Consumers, security and electronic health records

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Abstract

Health care has entered the electronic domain. This domain has improved data collection and storage abilities while allowing almost instantaneous access and results to data queries. Furthermore it allows direct communication between healthcare providers and health consumers. The development of privacy, confidentiality and security principles are necessary to protect consumers' interests against inappropriate access. The electronic health systems vendors have dominated the transition of media, claiming it will improve the quality and coherence of the care process. However, numerous studies show that the health consumer is the important stakeholder in this process, and their views are suggesting that the electronic medium is the way forward, but not just yet. With the international push towards Electronic Health Records (EHRs) by the Health and Human Services (United States of America), National Health Service (United Kingdom), Health Canada (Canada) and more recently the Ministry of Health (New Zealand), this paper presents the consumers' role with a focus on their perceptions on the security of EHRs. A description of a study, looking at the New Zealand health consumer, is given.

Introduction

In the health industry the doctor-patient relationship is bound by trust. A trust that has stemmed from a clause in the Hippocratic Oath:

"All that may come to my knowledge in the exercise of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal. " [1].

As healthcare enters the electronic domain, the doctor-patient relationship is changing. Patients are being referred to as consumers. These changes have triggered a gradual transfer of some responsibility from the doctor to the consumer. The consumer is now playing a greater role in their healthcare than in the past [2].

A result of these changes combined with the desire to improve the efficiency and effectiveness of the health system is the Electronic Health Record (EHR). Pyper et al. [3] regard EHRs as a longitudinal record of the consumer's health care that the consumer can access. Ultimately the aim of the EHR is to contain all consumer health information from "the cradle to the grave" [4].

In New Zealand the majority of health care records still exist as paper records. This is despite the fact that a large majority of primary care practices have some form of electronic system.[3] New Zealand is regarded as a leader in the field of merging information technology and health information [5]. Despite its transition to an electronic domain clinicians still tend to keep their own records. This has resulted in a fragmented picture of an individual's health history and their current needs when they visit different clinicians. These clinicians only record information that is specific to their needs without having access to the "full picture". Increasingly, the potential for EHRs to improve the efficiency, safety and quality of care over paper based systems is being recognised across the health industry [6]. An increasing focus is aiming for "seamless delivery of care", particularly for the elderly, chronically ill and others with complex needs highlights the need to improve information exchange between health service providers [7].

According to Gillies and Holt [6], the ability for EHRs to store and retrieve information while allowing flexible queries is a major advantage. It will allow consumers to interact with their medical records. Currently, consumers have little or no interaction with their records. Not many health consumers in New Zealand are aware of their right to see and comment on items in their record as legislated by the Privacy Act 1994 [5]. According to the Institute of Medicine [8] up to 98 000 people in the U.S.A. die every year from medical errors that have resulted from incomplete or incorrect health records. With a correctly monitored EHR system and more consumer interaction, the number of medical errors could be reduced by up to 90 percent [9].

Therefore, EHR's provide a powerful tool to link the isolated fragments of information that currently exist between services. They also allow providers immediate access to essential clinical data. Integrated EHR's will potentially provide consumers with the capacity to provide essential information about their health care to the providers of their choice at anytime and anywhere.

The implementation of EHRs is not a case of "if it will happen?" rather it is a question of "how long till it is completed?" The American president, George Bush, announced that he wanted most Americans to have an EHR by 2014 and allocated a capital budget of US$100 million to ensure this does happen [10]. The United Kingdom has set aside £2.3 billion to ensure 50 million patient records are digitised by 2010 [11]. The foundations have been laid for a fast uptake of EHR's.

In New Zealand, there has been a shift towards the electronic media. Didham et al. [12] found that almost 90% of General Practices in New Zealand have some sort of electronic Patient Management System (PMS). This high adoption rate, the existence of the unique National Health Index (NHI) number, existing Health Intranet and HealthLink systems indicate that the infrastructure to build a complete EHR system is already available. However, the New Zealand health consumer does not feature strongly in the currently run systems. The Ministry of Health in their Health Information Strategy for New Zealand 2005 [5] recognised the importance of involving the consumer and have also identified the security concerns associated with the development of a complete EHR. The purpose of this review is thus to look at consumers and their importance to the health care team. It is also important to look at the security concerns that exist.

Literature suggests that the advantages of EHRs far outweigh the disadvantages. However, as government and industry advocate the move to the electronic media, not enough attention has been given to the consumer.

Consumers

Traditionally, the health consumer has been the "least consumer-like" and the least informed stakeholder when compared with other industries. [7].The health consumer was least informed because they were protected from social stigma as well as the feeling that patients would get sicker once they knew their medical condition. With expanding populations and the increasing occurrences of epidemics, medicine became more scientific and thus medical knowledge started becoming available to the lay public [7]. In the last twenty years the emphasis has changed from cure of health conditions to prevention, with an emphasis on health and wellness [13]. Also the advent of the Internet has put evidence based treatment in the public domain [14]. According to Amatayakul *"Patients have become interested in making* ***choices*** *for themselves about their physicians, treatments and lifestyles"* (p. 54) [7], this can be clearly observed in the change of terminology from medical care to health care [7]. The term medical care focused primarily on processes administered by a physician, where as health care encompasses a broader range of services and procedures such as self wellness and holistic approaches [15].

