

Building Public Trust for Electronic Health Records

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Abstract—Governments and healthcare providers are moving to electronic health records (EHRs) to lower the cost of healthcare, improve patient care, and reduce medical errors. A critical issue in the transition to EHRs is the privacy, confidentiality, and security of the information stored. This issue has made some patients and healthcare providers reluctant to accept electronic records. To help motivate our analysis of the issue, we conducted a literature review of public opinion polls and surveys regarding electronic health records. We present a summary of the data gathered in this review.

I. INTRODUCTION

The proper management of personal health information is important to our healthcare system. Patients share information with their physician in the expectation it will be used to improve their health and comfort. The physician adds information regarding his or her diagnosis and treatment of the patient. Information is also generated by laboratories, pharmacies, hospitals, and other healthcare stakeholders. In totality, this information comprises the patient's health record, which may be segmented in physically separate locations under the custodianship of several different healthcare providers.

This largely paper-based administration accounts for 16.7% of all healthcare expenditures in Canada, and for 31% in the US (roughly \$300 billion USD) [1]. The government and key healthcare stakeholders in both countries are pushing for a change from paper to electronic health records (EHRs). Many stakeholders in the healthcare system see electronic health records as a way to improve the quality of care while decreasing costs. While this potential remains to be proven in practice, individual doctors, hospitals, and even entire provinces are moving toward EHRs [2]. In Canada, The Romanow and Kirby reports recommended electronic health records, as did separate provincial studies in Alberta, Quebec, New Brunswick, and Alberta [2]. Canada Health Infoway [3] is designing a national electronic health record infrastructure and working with Health Canada and provincial health departments to begin the deployment of this infrastructure. In America, the President used his State of the Union address to announce a plan that ensures most Americans have electronic health records within the next decade [4].

As we make this transition from paper to electronic records, it is critical that we address the privacy, confidentiality, security, and trust issues that will arise. Technical people do not always see the perspective of those who will be affected by

a move to electronic records. Therefore, in cooperation with the Canadian Medical Association (CMA), we undertook a literature review to assess public opinion (and the opinions of other healthcare stakeholders) regarding health information-related issues. This paper shares public opinion data on a few of the issues the review addressed. The conclusions we reached based on this data are presented in a later publication.

II. DEFINITIONS

When discussing topics related to privacy, different organizations will use slightly different definitions of the terms (e.g., [5]–[10]). In general, definitions include informed consent and the right to make decisions about how one's own information is used. However, it is important to be aware of the terminology differences when examining the results of studies conducted by these different organizations. In particular, the general public does not have a precise definition of any of these terms. As we see it, the notion of privacy when discussed by the general public often encompasses far more than strictly privacy; many survey results will reflect the public's opinion of a combination of privacy, confidentiality, and security. Therefore, we use the term 'privacy' in the same general way (namely, as encompassing both confidentiality and security), unless specified otherwise. While less precise, this practice is consistent with the data available.

III. THE IMPORTANCE OF PRIVACY AND TRUST TO HEALTHCARE

Individuals consider their personally identifiable health information (PIHI) to be private - they have a right to decide who gets to see it, and once they reveal it to that party, they expect it to remain confidential. Most rank it as being the most sensitive personal information, at the same level as financial information [11]–[14]. If patients are not able to trust that their personal health information will be adequately protected by the health record system that stores it, they may not fully participate in their healthcare by refusing to reveal sensitive information that is important to their well-being. [15].

In Canada, surveys show that 11-13% of Canadians have held back information from a health provider because they were afraid of who would see it and for what it would be used [16], [17]. A 1999 survey of American citizens found that 15% of individuals were taking action to keep their personal

medical information private by not seeking treatment, 'doctor-hopping', paying out of pocket, giving inaccurate or incomplete information, or asking their doctor to keep information out of their record [18]. A 2005 survey of Americans found that 65% were very or somewhat concerned that "people will not disclose sensitive but necessary information to doctors and other health care providers because of worries that it will go into computerized records" [19]. (Note that the question did not ask if they would personally refrain from disclosing personal information; it asked if they were concerned about other people not disclosing their own information.)

