

**Title Page**

**Title of Project:** MyHealthPortal: Using an Electronic Portal to Empower Patients with Breast Cancer

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## Structured Abstract

### Purpose:

Patient use of online electronic medical records holds the potential to make incremental improvements in health outcomes. Breast cancer is the most common cancer in the US and a diagnosis of breast cancer often evokes fear and distress. Breast cancer patients report unmet needs in information and skills to manage their illness and deal with the major life changes and potential emotional problems that occur.

### Scope:

To bridge the divide between patients and the healthcare system, this study was aimed to develop and evaluate a patient portal that integrates personal medical records with educational and support content for newly diagnosed breast cancer patients.

### Methods:

The patient portal was developed through literature review, web portal survey, patient and provider interviews, health literacy evaluation, cognitive user testing and usability testing. The final portal system was evaluated in a pilot RCT.

### Results:

Through an iterative process of development and testing, the quality adequacy, and appropriateness of the personal health record presentation, educational content and interactive tools were established. A total of 38 patients randomized to the control group and 36 to the portal group. Information competence and self-efficacy scores in the intervention group were slightly higher than those in the control. We did not find any significance in quality of life scores between groups. The mean number of intervention logins was 11 with a mean duration of 15 minutes. 88% of intervention participants indicated that the portal was easy to use and helpful.

### Key Words:

Patient portal; breast cancer management.

## A. Purpose

The career development and training specific aims were unchanged from the original application. The training goals of the grant were to gain skills in areas of 1) health services research, focusing on designing and conducting RCTs, 2) medical informatics for clinical research, and 3) usability evaluation/human factors that complemented my existing research and program development skills.

The goals of the training were to develop:

1. My ability to develop effective patient-centered clinical informatics applications in the context of health services
2. Build my capacity for using and evaluating information technology systems for health services.
3. My skills to effectively use human factors/usability evaluation to enhance health information technology system design and improve interaction with users and organizations

The training plan included formal course work, research seminars, conference and workshop attendance, research ethics training, implementation of the proposed research study and regular interaction with my mentors and advisors.

The specific aims for the research project remained unchanged from the original application. The aims are:

**Aim 1:** Develop a patient-centered web-based portal (MyHealthPortal) for breast cancer patients undergoing treatment in a Comprehensive Cancer Center. Users will be provided with tools that are integrated with their personal medical records to learn about their diagnosis, treatment, and to manage their care through resources such as: health information, decisional and emotional support, and clinical communication capability.

**Aim 2:** Pilot Randomized Controlled Trial Study – To assess the feasibility and potential impact of the MyHealthPortal system with early-stage breast cancer patients.

Using an iterative developmental process, aim 1 was accomplished through four phases of the research plan to ensure a user-centered design and the acceptance of the portal among both the target audience and health care providers. Phase 1 included survey research to assess our existing institutional portal users' satisfaction with the current portal and identify features in need of improvement. Phase 2 consisted of a qualitative study to identify breast cancer patients' information needs and preference for a personal health records-integrated portal. Phase 3 included a qualitative study to explore breast cancer clinicians' attitudes and expectations regarding the implementation of a patient portal which integrates shared medical records and e-communication capability that might impact on doctor-patient relationship. Phase 4 included both cognitive user and usability testing for system refinement to maximize MyHealthPortal's usefulness and patient satisfaction. The Aim 2 study evaluated the feasibility of the portal system in a pilot randomized controlled trial study with 74 breast cancer patients to examine the impact of the MyHealthPortal system on patient outcomes including: cancer-related distress, information competence, coping self-efficacy, physical quality of life, and doctor-patient communication. Satisfaction and usage with the MyHealthPortal system were evaluated among the intervention participants. The findings of this research and the developmental process will not only be applicable to the breast cancer population, but could also serve as a model for personal health records-integrated system development and implementation among other cancer populations.

