

Patient Views on Electronic Health Information Privacy

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Abstract

Background

Health information privacy and security is reported to be a prominent concern of patients, but few reports explore the balance of perceived risks and benefits of electronic health data. In previous research, we have detailed patients' concerns about health information privacy. In this study, we sought to systematically study patients' perceptions of privacy risks compared to potential benefits of electronic health record systems.

Methods

Subjects were 496 patients with diabetes participating in a study investigating the effectiveness of a Web-based personal diabetes track linked to the physician's electronic medical record. All patients answered telephone questionnaires, one of which was the Health Information Privacy Questionnaire.

Results

While patients had mixed opinions on the ability of computers to keep their health information private (40.1% strongly agree (SA) or agree (A) vs. 37.7% strongly disagree (SD) or disagree (D)), there was wide support for the usefulness of computers to share personal health records amongst their health care professionals (80.9% SA/A vs. 3.0% SD/D), to inform their physician about their allergies, labs, medications (93.1% SA/A vs. 1.8% SD/D), or to advise on how a condition should be treated (91.2% SA/A vs. 1.2% SD/D). Although most patients judged the benefits of computers to outweigh the confidentiality risks (57.9% SA/A vs. 29.3% SD/D), they were more concerned if their health information was to travel via Internet. Many patients did not want outside organizations to access their health information even if personal identifiers were removed (government 40.3% SA/A, private insurers 77.2% SA/A, pharmaceutical industry 45.2% SA/A, university or hospital-based researchers 21.6% SA/A).

Conclusions

Patients appear to value the potential benefits of electronic health records more than the potential risks, if in the hands of their own providers. They are less inclined to share their health information with other healthcare groups.