The emergence of communication technologies and the incentives in the health sector to include consumers in their operations are some of the factors in increasing the importance of the consumer in the healthcare setting [15]. The biggest factor in cementing the role of the patient as a consumer is through the growth and the innovative capabilities of technology and the importance that is placed on informed consent. The increasing availability of interactive information systems has enabled many services to be online. Health information is now only a mouse click away, with many Internet users visiting websites that contain health information and treatment options. The growth of discussion boards and bulletin boards has allowed individuals to share experiences with specific diseases and treatments [16]. This has introduced another dimension into the healthcare industry where consumers are more knowledgeable and understand the terminology and procedures that are used in the health sector. According to Eysenbach [17], the technology initially had been looking at development and growth through the eyes of the medical professional, with the drive towards consumerism; this has changed and has seen the birth of consumer health informatics. Consumer health informatics is defined by Eysenbach [17] as *"the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems."* (p1713). This definition agrees with Amatayakul's [7] statement that the *"principle of consumer health informatics is that of empowering individuals to play a greater role in their own health care and to be active participants in the decisions that affect their health care"* (p 61-62). The aim is to empower the consumer to be a part of their own treatment plan rather than feel like an outsider.

Another element that has influenced the move towards a consumer based approach has been the change in the way patients pay for their health services. From the earliest times, when health services were bartered like a normal commodity through the respective healers, patients became even less like consumers as the payment for their health services was done by third parties in the form of Medical Aid Companies [7]. When the third parties became a key player in the health sector, patients lost consumer identity totally as they did not directly purchase health care services. However, with the shift towards managed health care and health plans, patients have to pay for more to get more choices [7]. Thus they ceased from being just patients, and have shifted more into a consumer role, as they demand more information about their health care providers, diseases and treatments.

Empowerment will only occur if the consumers themselves are allowed to interact with the healthcare system. An interaction in which they do not receive just limited feedback, but one that promotes multi-way feedback, so that all parties benefit. This idea has been adopted by the European Union, who realised that the greatest interaction would occur if patients have access to their records [17]. In October 1998, the European Union required that each of their member countries pass legislation that would ensure consumers in those countries have access to all their health records [17]. With governments recognising the need for patients to become key stakeholders of their own health, now is the perfect time for the push towards the implementation of the Electronic Health Record. On the other hand this push is filled with many barriers. The main concern consumers have regarding EHRs is their security [18].

Security

Concerns about the security of patient data are not new. They have existed from the dawn of medical history and are still a major concern in modern times. The Hippocratic Oath is founded on the principle of confidentiality, and has thus become a time honoured practice in medical ethics. The Irish Government in their statement on access to medical records show that patient records, both paper and electronic, have to be safeguarded to ensure the privacy and confidentiality of the patient [19]. Preserving the confidentiality of patient information is of vital importance; confidentiality gives rise to trust. The health sector is founded on trust and thus looking at the security concerns that EHRs pose is imperative (See Health Information Privacy Code 1994).

Security of health records primarily encompasses privacy and confidentiality. These issues have been a problem even with paper based records [7]. One of the functional disadvantages of the paper-based records can be seen as an advantage. The nature of its storage volume makes it difficult for someone to access a large number of records. This is one of the strongest fears of EHR's. With centralised and distributed databases and linkages between various electronic systems, the chances of accessing large volumes of patient information as an unauthorised person, increases significantly. Silverman [20] echoes this feeling when he says *"Unauthorised access to paper records was always feasible, but the computer takes a small problem and has the potential to magnify it enormously"* (p29).

Consumers' fear is driven by the nature of information that is stored in their health record. It is regarded as being private and more so when it contains information regarding mental or sexually related medical conditions [21]. Unauthorised access to this information has already resulted in a number of publicised cases.

- Doctors in Australia selling their patients' medical records to marketing firms. The Doctors in this case claim that they are allowed to give out the information as long as there is no identifiable information about the patient in the record. However it is argued that by simply recognising the medical conditions in the records it was very easy to identify the patient [22].

- A public health worker in Florida who had access to the names of HIV patients that were in his treatment care, released them to the press. A total of 4000 names were released and printed for the readers of those papers [23].
- Administration staff that have access to electronic records are able to see the entire history of the patients record not only the areas that concerns them. With the paper record administration staff would find it more tedious to read a patient's medical history [24].
- A computer hacker that managed to hack into a GP's database to use the information to carry out more heinous crimes. The hacker would telephone potential victims and identify himself as a doctor, which would be verified by the detailed family medical history he would give out. He targeted young woman whose confidence he could win easily, and would proceed to carry out sexual crimes [25].

