Hospitals. Those Saudi institutions are: KCUH- King Khalid University Hospital, including KAUH King Abdulaziz university hospital and KFMC- King Fahd Medical City.

Established in 1982 in Riyadh city, King Khalid University hospital (KCUH), as the teaching hospital of King Saud University, is considered the largest teaching hospital in the Kingdom with more than 800 beds and 500 medical specialists. Additionally, as the first educational hospital in Saudi Arabia with 250 beds, King Abdulaziz University Hospital (KAUH) was established in 1975. Collectively, the system of the King Saud University hospitals (KSUH) is consisting of these two educational hospitals.

King Fahad Medical City (KFMC), on the other hand, which was established to be a tertiary referral medical centre, is one of the largest medical cities in the region with more than 1094 beds distributed through numerous facilities such as the main hospital, rehabilitation hospital, women specialist hospital, and children hospital. In addition to diabetic centre, centre of Hematology and Oncology, neuroscience centre, and heart centre.

A survey was conducted to check security safeguards in terms of five categories: 25 administrative requirements, 12 physical requirements, 10 technical requirements, 4 organizational requirements and 5 policies requirements.

The results showed that from the 25 administrative security requirements, KSUH achieved only 11 requirements while KFMC achieved only 19 requirements. Moreover, physical security requirements comparing in the two organizations indicated that KFMC is much better than KSUH as it scored ten points out of twelve, while KSUH

achieved only four physical security requirements completely and two partially. Additionally, when it comes to technical/logical security side/ area, KSUH was a little bit better than KFMC; however, a room for more enhancements was suggested. Furthermore, the policies in both KSUH and KFMC were approximately identical and almost the same can be said about organizational security, nevertheless, serious concerns about introducing and establishing security safeguards in actual day-to-day procedures was expressed as well.

As a result, the survey concluded that the two health security information systems in both KSUH and KFMC are relatively close to each other, however, procedures and implementations in KFMC were somehow better. Most importantly, the fact that those deficiencies and weaknesses revealed by the survey can lead to more healthcare data breaches if not dealt with, is an open invitation to patient's private information invasion and is a privacy violation waiting to happen.

Moreover, Nabil stressed the importance of considering how can both hospitals patients' data be compromised or stolen due to the identified deficiencies related to the risk treatment that can originate from either inside (e.g. lapses in processes, users' innocent mistakes, mobile employee data access) or outside (e.g. Malicious attacks, collaboration and partner data exchange) hospital healthcare environment. Furthermore, a suggestion of constant security training relating to the health information vulnerabilities and protection procedures for all staff members including clinical, academic, students, and administrative was made as well.

At the end of the report, Mr. Alrajeh came to a result that "Ministry of health should have a national policy for health information security based on HIPAA model. Such a policy targets not only the setting up of healthcare information security programs in all Saudi hospitals, but also the implementation of appropriate HIPAA based feedback mechanisms enabling each hospital to assess its compliance with security safeguards requirements"<sup>10</sup>.

Such findings and recommendations can tell enough about the negligence, whether deliberate or not, that health information privacy is suffering from. So in the state we are living in of health information privacy laws absence, there is no necessity or guarantee that such weakness in protecting our medical records privacy will be corrected in the near future.

### **3. Conclusion:**

In this paper, the points presented support our position that stringent healthcare policies are needed and will empower the patients and improve the patient-clinician relationship. The absence of patient privacy laws and policies in some of the Arab world, particularly the KSA, should be rectified by establishing strong privacy policies and ensure that they are being followed. Also, the differentiation between the concept of privacy and confidentiality should be clearly defined. The absence of regulations such as HIPAA in the Arab world and the developing countries can cause countless privacy violations. Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule provides a suitable protection especially if it is tailored according to these



countries' individual needs and requirements. Therefore, based on Alrajeh recommendations, a national policy for health information privacy that is based on HIPAA, should be enacted in every Arab country in particular and in the developing world in general. Educational campaigns should be carried out to educate both patients and employees about their rights and obligations. Training sessions also in privacy protection procedures should be made available to the employees, academics and students as well. Mechanisms that ensure appropriate level of compliance with this policy should also be created. A national council, with legal advisory counselors, that include members of all the hospitals around the country must be formed, as well, to help develop new strategies and solve any problems that may arise. Impose sanctions on offending hospitals may be one way to ensure the application of these new laws and policies.

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