## B. Scope

### **Breast Cancer Patient's Needs**

Not only is breast cancer (BC) is the most common cancer among women in the United States but multiple complex decisions and care management issues are required along the continuum of BC diagnosis, treatment, and follow-up. Many BC patients express a desire to more actively participate in their care management and

decision-making. In order to communicate more effectively with the clinical team, patients need resources for better understanding their diagnosis, treatment options, potential outcomes and prognosis. Indeed, BC patients are frequently dissatisfied with the information received from their health care providers, as evidenced (in part) by the increasing use of the Internet to access additional health related information. They have concerns about the quality of communication with their clinicians including implications of the diagnosis, treatment decisions, and treatment management. The types of information most desired include stage of disease, extent of spread, treatment options, likelihood of cure, side-effects, treatment management, and supportive services.

The early and late stage physical effects of BC and its treatment, including fatigue, depression and changes in physical appearance and hormonal changes, can have a devastating impact on quality of life, affecting women's emotional welling and self-image. The ability to develop coping strategies for understanding medical records, dealing with complex information and treatment decision making, managing treatment side-effects, obtaining emotional support, initiating effective communication with the clinical team, and participating as desired in one's care become crucial in minimizing the negative implications of diagnosis, treatment, and follow-up. Web-based systems provide a venue for interventions that can provide multiple services (e.g. rapid access to medical records and tests results as they become available, educational information, emotional and decisional support, and e-communication with the clinical team). Further, this information can be delivered in an integrative fashion as a comprehensive system, without simultaneously taxing the system and provider in terms of time and on-site access.

### **Public Internet Access and Web-based Applications for Breast Cancer Patients**

Data indicates that more than two-thirds of U.S. adults have access to the Internet at home, and Internet access is increasing each year including population segments in seniors and many minority and underserved groups. 75% of Americans use the Internet on a regular basis, and the impact of Internet applications on doctor-patient communication and health care delivery continues to expand. Individuals are willing to play an active role in health information gathering, analysis, and decision-making. BC patients reported that the Internet is second only to their healthcare providers as a first choice for where they would go to obtain cancer information. As an increasing number of BC patients turn to the Internet for information and support, many web-based systems are being developed to help women cope with BC diagnosis and progression. However, a serious lack of the existing systems is that the web-based information provided is not personalized, nor integrated with patient accessible medical records.

### **Patient Accessible Electronic Medical Records and Patient Portal Applications**

Web portal technologies have great potential to provide patients unprecedented online access to view and thereby to contribute to their medical records and clinical care. Personal health medical records are generating interest because they offer tremendous new opportunities to provide tools to assist patients as they make treatment choices and manage their illness and recovery, and thus to influence the quality of their health outcomes. However, virtually no programs using portal technology couple the clinical information from the patient medical records with theory-guided educational and support needs to help BC patients cope and navigate through the challenging diagnosis, treatment decision making, and treatment management process. Patients reported that simply providing access to electronic medical records has little usefulness on its own. Enhancement could be accomplished by embedding links to credible educational sites or adding information of primary interests to patients, such as patient-relevant decision support. Patient education is advocated for helping patients understand their medical records, make treatment decision, and manage their care to ensure the best possible health outcomes. Therefore, MyHealthPortal extended beyond the personal health records by providing theoretically-driven integrated content and services, while simultaneously linking BC patients directly to their health information in the providers' electronic records. By introducing new patient portal formats with personal health records-integrated information and resources to the growing consumer movement, the online revolution may become the engine driving the next generation of self-care and accelerate the changing of patients into partners for health, thereby allowing patients to understand and manage their own health in a more time- and cost-efficient manner.

## C. Methods

**Aim 1:** Develop a patient-centered web-based portal (MyHealthPortal) for BC patients

Aim 1 - Phase 1: To assess current FCCC patient portal users' satisfaction and their preferences for portal improvement. For those existing FCCC portal users with BC, an introductory email letter inviting participation in an online survey were sent. Those who participated accessed the survey through a secure link to review and sign the detailed study description with an online consent form. Survey questions included satisfaction with different features of the current portal; user's Internet behaviors; and new portal services endorsement. Descriptive statistics of frequencies and percentage of answers were computed for each satisfaction evaluation item. The average ranking for the new service endorsement data was summarized by the mean ranking and standard deviation. For each service endorsement item, the percentage of participants who report the item being the most important was computed.