Patients also have privacy concerns about paper records; some individuals do not want their ailments recorded in any format. Although it is difficult to directly compare public opinion on this issue, the numbers suggest that many more individuals have concerns when the format is electronic. If these concerns are not resolved before the widespread introduction of electronic health records, people may not trust EHRs enough to reveal sensitive information, or to allow their doctor to record this sensitive information. This will be detrimental to the quality of care the patient receives and to the ability of other stakeholders to maintain high standards of care.

It is in the best interests of everyone involved (the patient, clinicians, researchers) to have accurate and complete information. Patients have a high level of trust for their family physician, which gives them the comfort necessary to reveal personal and sensitive information [20]. However, if both the patient and the doctor have misgivings about electronic health records, all of the patient's information might not be stored in the record. A 2001 poll of doctors conducted by the Association of American Physicians and Surgeons (AAPS) found that 87% of doctors had a patient who had asked them to withhold information from their medical record. The same poll found that 78% of doctors had withheld information due to a patient's "privacy concerns" [21].

IV. TRUST WITHIN THE HEALTHCARE SYSTEM

Physicians receive high trust ratings (above 90%) from the general public when it comes to "doing the right thing" for a patient and/or a patient's healthcare, and when it comes to telling the truth [14], [22]–[25]. In a 2000 Canadian poll, nurses, pharmacists, and doctors were trusted by over 90% of respondents when compared to other professions such as judges and stock brokers (Fig. 1) [23]. When asked about personal health information in particular, 75–80% of Canadians polled felt that the information they gave their physician was kept confidential. Only 17% felt that this information was not kept confidential. Provincially, this trust ranged from 75% (Alberta) to 85% (Atlantic Provinces) [16], [17].

There are differing levels of trust for different stakeholders in health care. While 96% of Americans trusted their doctor to "do the right thing" for them and their healthcare, only 54% feel the same about their managed care company (Fig. 2) [25]. Focus groups in the UK felt that their physician should have unrestricted access to personal health information,

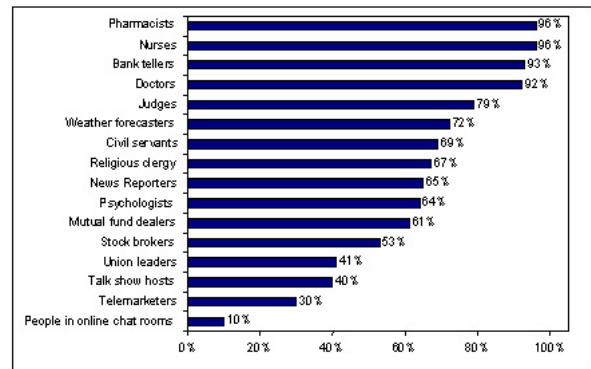


Fig. 1. Trust Canadians expressed for selected professions [23]

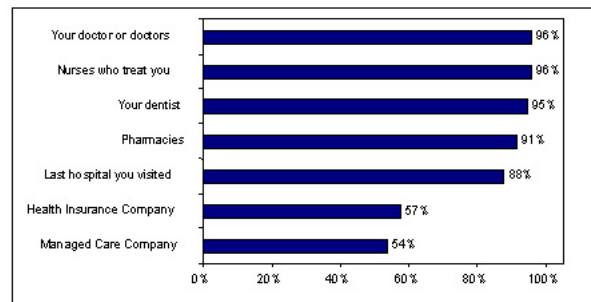


Fig. 2. Trust Americans expressed for various health-related professions [25]

that specialists and surgeons should have limited access based on the context, and that office receptionists should not have access at all [26]. A Gallup poll conducted in 2000 found that Americans had strong opposition to non-medical groups seeing their medical records [14] (see Fig. 3), with the government being the group least likely to be granted access. This mistrust extended to agencies controlled by the government; a provincial survey found that only 33% agreed with that all health information should be controlled by a central agency responsible to the government [13].

