

# RE-EXAMINING PERCEPTIONS ON HEALTHCARE PRIVACY

## *Moving from a Punitive Model to an Awareness Model*

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Abstract: In this position paper, I argue that, in the near future, the advent of social media, patient empowerment, and post-privacy will lead individuals to openly share their personal health information online with other individuals and groups. These actions will undermine the need for current privacy legislation, which cannot prevent individuals from divulging their own personal health information. As a result, current privacy legislation must change from a punitive and restrictive model to a model that empowers and promotes awareness about how individuals use their personal health information online.

## 1 INTRODUCTION

Over the years, there has been great emphasis on the protection of patient privacy through the implementation of various laws to protect health information. One of the earliest papers on the subject of privacy and confidentiality in health information was published by the *New England Journal of Medicine* in 1968 (Curran, Steams, & Kaplan, 1968). In the paper, the authors advocate for state laws that provide ethical and clearly defined regulations for the protection of health information. It was not until 30 years later that the United States passed the Health Insurance Portability and Accountability Act (HIPPA) to protect the privacy and confidentiality of health information (Wager, 2005). Although various laws have been enacted to protect health information, a recent Markle survey on health reported that privacy related to the exchange and use of health information was a primary concern for physicians and patients (Lewis, 2011). Patients may fear that their health information will be violated and used by unscrupulous individuals or organizations, as reported by the Health Privacy Project (Wager, 2005), which found health privacy violations such as the following:

- 1) A woman's medical records were posted on the internet after she was treated for complications resulting from an abortion
- 2) A man was fired after an insurance company informed his employer that he had received

treatment for alcohol abuse

- 3) A clerk working in a hospital stole social security numbers and used them to apply for credit cards and open bank accounts
- 4) Files of persons living with sexually transmitted diseases were sold by a U.S. state.

Over the past few years, the introduction of social media such as Facebook, Twitter, and YouTube has revolutionized the way individuals seek, share and use information, specifically health information. A recent study on the sharing of sensitive health information through Facebook found that Facebook users openly sought and shared information related to behavioral, mental, and genetic information (Househ, 2011). An interesting finding from the research was that most Facebook users included in the study publicly identified themselves by divulging their name, photo, and location when seeking sensitive health information through online postings. The author of the study suggested that the growing use of social media and sharing of personal information may be changing society's perceptions on privacy from a strict implementation of privacy to one that is more lenient.

Over the past few years, the post-privacy movement, which advocates the end of privacy rules and legislation, has begun to gain traction. Post-privacy advocates argue that even though laws protect how information is shared and used by organizations, there are no laws to prevent individuals from sharing their own information

(Heller, 2010). There are indications that a post-privacy world is beginning to emerge in healthcare, especially through the website Patients Like Me, where individuals can post their health information online and share it through a social network.

In this position paper, I argue that with the advent of social media, patient empowerment, and post-privacy, individuals will openly share their personal health information online with other individuals and groups, undermining the need for current privacy legislation. As a result, current privacy legislation must change from a punitive model to one that promotes awareness about how individuals use their personal health information online.

## 2 HEALTHCARE PRIVACY

In the United States, privacy has been defined as the

“constitutional right to be left alone, to be free from unwarranted publicity, and to conduct [one’s] life without its being made public” (Wager, 2006).

Within healthcare, privacy and confidentiality define how health information is shared; these factors form the basis of all healthcare privacy legislation. Privacy is viewed as an individual’s right to place limits on who can use his or her personal health information (Wager, 2006). Confidentiality relies on trust that healthcare providers and organizations will not use healthcare data for purposes other than those intended, such as treatment or research. These two fundamental principles have guided United States legislation, such as the Freedom of Information Act (1966), The Privacy Act (1974), and the Health Insurance Portability and Accountability Act.

The two basic concepts of privacy and confidentiality can be summarized as follows:

“As an individual, I have the right to limit who can use my healthcare information. When I am a patient, I will share my personal health information with my healthcare provider because I trust that they will not use it in any way to harm me.”