Aim 1 - Phase 2: To collect qualitative data to explore BC patients' information needs, interaction experience with the health care system, and attitudes toward a personal health records-integrated portal. Interviews with BC patients were conducted using the Critical Incident Technique (CIT) by the PI. The interview started with the identification of a critical incident regarding the specific situation where the patient feels her needs have not been met. In the first part of the interview, participants were asked to tell the story of their BC diagnosis and treatment journey with respect to the critical incident identified including both positive and negative experiences regarding their informational needs and the nature of their contacts with the health care system. Digital audiotapes of each interview were transcribed. We coded the interview transcripts for the content and frequencies of specific responses given with respect to key themes that emerge. Themes of BC patient experiences were identified, conceptually confirmed, and organized with our literature review findings and theoretical framework to guide the content topics and service functionalities to be covered within the portal.

Aim 1 - Phase 3: To explore and elicit BC clinicians' attitudes, concerns, and suggested solutions regarding the implementation of a patient portal integrating shared medical records and e-communication to improve patient care and experience. We interviewed members from our FCCC BC care team including medical oncologists, surgical oncologists, radiation oncologists, pathologists, social workers, and oncology nurses to understand their attitudes regarding patient's use of a portal system that integrates shared medical records with educational information, and secure messaging communication. Individual interviews focused on issues related to how a shared medical records and e-communication in an integrated patient portal with evidence-based content and resources might influence the care delivery and doctor-patient relationship. Since integrating a patient portal into day-to-day patient activities is a complex endeavor with significant impact for workload and workflow, we will also elicited clinicians' suggestions regarding technical, operational, and organizational issues that need to be addressed in order to overcome implementation barriers. For each issue, responses were analyzed through content analysis to inductively identify themes that emerge from the discussion. Two independent coders reviewed all the interview transcripts and generate a set of possible themes to analyze the data.

Aim 1 - Phase 4: To conduct iterative user and usability testing to maximize the usefulness and satisfaction of the MyHealthPortal system for a user-centered design. We conducted two rounds of user and usability testings: 1) an initial user-testing with BC patients to evaluate high-level concepts and content topics of the portal prototype using mock-ups and 2) usability testing employing heuristic evaluation method health communication testers; and usability testing employing a think-aloud protocol with BC patients. For the initial user testing session, participants were asked to assess the extent to which the medical record mock-ups and other content areas/services are personally relevant, easily interpreted, and comprehended. Participants were probed for suggestions to enhance the salience, appearance and visual of the graphics and content. For the first round of usability testing, using a prototype developed according to the feedback from the initial user testing, we

conducted with two patient education specialists. Specialists were asked to review all aspects of the MyHealthPortal prototype at least twice. Each specialist completed a heuristic evaluation checklist and an overall 5-point Likert rating scale for each principle (from 0: no usability problem to 4: usability catastrophe). The second round of usability testing were guided by the NCI's usability guidelines ([www.usability.gov/guidelines](http://www.usability.gov/guidelines)). Participants were requested to look for specific information or tool by navigating through the portal prototype. Using the well-established think-aloud method, participants were asked to express their reactions to different components, such as excitement, frustration, or boredom, during the navigational process. To analyze the participants' reactions to the MyHealthPortal prototype from the testing session, we summarized the frequencies of specific responses with a focus on satisfaction with comprehension, sensitivity, relevance, and appeal of the portal. We also paid attention to participants' time to complete task, expressions of frustration, question asking for clarification and overall satisfaction. We used participant feedback to make recommended revisions to the portal production to maximize relevance and feasibility

**Aim 2:** Pilot Randomized Controlled Trial Study – To assess the feasibility and potential impact of the MyHealthPortal system with early-stage breast cancer patients.

Participants. Participants were included if they are: 1) 18 years of age or older females; 2) BC stages I, II & III patients within 1 month of initial FCCC appointment and decide to receive care at FCCC; 3) able to communicate in English; 4) able to give consent; 5) no evidence of significant cognitive impairment, and 6) have Internet access.

