MyHealthPortal: Using an Electronic Portal to Empower Patients with Breast Cancer

**Principal Investigator:** Wen, Kuang-Yi, Ph.D., M.S.

**Organization:** Fox Chase Cancer Center

**Mechanism:** PAR: HS09-087: Mentored Research Scientist Research Career Development Award (K01)

**Grant Number:** K01 HS 019001

**Project Period:** August 2011 - July 2016

**AHRQ Funding Amount:** $747,959

**Summary:** Patient use of online electronic medical records has the potential to improve health outcomes. Educational materials that are made available within a patient-accessible electronic medical record (PAMR) help patients understand their clinical data and support them through use of integrated behavioral and health communication strategies in a comprehensive format that contributes to optimum care.

Studies show that breast cancer patients report that providers often fail to understand their psychosocial and communication needs. In addition, they report the need for information and skills to manage their illness and the major life changes and emotional problems that usually accompany it. One objective of this research is to integrate personal information from an electronic medical record with educational and support content about breast cancer treatment decisionmaking and care management into the MyHealthPortal patient portal. A second project objective of this Mentored Research Scientist Research Career Development Award is to enhance Dr. Wen’s career development through education and training activities.

Using an iterative developmental process, this work will be accomplished through a four-phase research plan to ensure a user-centered design and the acceptance of the portal by the target audience and health care providers. Phase 1 includes survey research to assess existing institutional portal users’ satisfaction with the current portal, and to identify features in need of improvement. Phase 2 consists of a qualitative study to identify breast cancer patients’ information needs and preference for a PAMR-integrated portal. Phase 3 includes a qualitative study to explore breast cancer clinicians’ attitudes and expectations regarding the implementation of a patient portal that integrates shared medical records and e-communication capability that will affect doctor-patient relationships. Phase 4 includes both cognitive user and usability testing for system refinement to maximize MyHealthPortal’s usefulness and patient satisfaction. Once fully developed, the study will evaluate the feasibility of the portal system in a pilot randomized controlled trial study with 120 breast cancer patients to examine MyHealthPortal’s effects on patient outcomes including cancer-related distress, information competence, coping self-efficacy, physical quality of life, and doctor-patient communication. Intervention participants’ satisfaction with and usage of the MyHealthPortal system will also be evaluated.

Dr. Wen identified a mentorship team to provide expertise in major areas of relevance to the research activities. Enrollment in three core courses will advance his career and research goals. He will attend a series of seminars and workshops and will attend and present at annual meetings and conferences on a
variety of research topics directly related to the training needs identified by the mentorship team.

**Specific Aims:**

- Develop a patient-centered Web-based portal (MyHealthPortal) for breast cancer patients undergoing treatment in a Comprehensive Cancer Center. *(Ongoing)*
- Conduct a pilot randomized controlled trial study to assess the feasibility and potential impact of the MyHealthPortal system with early-stage breast cancer patients. *(Ongoing)*

**2012 Activities:** The project team worked on the development of text, narrative, front-page interface, and user refinement of the front-page interface. The team reviewed other patient portals and a study by the Robert Wood Johnson Foundation that developed a personal health record application that presents data to patients with chronic disease.

Assessment of the Web portal survey to understand patient preference was underway during this period, with approximately 70 people recruited. In order to increase recruitment goals, the strategy was changed from online recruitment and survey completion to identifying people in the lobby and cafeteria to have them manually fill out the survey. This revision was approved by the institutional review board. Thirty-two patient and 19 provider interviews were completed. Preliminary results were presented at the 2013 Society of Behavioral Medicine Annual Meeting in March.

**Preliminary Impact and Findings:** This project has no findings to date.

**Target Population:** Cancer: Breast Cancer, Women*

**Strategic Goal:** Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions and the electronic exchange of health information to improve quality of care.

**Business Goal:** Implementation and Use

*This target population is one of AHRQ’s priority populations.*