

**Project Title:** Consumer Engagement in Developing Electronic Health Information Systems  
**Principal Investigator:** Kerwin, Jeffrey, Ph.D.  
**Organization:** Westat  
**Contract Number:** PSC TO#07R000131, IAA Number 06-443R-06  
**Project Period:** 09/07 – 06/09  
**AHRQ Funding Amount:** \$251,114  
**Summary Status as of:** December 2008

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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

**Summary:** One important way that health information technology (IT) can improve the safety, quality, efficiency, and effectiveness of health care is through better supporting consumer engagement. This can be through directly providing a consumer interface into a health IT system, or through giving information to health care providers to assist in their patient interactions. As interest increases in reaching consumers and patients directly through information systems, it is important to understand what consumers want and how to get their feedback.

AHRQ has been funding research for novel patient safety and health IT projects, including projects in health information exchange (HIE). The value of IT investment in improving quality and safety depends a great deal on participation by the ultimate beneficiary: the patient/consumer. Health IT has the potential to reduce disparities and increase consumer participation in their self-care, as well as coordinate care for a patient-centered experience, but consumers have expressed a distrust of some health IT efforts. The utility of any health IT or HIE system will be greatly enhanced if a system designed to benefit the patient actually involves the patient in the planning, development, and implementation. Therefore, it behooves us to understand how to best engage patients and consumers. This contract will be used to fund an exploratory research study to gain insight into consumers' understanding, misunderstandings, fears, mistrusts, and concerns related to health IT and HIE in order to devise strategies to better engage consumers in the development of electronic health information systems.

We will conduct 20 focus groups with health care consumers in selected cities around the United States. In general, the groups will be homogenous with respect to the presence or absence of either of the following characteristics: 1) managing a chronic health condition (or the condition of a close family member), or 2) having visited at least three health care providers in the past 2 years. Consumers with a relatively "heavy" dependence on health care might be expected to have a very different frame of reference in considering health IT, as compared to persons with a lighter use of health care. We would expect that both the potential benefits and risks of health IT will be more immediately clear to those more dependent on health care, relative to the latter group. We will also construct several groups that are homogenous with respect to whether or not participants are covered by an HMO. Approximately two-thirds of physicians who practice within an HMO are using electronic medical records (at least partially), as compared to only about one-fifth of those in practices owned by the physicians themselves. Consumers who avoid HMOs often do so at least partly because they want maximum choice and independence with respect to the health care providers they visit, and this characteristic may be related to their perceptions of certain aspects of health IT (e.g., sharing of information among providers). Finally, it should be noted that four of the focus groups will be conducted with Spanish-speaking patients.

The project is expected to be completed by June 2009. AHRQ will receive the results in the form of intermittent summaries and a final report.

### **Specific Aims**

- Conduct 20 focus groups with health care consumers. **(Ongoing)**
- Prepare detailed report of study findings. **(Upcoming)**

**2008 Activities:** After obtaining OMB approval for the study in late summer, we first conducted two pretest focus groups, as a test of the moderator's discussion guide. The pretest groups provided valuable feedback for improving the discussion guide. We then conducted focus groups in Ohio (Columbus, as well as a medically underserved rural county); Denver, CO; and Providence, RI. Findings for each region were summarized in written reports.

**Preliminary Impact and Findings:** Findings thus far suggest that health care consumers do want to be engaged in at least one health IT issue: the sharing of their personal medical information (with other doctors, researchers, etc.). They would like to communicate directly with their health provider about who will have access to their medical information.

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### **Selected Outputs**

None Available.