May 2016

Exploring Interactive Survivorship Plans: Patient Perceived Value, Acceptance and Usability Evaluation of an Online Breast Cancer Survivorship Tool

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EXPLORING INTERACTIVE SURVIVORSHIP PLANS: PATIENT PERCEIVED VALUE, ACCEPTANCE AND USABILITY EVALUATION OF AN ONLINE BREAST CANCER SURVIVORSHIP TOOL

by

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A Dissertation Submitted in

Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

in Biomedical and Health Informatics

at

The University of Wisconsin-Milwaukee

May 2016

ABSTRACT

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The University of Wisconsin-Milwaukee, 2016
Under the Supervision of Professor Priya Nambisan

Introduction: Having recently been discharged from the hospital, several breast cancer survivors find themselves unable to adjust to the transition and take charge of their own health, away from the confines of the hospital.

With the rapid advancement in treatment methods and techniques, the rate of breast cancer survivors has grown exponentially. It is crucial to provide adequate means to support cancer survivors in an active manner. This includes regular monitoring for recurrence (or occurrence of new cancers), handling any related and non-related comorbidities, provide recommendations for preventive care as well as dealing with any long term side effects from the treatment.

The specific objective of this research is to design and develop a personalized web application to support breast cancer survivors after treatment

(chemotherapy and/or radiation), as they deal with post-treatment challenges, such as comorbidities and side-effects of treatment.

Methodology: I used an iterative design and development approach to produce a web application for breast cancer survivors that help them monitor their quality of life, provide them with personalized alerts based on their breast cancer related medical history as well as timely alerts, to remind them of follow up visits. Finally, I utilized a combination of qualitative methodology (thematic analysis), as well as user task analysis to assess the acceptability and usability of the prototype among a group of breast cancer survivors. User feedback was gathered on their perceived value of the application, and any user-interface issues that may hinder the overall usability among lay users were identified.

Results: Fifteen breast cancer survivors participated in the acceptability and usability testing of the prototype. The prototype was found to be perceived as unique and valuable among the participants, in its ability to utilize personalized breast cancer related medical history. The application's portability and capability of organizing their entire breast cancer related medical history as well as the at-home tracking of various quality of life indicators were perceived to be valuable features. The application had an overall high usability, however certain sections of the application, such as viewing observations history were not as intuitive to locate. While participants appreciated the visual and graphical elements of the

website, the overall experience of the application would benefit from incorporating some sociable elements that exhibit positive re-enforcement within the end user and provide a friendlier and fun experience.

Conclusion: The results of the study showcase the need to provide more personalized tools and resources to breast cancer survivors to support them in self-management after completion of treatment. It also demonstrates the ability to integrate breast cancer survivorship plans from diverse providers and paves the way to add further value-added features in consumer health applications, such as personal decision support. The feedback received from end-users will be used in order to further improve the prototype and address any existing user-interface issues. It is hoped that making such tools more accessible could help in engaging survivors to play an active role in managing their health and also encourage shared-decision making with their providers.

To

my grandmother

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

ACESO	After Cancer Education and Support Operations
ASCO	American Society of Clinical Oncology
BFI	Brief Fatigue Inventory
CDSS	Clinical Decision Support System
CES-D	Center for Epidemiologic Studies – Depression (scale)
EMR	Electronic Medical Record
IRB	Institutional Review Board
ITHSDO	International Health Terminology Standards Development Organization
NCBI	National Center for Biotechnology Information
NCI	National Cancer Institute
ODL	Observations of Daily Living
PHIM	Personal Health Information Management
PHR	Personal Health Record
PSQI	Pittsburgh Sleep Quality Index
PRO	Patient reported outcomes
SNOMED-CT	Systemized Nomenclature of Medicine – Clinical Terms
TAM	Technology Acceptance Model
US-FDA	United States Food and Drug Administration
WSFQ	Watts Sexual Function Questionnaire

ACKNOWLEDGEMENTS

Firstly, I would like to express my sincere gratitude to my advisor, Prof. Priya Nambisan, for the continuous support of my Ph.D. study and related research, for her patience, motivation, and immense knowledge. Her guidance helped me in the entire duration of my research and writing of this dissertation. I could not have imagined having a better advisor and mentor for my Ph.D. study.

Besides my advisor, I would like to thank the rest of my dissertation committee: Prof. Ron Cisler, Prof. Alexandra Dimitroff and Prof. Jake Luo, for their insightful comments and encouragement, but also for the hard questions which incented me to widen my research from various perspectives.

My sincere thanks also goes to thank my other family: Thomas Jacobsen, Janet Jacobsen, Karl Jacobsen and Ellen Kowalczyk who have been my pillars of strength during this time consuming process. Without their encouragement and support, I would not have been able to undertake this daunting task.