Sampling and recruitment. Participants were identified through the scheduling office at the BC Evaluation Clinic of FCCC and tracked for eligibility. An RA approached eligible patients in clinic and invite them to participate in the study. The RA described the study in detail, answered participants' questions, and obtained written informed consent. Eligible women who provided consent were scheduled for a baseline phone assessment.

Data collection procedure and description of study conditions. After determination of eligibility and receipt of informed consent and completion of the baseline assessment, each participant was randomized (using a random permuted block procedure) to the intervention or control group. Within one week after the baseline assessment, participants received mailed materials pertaining to their assigned interventions. Control group participants received a *What You Need to Know about Breast Cancer* booklet published from the NCI, Intervention participants received a package with detailed information concerning the objectives of the MyHealthPortal system and its content coverage and functionality, as well as information about how to access the website. After 3 months, participants in each condition were contacted to complete a follow-up assessment. The follow-up assessment for the intervention group participants also included satisfaction questions evaluating the MyHealthPortal system intervention. Participants received a modest monetary compensation (\$20) for each assessment that they completed.

### Measures.

- a) Sociodemographic. Participants were asked to report their age, race/ethnicity, marital status, income, educational level, and computer experience.
- b) Outcome Measures. 1. Information competence was measured with a 5-item scale. 2. Coping self-efficacy was measured by Chesney's 26-item scale. 3. Physical quality of life was assessed with the Functional Assessment of Cancer Therapy – Breast (FACT-B). 4. Cancer-related distress was measured by the Impact of Event Scale (IES). 5. Doctor/patient communication was assessed by the CARE-SF communication subscale to assess the quality of communication.
- c) Satisfaction and Feasibility Evaluation. We assessed intervention participant's satisfaction of the portal with respect to diagnosis, treatment, concerns about the disease, and treatment management. Final evaluation included a survey and phone interview.

Analytic Plan.

- a) Feasibility and acceptability of the MyHealthPortal Intervention. We assessed multiple indicators of acceptability and feasibility among the Intervention subjects, including the acceptance rate, reasons for study refusal, and difference between those who remain in the study and those who drop out (using independent sample t tests and chi-square tests).
- b) Portal satisfaction evaluation ratings were analyzed with frequencies and descriptive statistics to explore how users perceive the helpfulness of the portal with regard to understanding their diagnosis and treatment options, managing care, and coping emotional adjustment.

**D. Results**

Aim 1 – Phase 1: To assess current Fox Chase patient web-based portal users' satisfaction/ preferences for improvement.

The majority of the study participant's (n=88) using MyFoxChase were either "satisfied" or "very satisfied". The feature liked most by participants was the ability to view their appointment schedule. Other features participants liked were the ability to check their labs and communicate with their doctors. Some participants expressed their dislike with MyFoxChase because of log-in issues, incorrect or duplicate information listed in their appointment schedules, and the limited access to medical record information outside of lab results. More often participants identified MyFoxChase had saved patients a phone call to FCCC versus saving them a trip to FCCC. 95% of participants who responded indicated they would use MyFoxChase in the future. In fact, many participants indicated they would be willing to pay for a least one of the existing features. The most important service was the ability to securely view portions of a patient's medical records. Additionally there were 50 participants who completed the in-clinic paper survey. The results of the paper survey were very similar to the results of the web portal survey, though many of the paper survey participants were not familiar with any portal systems. Table 1. lists some satisfaction data results.

<b>Table 1. Satisfaction with current portal functions</b>	Web Portal Survey ( n = 88)
Overall satisfaction	52%
Satisfied	
Pros and helpfulness of the portal	
Ability to check appointments	30%
Ability to see lab results	17%
Cons of the portal	
Difficulty Logging On	9%
Would like all up-to-date lab results including a way to interpret them	10%
Would like to be able to reschedule appointments and have an up-to-date list of appointments	7%
Use of portal saves a phone call	
Yes	53.4%
Use of portal saves a visit	
Yes	6.8%
Preference of scheduling via online portal vs. phone	
Portal	11.4%
Phone	