This is a valid assumption currently held by many individuals. It stems from the fear that other individuals may access one’s personal information, resulting in societal and economic repercussions. For example, if people find out that an individual suffers from a drug problem, their friends and neighbors may ostracize or reject them, or the individual may

lose his or her job. Other examples may include cases of sexually transmitted diseases or genetic diseases, where people can be harmed as a result of healthcare privacy violations.

The various privacy laws attempt to reduce privacy violations and punish those who commit these healthcare violations. The government has taken the responsibility of protecting individuals from improper use of their healthcare information and has established laws that allow healthcare information to be released without the patient’s consent in cases of communicable disease (e.g., AIDS), patient transfers to another hospital, billing or court cases (Wager, 2009).

In sum, the government has taken the liberty of enacting laws to protect the privacy and confidentiality of health information from improper use. Nevertheless, if privacy is an individual right, then government should not implement punitive measures to limit how health information is shared. Rather, the individual should decide who may access their personal health information. It is assumed that the government puts individual interests before its own, but the government also divulges information for court orders and in cases of communicable disease. Therefore, privacy legislation does not empower the individual; rather, it empowers the government by allowing it to control the flow of health information. This shows that situation is beginning to change as the consumer becomes more informed and empowered through access to and control over their health information.

## 3 EASTERN SOCIETIES

For years, Middle Eastern societies have existed without the need for privacy laws. The concepts of privacy and confidentiality within healthcare, and in society in general, is of little concern. This may be because the use of healthcare information has not matured to the point that it is seen as a threat. More likely, this situation stems from the cultural attitudes of society.

In Middle Eastern societies, when someone is suffering from a health problem, family members, close friends and neighbors become aware of the situation and visit the family at home and at the hospital. They bring food and offer emotional and financial support, if needed. This practice has existed for hundreds of years and is rooted in Islamic religious practices.

However, people in Middle Eastern societies are less likely to discuss sensitive issues, such as drug

addiction, sexually transmitted diseases, and genetic disorders. Discussion of these subjects could result in the individual being socially ostracized.

In sum, in Middle Eastern cultures, awareness of healthcare privacy is of little concern. Healthcare privacy is necessary when there are social repercussions for sharing sensitive health information, especially regarding sexual, genetic, or addiction issues.

Advocates of the post-privacy movement agree with these assertions and see social media as a conduit for changing perceptions of healthcare privacy. The post-privacy movement promotes the individual's freedom to share information with others who share the same disease, values, or norms (Heller, 2010). In a post-privacy world, a person ostracized from their society can create an online society that is more accepting and tolerant. The individual is no longer bound by the norms of the physical world; he or she is free to create virtual societies with individuals who share the same goals, views, values and challenges.

#### 4 THE ROLE OF SOCIAL MEDIA

There has been recent growth in the use of social media, especially online social networking, within healthcare. One of the earliest studies on the use of social media in healthcare examined the use of the Bulletin Board System for nurses' education (Russin & Davis, 1990). The study found that the major impediments to implementing such a system included cost, maintenance, and the lack of preparation for the technology in the nursing profession.

With the current widespread use of the internet and its relatively inexpensive bandwidth, social media, particularly social networking, is beginning to be used by healthcare professionals and patients. In a commentary published by the *Journal of the American Medical Association*, authors Shachak and Jadad argue that the use of social networks will eventually lead to a more people-centered healthcare system that will improve communication and information flow between patients, providers, and administrators (2010). Other studies have shown that users of Facebook seek health information online (Househ, 2011). Websites for social networking, such as Patients Like Me, are beginning to cater to the need for social networks for health information support.

There is a growing awareness within society about patients' engagement and empowerment in

taking control of their health. For example, Sunnybrook Hospital in Canada has recently provided its patients with full access to their personal healthcare records (CBC, 2011). Google Health and similar technologies empower patients to manage their own health. Facebook provides a platform for individuals to connect with others suffering from the same disease or disorder. With over 500 million users (Facebook, 2011), the potential to connect with people suffering from the same disease or disorder is higher on Facebook than on any other social media networking site.