It appears that patients make determinations on who they trust with their information based on the potential trustee's role and the context of the situation. Their trust for healthcare professionals with whom they have firsthand contact is high. Those who are professionals but do not have contact with the patient - specialists, researchers, and the like - are trusted less, and administrators are trusted least of all (perhaps because there are fewer professional codes of conduct for healthcare administrators).

When considering electronic health records in particular, more than half of American citizens polled in 1999 felt that a move from paper to electronic records would make it "more difficult to keep personal medical information private and confidential" [18]. An Albertan study found that 82% of Albertans felt it was appropriate to place patient information in an electronic record (with the condition that they could control who has access to the record). When asked to pick their number one concern about electronic health records, the

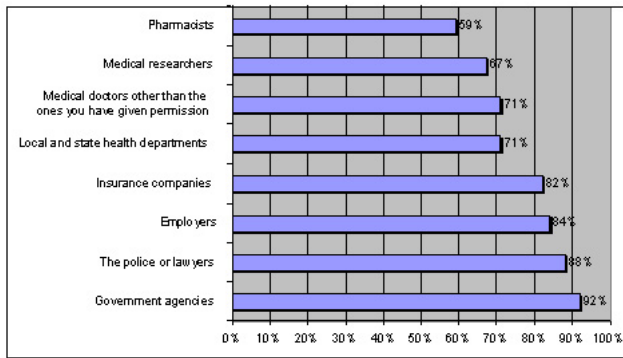


Fig. 3. Americans opposed to allowing group to see medical records without permission [14]

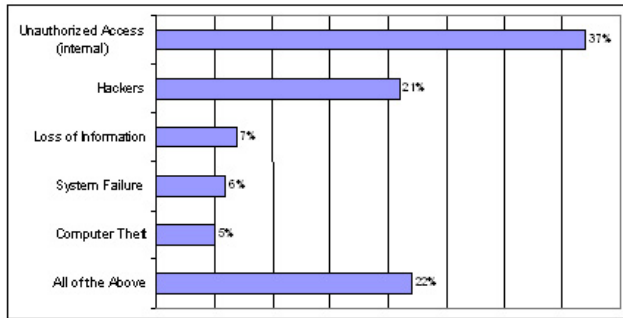


Fig. 4. First place rankings for concerns about Electronic Health Records [11]

majority were concerned with inappropriate access to their information (Fig. 4) [11].

Nationwide, 66% of Canadians agree electronic health records should be implemented to "improve the integration of services and monitor the use of many health care resources, even if this means that the records will be accessible by other health care providers" [27].

A 2005 Harris telephone poll of Americans [19] found that 71% had not heard that the White House was actively calling for a nationwide program for electronic health records. After being informed about the project and the definition of an EHR, respondents were asked to gauge their level of concern regarding about some of the potential negative impacts of EHRs. Approximately 70% were concerned about data leaks, medical information being shared without their knowledge, poor security, and increased medical errors. The full results are in Table I. The poll is not clear on whether they were concerned that this would happen, or whether they would be concerned if it did happen. It also did not distinguish between asking if the respondent would personally behave in a certain way or if they were afraid that other people would behave a certain way.

The same survey [19] found Americans were split on whether the potential benefits of electronic health records outweighed the risks - 48% said that the "expected benefits outweigh the risks to privacy", and 47% said that the "privacy risks outweigh the expected benefits."