Aim 1 – Phase 2: To collect qualitative data to explore breast cancer patients' information needs/interactions with their providers and health care system/ attitudes toward a personal health records-integrated portal. Participants (n=42) had varying positive and negative experiences when interacting with either the health care system or their providers. However, many of the positive experiences included doctors and/ or nurses who were personable or made the patients feel like they cared about them and that they were not alone. Challenging issues to cope with after being diagnosed were: the thought of dying, physical side effects (i.e. losing their hair during chemotherapy), trying to stay positive for their family, having little or no release for their emotions, trying to resume a “normal” life during their treatment, and trying to communicate with friends and family about their diagnosis and treatment. Many participants found ways to cope with these challenges; however, few had not found methods that worked. Many participants utilized the internet as a tool to understand their diagnosis and treatment. Specifically, BC patients highly emphasized the importance of having access to their personal health records including laboratory tests, which will help them understand their diagnosis and treatments, as well as track their health status. Some described they would like to view what the doctor had written about their diagnosis and prescribed treatments, and hope that their accessible personal health records would contain understandable explanations and clarifications of what had been conveyed in the clinical encounters. A sense of empowerment, feel more in control as partners in their own healthcare in collaboration with their providers have been frequently cited as one of the main benefits for having access to their personal health records. One woman said *“I would like access to my blood results. I would like access to all the labs...if I wanted to print something out again... I would use it to make charts of...my progress, how my blood levels were going, even though I know they keep track it just made me feel more in charge”*. One major concern we found was that many participants reported significant privacy and confidentiality concerns about their personal health information if accessing electronically. Participants expressed their desire for appropriate protection of their private information to ensure that their personal information can only be accessed by themselves and their providers. Their worries could be illustrated by the quote from one woman *“Something secure that other people won't have access to and won't jeopardize the privacy of the patient. Special number for the patient to login instead of name and social security... security is important”*. Table 2 listed patient characteristics across three phases.

Aim 1 – Phase 3: To explore/ elicit breast cancer health care support staff & providers attitudes/ concerns/ suggested solutions related to the implementation of a patient web-based portal/ integrated shared medical records/ secure e-communication to improve patient care & experiences.

The summary of breast cancer clinician interviews (n=19) has indicated a patient portal containing electronic health records, supportive and educational content can be useful for providing patients with resources and accurate information regarding care and treatment. For example, one clinician commented *“I think the patients are entitled that it's their body, they have every right to their medical records. I think in a lot of cases it's helpful to the patients. If they are reading alarming information they have the contact to answer questions and put it in the context”*. However, the majority of clinicians who were interviewed were concerned that a patient's medical record contains terminologies which can be unfamiliar and confusing creating unnecessary worry. A radiation oncologist commented *“I think it can be challenging for patients to read through radiology reports... but it generates a lot of anxiety and concerns that are unnecessary because the report is designed for health care provider not for a patient”*.

Aim 1 – Phase 4: To conduct iterative user and usability testing to maximize the usefulness and satisfaction of the MyHealthPortal system for a user-centered design.

Eleven patients completed a user testing interview. Overall the responses were positive related to the features of the portal. A few participants had difficulty identifying various features of the portal; however, this information has been collected to refine the system in order to more accurately meet a user-centered design. As a result, the following feature names have been changed: “Breast Cancer Facts” to “Breast Cancer Basics”, “My Monitoring” to “My Symptom Tracking”, and “My Medical Records” to “My Condition”. Since these changes have been implemented, more participants have been able to correctly identify portal features. Participants viewing the “Breast Cancer Basics” component had various suggestions of specific topics to include, which



were considered when further developing this content. Majority of participants viewing the “Labs” page had difficulty identifying what the lab acronyms (i.e. WBC, CBC) and lab values meant so additional information were added for explanation. Seven patients completed a usability testing interview. Additional technological glitches and errors were identified, such as dysfunctional links and typos.

