

Patient and Provider Health Data Privacy Concerns

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Introduction

The increasing use of computers and information communications technology (ICT) in healthcare amplifies concern about privacy and confidentiality. The COMPETE study (Computerization of Medical Practices for the Enhancement of Therapeutic Effectiveness) is a community-based electronic health project conducted by the Centre for Evaluation of Medicines, an academic research centre affiliated with McMaster University, Hamilton, Ontario. The 33 family physicians who participated in the study converted their practice, both administrative and clinical functions, to an electronic health record (EHR) system. One of our research objectives was to study health data privacy perceptions of providers and patients.

Methods

Three sequential methods were used:

1. Focus groups were conducted to find the range of opinions present within the general public and among family physicians. Focus groups were conducted with three different stakeholders: Family physicians in the Hamilton area (N=13); younger lay people (Age 35-55; N=15) and older lay people (Age 56-80; N=16). Each layperson had interacted with the healthcare system at least twice in the past year and had expressed an interest in participating in focus groups on "health issues."
2. One-on-one structured interviews were conducted with 18 patients from physicians in the COMPETE study. These interviews explored the issues raised during the focus groups. All interviews were taped, transcribed and coded independently by two reviewers.
3. A fixed-response questionnaire was given to 106 patients in 11 practices of physicians participating in the COMPETE study. This questionnaire aimed to provide a more quantitative estimate of opinions and concerns around the research uses of the EHR, the sponsors of such research, and how best to obtain consent.

Results

Focus groups: Physicians' responses indicated practical and conceptual difficulties with privacy issues. They expressed concern about the burden of asking for consent. They had few concerns about sending anonymized data to researchers. There were questions about whether they or their patients could accurately articulate the issues required to obtain a valid consent. Lay people generally wanted their permission sought before using their health information, even if their health information was anonymized. The younger group expressed less apprehension over the computerization of their health record.

One-on-one interviews: Patients presented with variable knowledge and understanding of issues related to the use of health information for research purposes. Most expressed wanting to be directly informed by their physician that their health information would be used for research and felt it important that they provide consent for this use. Patients were positive about the potential benefits of research but simply wanted to ensure that their privacy would not be compromised.

Quantitative survey: Over half of those surveyed (57%) wanted very specific information about the study – particularly the name and goals of the study, and what would happen to the information once it was collected. There was less interest in knowing who was paying for the study. Seventy-five percent thought some type of consent (either verbal or written) should be obtained.

Conclusions

Although generalizability of this small sample is difficult, it appears that many patients wish to have influence in the use of their personal health information. Since the use of the electronic health records will increasingly blur the boundaries between clinical, research and administrative uses of medical information, privacy standards will be required and their impact will need to be evaluated.