Are lay people ready for health information exchange?

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Abstract

The purpose of this study is to better understand lay people’s readiness to participate in electronic health information exchange (HIE) by assessing their expectations and understanding towards these systems. This study continues the work of a project assessing lay people’s understanding of personal health records (PHRs). Results of this exploratory work will be used to select terms to use in larger studies aimed at eliciting lay people’s preferences and values related to participation in HIE.

Introduction

As HIE strategies emerge, lay people will be faced with complex choices about granting access rights to their medical record within these systems. A first step in gauging whether lay people are ready and willing to participate in these exchanges is by more clearly assessing what they understand about and expect from HIE. Lay people’s perception of benefits and concerns regarding HIE will be an important factor in their choice to set access policies in accord with their values and preferences. This is the second of two studies designed to understand lay people’s expectations and understanding about HIE in their own colloquial expressions and vernacular. The first study examined lay people’s understanding of a PHR and revealed that most of participants held positive attitudes about having electronic access to their own health records but required explicit guidance to understand system characteristics including features, privacy, and functions¹. This study complements the exploration of selected features of PHRs by providing preliminary understanding of consequences likely to occur when PHRs become widespread.

Methods

This study involves twenty 20-minute semi-structured telephone interviews conducted with informants who are residents of a Midwestern county. The interview questions, guided by Diffusion of Innovations Theory², address the perceived relative advantage of electronic exchange of medical records over paper exchange of medical records and the compatibility of the system with a person’s values and needs by understanding what they think the system will do. We assess participants on the Hollingshead Four Factor Index of Social Status³ (age, gender, education level and employment type), known to impact lay people’s health behaviors and may impact their understanding of or choices to participate in HIE. We also ask participants how they manage their medical records.

Results

The first study showed that although participants had generally positive attitudes towards personal health records, they also had concerns that could be grouped under five areas: functionality, reliability, privacy and security, access and setting permissions¹. This study reports lay people’s understanding of, expectations about, perceived benefits of and concerns about HIE as well as reports variations on these benefits and concerns based on the exchange medium.

Discussion

Many projects demonstrate that HIE is both feasible and acceptable among health care institutions. As these systems come into place, lay people will be faced with complex choices about whether to participate in such systems. Because HIE is a foreign concept to lay people, it is important to understand the terms they use to describe HIE. This language can then be integrated into larger studies aimed at eliciting lay people’s preferences and values related to their participation in HIE.

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