With the advent of social media, millions of people seek and share health information online. As Househ's study revealed, individuals are creating groups to share information relating to sensitive health information, such as AIDS and cystic fibrosis (2010).

In 2004, I conducted a research study on online forums where people shared information on bipolar disorders. I found that many people shared psychological, spiritual, and relationship advice on the internet. The online forums were anonymous, and it was difficult to identify a person unless he or she shared personal information, which did not happen often. However, with the increasing use of Facebook, people are beginning to share personal health information online. This becomes an issue when sensitive health information is shared, such as information relating to sexually transmitted diseases, addictions, and genetic disorders. Many people create their own groups to discuss and share information relating to various diseases, and they openly reveal their identities. These individuals create their own societies of people facing similar health problems that cannot be discussed outside of these online communities.

Thus, the concepts of privacy and confidentiality are changing as a result of social media. People are taking ownership of their own data and sharing this information with others with similar characteristics. There is currently no legislation to prevent individuals from sharing their information. This is the dilemma: governments have introduced privacy legislation to limit the use of health information and to protect the individual's right to privacy, but with the advent of social media, individuals are taking ownership of their own health information and sharing it with social networking and media groups.

With these changes in perceptions of privacy and the use of health information, many questions arise about the usefulness of privacy legislation. I suggest that privacy legislation should be re-examined in the wake of social media because this type of legislation

is ineffective when individuals decide to share their information publicly. The current privacy laws are mainly applied to the organizations that house the data, such as medical facilities. No legislative authority can prevent a person from sharing his or her information online.

A comparable situation is the U.S. witness protection program. The government established this program to protect witnesses before, during, and after trial. The government provides witnesses with new identities and relocates them in an attempt to protect the individual from harm. However, the individual choose to leave the program at any time may and make his or her whereabouts known. The government may advise against it, but the choice remains with the individual, and he or she is responsible for the consequences that arise as a result of his or her own actions.

Today, many individuals share their health information online without knowing or caring about the potential consequences of their actions. These individuals may feel that the potential to create and join online societies through social media sites provides them with support and acceptance from others. They become part of a community of individuals who share the same values, norms, or disease, where they can seek emotional support, health information, and guidance. They do not feel judged within these groups because all of the members share similar identities.

I suggest that, as a result of these changes, privacy legislation will be repealed or changed dramatically as more individuals feel empowered by social media to post their personal health information online. With the growing awareness of patients' engagement and empowerment in control of their health, individuals will ultimately have the sole responsibility of deciding who can use their health information, how it can be used, and where it can be shared. The government's role will be to ensure that proper mechanisms are in place for the patient to access his or her personal health record. In this emerging trend, patients are becoming increasingly empowered to take control of their personal health information.

Given these social changes with respect to the use of health information by individuals, I suggest that privacy legislation must move from a model that is punitive and restrictive to one that creates awareness and openness about the sharing and use of health records.

The privacy awareness model should focus on creating policies that allow the patient full access to his or her personal health record. The individual

becomes the sole owner of this information and can use information technology to determine which hospitals, physicians, groups, and individuals can view his or her health record. Policies should be created to ensure that individuals have the sole responsibility for viewing and controlling access to these records. Furthermore, guidelines should be developed to educate individuals about what it means to maintain control of their personal health records.

In conclusion, this paper argued that the current societal changes as a result of social media, patient empowerment, and the post-privacy movement will change current perceptions about privacy and privacy legislation. The current privacy legislation empowers governments, although the individual is the owner of the patient record. Current privacy legislation imposes punitive measures on organizations and individuals that violate the health privacy laws. The move toward an awareness model, in which patients have control and access to their health records, requires a model that focuses on educating individuals about how to understand, use, and share their personal health information. The goal of the personal health information record should be to give patients the freedom and liberty to use their health information as they see fit.

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