I would also like to especially thank my cat Phoebe for spending countless hours cheering me on at my work desk, as I worked on my dissertation. Her valiant efforts are especially appreciated.

I am greatly indebted to After Breast Cancer Diagnosis (ABCD) as well as all the participants in this study, for granting me their time, knowledge and patience.

Chapter 1: Introduction

1.1 *Problem Definition*

Newly discharged breast cancer patients are often faced with a very difficult situation. While in hospital, most of their health needs are actively taken care of by the hospital staff, such as what tests to perform and when, what, how much and when medication is to be administered, in addition to continually monitoring the patient's condition and response to treatment. During the course of the treatment, almost the entire responsibility of administering treatment and care lies with the hospital and its staff including the nurses and physicians.

Upon discharge from the hospital, the patients suddenly find themselves having to take care of themselves, often without the proper training and understanding of their current condition, and what to expect in the near future, in the form of side effects of treatment as well as possible recurrence (Cappiello et al., 2007; (Ganz et al., 2004); (Leedham & Ganz, 1999).

With better cancer treatments now available, the number of breast cancer survivors has also grown exponentially in the past decades. However, availability of adequate resources and tools for breast cancer survivors has not kept up with the rapid advancement in treatment options. Instead of being passive consumers of various healthcare services, patients wish to become more active and involved

in their health than ever before. However, they face several barriers, such as the lack of knowledge and understanding of their medical condition, coupled with the lack of specific tools and resources that enable them to achieve this (Fredette, Sheila; Cappiello et al., 2007; Paskett & Stark, 2000).

1.2 *Gaps in Research*

After a thorough online survey of popular health-related resources, such as National Center for biotechnology Information (NCBI), WebMD and National Cancer Institute (NCI) for breast cancer survivors related resources; it was found that currently, not many patient-driven and managed survivor care plans exist.

While most electronic cancer survivor care plans are generic in nature, failing to account for the unique individual characteristics and the nature of the patient's condition, another more customized cancer survivorship care plan does currently exist, in the form of a paper document that is handed to the patient before discharge. This form of a cancer survivor care plan assumes that the patient is capable enough to not only understand and retain all the terms and instructions contained within that document, but also remember to follow the guidelines it contains in the advised timeline.

Several computer based tools aimed at cancer survivors were also surveyed online via a web search, however, they were found to be more of a questionnaire driven training and learning resource tool, rather than a comprehensive cancer survivor care plan. Again, such tools assume the patient

remembers all aspects of their medical history and is able to answer the questions asked. This method is subject to recall bias as well as manual error. Moreover, being a generic one size fits all solution, they were found to be inadequate to fully capture the unique characteristics of the patient and deliver personalized information. Additionally, they also relied on the patient to be proactive and initiate the training session, rather than delivering advisories and content when necessary. On the other hand, interactive communication systems have been shown to educate and inform breast cancer survivors with various aspects of life after breast cancer (Shaw et al., 2007), thus investigating an interactive breast cancer survivorship care plan deserves further investigation.

1.3 *Developed Patient Self-Management System*

Named after the Greek goddess of healing, After Cancer Education and Support Operations (ACESO) provides an interactive way for patients to manage their condition using information residing in their personalized survivorship care plan, provided by their medical care provider. Several electronic medical record (EMR) systems available today allow a patient to view their medical record from the comfort of their home, using a computer terminal via a patient portal (Weingart et al., 2006). However, the information contained in a conventional survivor care plan is passive, usually in the form of a static paper document, and is designed such that a patient will need to proactively check and analyze and

interpret the information it contains, at the right time. Such a method for accessing personal health records is very passive and inefficient.

ACESO aims to be an active, intelligent tool that continually monitors the information derived from the patient's personalized survivorship care plan and the patient provided input, looks for periodic updates or changes, analyzes this information in real-time, and provides relevant feedback to the patient. This feedback could be in the form of various alerts, triggers or reminders, as well as related recently published news and journal articles, bringing critical information to the attention of the patient.

These alerts, triggers and reminders are based on a pre-constructed knowledgebase repository, derived from cancer survivor guidelines, as well as the patient's personalized breast cancer survivorship plan. The repository will contain a pre-defined set of rule-based alerts and triggers that can be activated based on the patient's condition, or any adverse event.

Chapter 2: Background

This chapter presents prior work in the fields of personal health information management, user-centered design, usability testing, online user experience, patient reported outcomes and observations of daily living as well as expert systems and personal decision support, all of which play an important role in the design, development and testing process of a novel personal health information tool for breast cancer survivors.

