

Project Title: Consumer Engagement in Developing Electronic Health Information Systems
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Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

Business Goal: Knowledge Creation

Target Population: General

Summary: The value of health information technology (IT) investment in improving quality and safety depends on participation by the ultimate beneficiary: the patient/consumer. Health IT has the potential to reduce health care disparities, increase consumer self-care, and provide a coordinated patient-centered experience. But consumers have expressed a distrust of some health IT efforts. The utility of any health IT or health information exchange (HIE) system will be greatly enhanced if patients are involved in its planning, development, and implementation; thus it is important to understand the best way to engage patients and consumers. This research study is designed to gain insight into consumers' understanding, fears, and concerns related to health IT and HIE to devise strategies to engage them in the development of electronic health information systems.

Twenty focus groups with health care consumers were conducted in selected cities around the United States, including four conducted with Spanish-speaking patients. Groups were divided by heavy users, defined as having a chronic disease or visiting three different health providers in the last year, and light users, individuals with at least one health visit in the last 2 years. Consumers with a relatively heavy dependence on health care might be expected to have a different frame of reference in considering health IT than people with a lighter use of health care. The potential benefits and risks of health IT are expected to be more immediately clear to those who are most dependent on health care.

Groups were also constructed by whether participants were covered by a Health Maintenance Organization (HMO). Approximately two-thirds of physicians who practice within an HMO use electronic medical records (at least partially), compared to only about one-fifth of those in practices owned by the physicians. Consumers who avoid HMOs often do so at least partly because they want maximum choice and independence in the health care providers they visit. This characteristic may be related to their perceptions of certain aspects of health IT (e.g., sharing of information among providers).

Specific Aims

- Gain in-depth understanding of health care consumers' awareness, beliefs, perceptions, and fears concerning health IT. **(Achieved)**
- Learn how/if consumers wish to be engaged in the development of health IT and at what point they should be engaged. **(Achieved)**

2009 Activities: A total of 20 focus groups were conducted to discuss consumer viewpoints, with groups located in the Northeast, Mid-Atlantic, South, Midwest, and Western regions of the United States to

capture differences in regional attitudes. Participants were required to have visited a health care provider at least once in the last 2 years for themselves or a family member.

Focus groups were conducted in two-part segments. The first hour of the discussion provided an opportunity for the moderator to educate the group to ensure everyone had a basic understanding of the capabilities of health IT. In the second part of the focus group, they discussed the role of consumers in influencing the design of health IT.

Impact and Findings: Focus group results provided insight from consumers on a number of topics including privacy, perception of benefits of use of health IT, and the consumer role in developing health IT. Overall, participants expressed optimism toward the use of technology and identified several benefits they had already experienced through the use of health IT. Privacy was a consistent concern across the groups, and there was support for the idea that health care consumers be asked for their consent before health data are stored electronically. Further, some participants suggested that access to electronic health data should be customizable based on patient preferences, for example, allowing the consumer to decide which other providers' data may be shared electronically. There was less agreement among focus group participants on the topic of using data for medical research and more concern for the use of data for pharmaceutical or market research.

The consumer role in designing and using health IT was not immediately identifiable for many participants. They believed that this work should fall to medical and technological experts and that consumers would not have knowledge to contribute. The one area consumers felt they would have a role in is in the areas of data security and privacy of information. Other findings involve perceptions of the role of the market, health plans, and government in the development of health IT and perceptions on the venues available for consumers to support health IT development. The focus groups suggest that public education about health IT is needed.

Selected Outputs

Schneider S, Kerwin J, Robins C, Dean D. Consumer engagement in developing electronic health information systems: Final report. (Prepared by Westat, Rockville, Maryland, under Contract No. 233-02-0087). AHRQ Publication Number 09-0081-EF. Rockville, MD: Agency for Healthcare Research and Quality. July 2009.