**Table 2. Participant Characteristics across Three Patient Data Collection**

Patient Characteristics	Web Portal Survey (n = 88)	Waiting Room Survey (n = 50)	Breast Cancer Patient Interview (n=42)
Female	76%	80%	100%
Age			
>60	32%	40%	28%
40-59	61%	54%	57%
18-39	7%	6%	14%
Annual house income <sup>a, b</sup>			
< \$45,000	5%	44%	33%
\$45,000-\$60,000	8%	12%	21%
≥\$60,001	76%	28%	33%
Education			
High school/GEM or less	18%	34%	19%
Trade/Some college	31%	24%	38%
College graduate	20%	28%	29%
Postgraduate degree	27%	12%	14%
Race/ethnicity <sup>a, b</sup>			
African American	2%	54%	36%
Hispanic/Latino	1%	22%	5%
Caucasian	95%	36%	64%
Other	1%	8%	0%
Cancer type			
Breast cancer	30%	18%	100%
Other GYN cancer	27%	30%	0%
GI cancer	12%	18%	0%
Blood cancer	3%	4%	0%
Skin cancer	5%	4%	0%
Other type	30%	38%	0%
Looked for cancer information on the Internet			
Yes	89%	76%	71%
No	4%	14%	24%

<sup>a</sup> Difference between Web Portal Survey and Waiting Room Survey respondents,  $P < .05$

<sup>b</sup> Difference between Web Portal Survey and Breast Cancer Patient Interview respondents,  $P < .05$

**Aim 2:** Pilot Randomized Controlled Trial Study – To assess the feasibility and potential impact of the MyHealthPortal system with early-stage breast cancer patients.

We have randomized 38 breast cancer patients into the control group and 36 into the intervention group. Table 3 shows their characteristics across two arms.

**Table 3. Participant Characteristics across two arms**

Patient Characteristics (%)	Control (n = 38)	Intervention Survey (n = 36)
Age		
>60	20%	10%
40-59	45%	40%
18-39	35%	50%
Annual house income <sup>a, b</sup>		
< \$45,000	30%	20%
\$45,000-\$60,000	40%	35%
≥\$60,001	30%	45%
Education		
High school/GEM or less	20%	13%
Trade/Some college	30%	27%
College graduate	40%	35%
Postgraduate degree	10%	25%
Race/ethnicity <sup>a, b</sup>		
African American	14%	17%
Hispanic/Latino	1%	0%
Caucasian	85%	83%

The mean number of logins was 11 with a mean during of 15 minutes. 88% of intervention participants indicated that the patient portal was easy to use and helpful in their understanding of breast cancer and treatments. All features were used by participants and rated 3 or higher on a 5 point scale. Information competence and self-efficacy scores were improved over time. For the quality of life FACT-B, we did not find any changes over time.

## CONCLUSIONS

Through a mixed-methods approach and integrating both patient's and provider's perspectives, this study contributes to the current body of literatures on electronic PHR patient portal, specifically in the context of oncology care. Our results indicated that using patient portal is feasible in breast cancer patients. Most users indicated that the patient portal was useful and easy to use. Medical terminology may be difficult for patients to understand but significant and relevant to patient's health behaviors and outcomes. Interactive and comprehensive PHR systems will need to provide educational or translational information for patients and families, ideally tailored to their individual circumstances and conditions. Having access to personal medical records that patients would not understand is just not enough, patients being able to do something through the PHR access and related tools, e.g., making cancer treatment decision, changing health behaviors, improving doctor-patient communication, would be the true value of patient-centered health information and management technology, requiring multidisciplinary team work and future innovative research. This type of work will bring us closer to the ultimate goal of helping all cancer patients be informed, Future research should focus on continued cancer patient and provider engagement in portal development, usage, ongoing patient support and self-management, and doctor-patient communication as well as the potential of interactive PHR portals that expand from cancer prevention into survivorship and the adoption of mobile technology delivery channel.

## E. List of Publications and Products

### K01 cited publications and conference presentations

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- **Wen, K.Y.**, Smith, R., Padmanabhan, A., and Goldstein, L. Patient Experience of Taking Adjuvant Endocrine Therapy for Breast Cancer: A Tough Pill to Swallow. 2017. Accepted and being published in *Patient Experience Journal*, volume 4, issue 3. Online first in November 2017.
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