There is also a concern of internal hackers. People within the organisation who break into records and obtain information that is not health related. This information is then used in commercial or criminal ways. [26]. These examples indicate that there is a legitimate reason for consumers to be concerned..

Privacy is the main concern that health consumers are worried about with any record system. In 1995 the Louis Harris Poll found that 100% of Americans surveyed saw benefits of having their health records computerised. However, 74% expressed concern about the negative effects of a computer-based system. Their concerns are based on the following points [18]:

- Lack of understanding the dynamics of information gathering
- Fear of having a lack of control over the use of their personal information
- Not understanding the privacy protection laws and regulations that do and do not exist
- Fear of errors, carelessness and poor judgement by those who may handle their personal information.

These concerns have stemmed from their previous experiences with computerised systems. More recently, the 2005 Harris Interactive survey found that 48% of American adults claim the benefits to patients and their well being outweigh any risks to privacy [27]. Nevertheless, almost 70% of these individuals are worried that sensitive health information may leak due to weak data security. The order of the concerns is now [27]:

- Sharing of medical information without a consumer's knowledge.
- An increase in medical errors rather than a decrease with the use of computers.
- Reduction of any existing privacy rules.
- Consumers not revealing all necessary information to their health care provider due to the fear of having their details being made available electronically.

In another survey conducted in September 2005 it was found that 72% of Americans surveyed agree with the notion of a national network for health information, yet 79% of them still raised security and privacy as being their major concerns [28]. The feeling that EHR's are a good way to store health records was shared by consumers surveyed by the NHS; however like their American counterparts, the British public also felt that security and privacy of their information is their major concern [29].

The trend for New Zealand health consumers seems to be in the same light, however there have not been many studies conducted at a national level to indicate the perception of the New Zealand consumer. A focus group study carried out in Dunedin 2004 found that the security of an EHR database is the main barrier resulting in low public support. Although the study was only conducted on a group of 20 people it was also found that the misuse of information and its disclosure to people other than health professionals was a major concern in the group [30]. This finding is in line with those from the United States and the United Kingdom. The concerns that were identified by Ryan and Boustead [30] were categorised as:

- Confidence in the privacy and security of creation and sharing of records
- The security aspects with regard to control of data and
- The risks that individuals that use the record may face.

All the concerns raised, stem from a lack of understanding of the various security measures that do exist and will make the EHR a secure system. By introducing the concept of firewalls, encryption, audit trails and anti-virus software to the health consumer, these feelings of fear will decrease. Also by informing the consumer that an EHR will be equipped with the five key security requirements this will further allay their fears. The security features ensure authentication, access control, accountability, authorisation and availability. Maintained at high levels these functions ensure that the data will be kept confidential and maintain their integrity.

Currently a study is being undertaken to find out more about what the New Zealand health consumer's perceive about EHRs and more specifically their feelings regarding the possible security problems that are associated with them. Unlike the Dunedin study in 2004, our study aims to be a national study thus we will be able to identify if there is a common trend in New Zealand and if that trend is the same as, or different to the trends that have been documented in the studies that have been mentioned. Unlike other countries, the process has found a high acceptance within the actual health care team, however it is now imperative to bring the health consumer on board, and include them as part of the care team.

Early results of our study indicate that the New Zealand health consumer is concerned about the security of their records. However, when told about the various security measures available, a large majority of them feel that with these measures correctly in place, their records would be secure in an electronic domain. Some participants have commented that with the correct security measures they would find EHR's a great asset in their health care. Despite a number of positive comments, comments such as "*there could be all sorts of reasons for electronic data to go down, natural disasters or terrorism",* indicate that there are still a large proportion of health consumers that are afraid of the electronic domain". The fear that many health consumers have may be due to a lack of understanding of the security measures that are available. If consumers are educated about the strength of electronic security, they will feel more at ease with it.

Conclusion

This review indicates that the transition to a fully electronic health system based on the EHR is not just something that has been proposed in theory. It is now a real idea and most first world countries are in the process of developing a fully integrated yet geographically distributed EHR.. Clinicians and other members of the health care team are regarded as the key members of the treatment plan, but with the advent of the EHR, there is now a greater call for including the health consumer as well. It is important to realise and understand their perceptions, as it is only by understanding their perceptions that we can hope to introduce a system that will be acceptable to all those involved in providing the best treatment plan available. Privacy and confidentiality have been identified as barriers to total acceptance by the health consumer. However by educating consumers on the available mechanisms and proving that they do provide a secure environment, this barrier should be overcome. With knowledge of authentication, access control, audit trials as well as understanding of firewalls and encryption consumers will find that storing their health information electronically will provide a number of benefits. By making it possible to access their own records, without any security concerns, consumers will be given the chance of taking a proactive approach in their health.

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