		Very Concerned	Somewhat Concerned
Sensitive personal medical-record information might be leaked because of weak data security	%	38	32
There could be more sharing of your medical information without your knowledge	%	42	27
Strong enough data security will not be installed in the new computer system	%	34	35
Some people will not disclose sensitive but necessary information to doctors ... because of worries that it will go into computerized records	%	29	36
Computerization could increase rather than decrease medical errors	%	29	36

TABLE I
CONCERNS ABOUT ELECTRONIC HEALTH RECORDS [19]

An unrelated Harris Interactive poll of online Americans [28] found that 76% of those polled believe that electronic medical records will improve their medical care, 73% believe it would reduce health care costs, and 63% believe it will reduce the frequency of medical errors. After acknowledging these benefits, 67% said they believe that electronic health records would make it more difficult to ensure patient privacy [28]. Some of these numbers, most notably the 63% who believe EHRs will reduce the frequency of errors, directly contradict the other Harris report we discuss above [19], which was released one month earlier. Harris has offered no explanation for this difference (One difference is the questions asked: the first poll prefaced each potential concern with this statement: "Here are some things that some people have said might happen under such a patient Electronic Medical Record system. How concerned are you that?" The second poll prefaced the question with this statement: "How strongly do you agree or disagree with each of the following statements?"). The important part to note is that despite their other discrepancies, in both polls the percentage who were concerned about the difficulties involved in protecting patient privacy are near 70%.

There are certainly concerns about the protection of personal health information stored in electronic health records. Many are concerned about authorized users abusing their access rights to access information that they should not. Another common concern is attackers from outside attempting to gain access. An EHR system needs to assure users that it can adequately protect their information. It also seems that the average individual is not well-informed about the basics of EHRs. The public may require extensive education regarding the benefits (and downfalls) of EHRs prior to their widespread adoption.

Some proposals for EHR systems include the use of unique identifiers that are assigned to each patient and associated with their entire medical record. A Princeton Research Associates poll conducted in 2000 found that when told about the

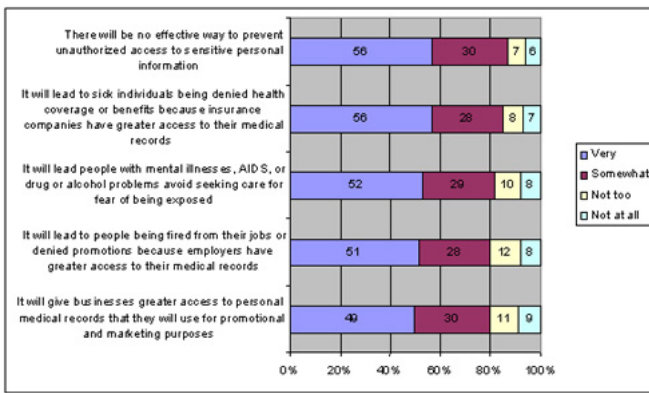


Fig. 5. Percentage of Americans concerned about potential risks of health identifiers [18]

potential benefits as well as the risks in adopting a system of unique identifiers, 39% of Americans favor health identifiers while 52% are opposed. The survey also asked how concerned respondents were about various potential risks of unique health identifiers (Fig. 5). According to the researchers, "The survey results confirm that medical privacy concerns currently play an important role in limiting public support for unique health identifiers" [18].

V. CONCLUSION

There are few reliable and trustworthy polls on the subject of public opinion regarding electronic health records. However, the information we do have indicates that while patients are optimistic about the benefits that EHRs can provide to the healthcare system, there is hesitance to adopt EHRs for fear of the potential for privacy violations. Further studies into both the root of these concerns and ways to alleviate these concerns can help EHR proponents spur the widespread adoption of EHRs. This information can also help us assess the viability of proposed EHR systems.

As healthcare leaders begin or continue the transition from paper to electronic records, we conclude that attaining and maintaining the trust of patients and the other stakeholders is crucial to their success. It is important that the privacy of the patient always be a foremost concern. Whatever entity holds the information, and whatever policies and rules are set in place, obtaining and maintaining the trust of the patient is a challenge that must be addressed. However, it is important to remember that privacy and security of sensitive information is not necessarily an issue where designers should ask for a "show of hands". The average individual does not have the technical knowledge to make informed decisions about how best to protect electronic health records. Public opinion can still be used to help motivate a solution, and to assess public resistance to adoption of a system, but more important is its role in helping leaders and educators develop strategies to attain individual trust for EHRs.

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