2.1 *Personal Health Information Management (PHIM)*

"Personal Health Information refers to activities that support consumers' access, integration, organization, and use of their personal health information." (Civan et al., 2006). An ideal PHIM system demonstrates efficient collection, storage and retrieval of health information. It is especially challenging for patients to be able to readily and quickly access their own personal health information. Since personal health information may be contained in a variety of documents, such as test results, reports, doctor's notes, appointment cards, immunization records, etc., it becomes challenging for patients to find a way to best manage this information (Brennan, 2003).

To further complicate matters, the nature of information contained in these documents requires that they be stored in a protected manner in order to ensure

privacy, while still enabling people to share their own health information at their free will. Currently, physically storing these documents at home by either filing them or keeping fragmented information in various places such as wallets, drawers, etc. are some ways most lay people choose to store this information (Brennan & Kwiatowski, 2003). This method leaves the information fragmented, making it especially challenging to find and retrieve accurate, complete and most recent information. Additionally, it fails to provide one with a more comprehensive view of the state of their health.

A personal health record is “an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment” (Markle Foundation, 2003). Moreover, it utilizes modern computers and information technology to automate and streamline several tasks, such as the updating and retrieval of records on a periodic basis.

A PHR gives the patient more control over their own information, allowing them complete access to their health information, anytime, anywhere. Having access to this complete set of information at their fingertips further empowers the patient to stay on track of their health plan, set personal health goals and most importantly, be able to make informed decisions that relate to their health (Ball et al., 2007).

There are several different kinds of PHRs in use today. The more common kind is the provider-based PHR, which is managed by the patient’s health care

provider. However, this kind of a PHR has two major limitations (Tang et al., 2006). First, the data is limited to whatever the provider is willing to provide. As a result, it might not contain complete and comprehensive data. Additionally, this approach does not solve the issue of fragmented information. Since a patient might have been to many different providers over several years, this results in multiple places where this information is being stored. This makes it challenging to get a complete picture of the patient's health, and look at their medical record, as a whole. Since the primary responsibility of managing these kinds of PHRs rests with the provider, it has been shown that users are more accepting and willing to use a provider-based PHR system. One such successful attempt has been with the My HealtheVet system being used by the Veteran's Health Administration.

Users of this system were found to be highly satisfied, and used the system quite frequently, mostly to access pharmacy-related features (Nazi, 2009). Similarly, users of another provider-based PHR by an HIV-AIDS clinic in San Francisco indicated successful adoption of the myHERO PHR, mostly to access laboratory results, medications and information on their health conditions (Kahn et al., 2009).

On the other hand, a second kind of PHR's, which are patient-managed leave the entire responsibility to manage personal health information in the hands of the patient (Tang et al., 2006). While this provides the user more control, and sports a more complete, unfragmented collection of their personal health

information, it is mired with a few drawbacks. The reliability of patient-entered data has often been questioned. Additionally, it has been found that long-term adoption of this kind of a personal health record system is very low, simply because the patients find it challenging to constantly keep up with new data and diligently enter it into the system (Kim et al., 2004). One such example was the GoogleHealth system. Google Health was a passive PHR, which served as a record-keeping tool, where patients had to manually enter various personal health data. This could have been one of the reasons for lack of adoption among the masses. Do et al (2011), in a study involving participants to compare different personal health systems, found Google Health to be the most unpopular tool, also scoring it low in usability. Thus, it is essential for an ideal personal health record system to not only passively allow the patient to record data, but also by being more interactive as well as proactive by providing them with feedback, alerts and guidance based on their current health condition.

Another newer approach has been one of a hybrid system, which combines both kinds of PHRs. This kind of a PHR, while it is managed by the patient, is equipped to get automated, frequent updates from the provider's PHR, while also allowing patients to enter data on their own, such as results of home medical tests. This results in a health record which is rich in information, comprehensive and provides complete and consolidated access to a patient's record. This kind of a PHR has gained recent popularity since it combines the strengths of both earlier kinds of PHR systems. Microsoft HealthVault is one such

kind of a system, which has shown to be more popular among a group of test users, compared to a completely patient-managed PHR, such as Google Health (Do et al., 2011).

More recently, another new breed of PHRs is being proposed, called iPHRs, or intelligent PHRs. Current research attempts to make the passive PHRs more intelligent, using triggers to provide efficient monitoring of an individual's health record and alert the user prior to any potentially adverse event (Luo, 2011).

Combining the strengths of the various kinds of PHRs mentioned above, while eliminating their weaknesses can result in a very powerful, robust and popular PHR system. A PHR system that automates the import of patient health records from a provider's EMR, resides in the cloud, and is accessible to patients anytime, anywhere on multiple devices, such as computer terminals and cell phones has the potential to transform and improve the overall health and quality of life for its users.

2.2 *User centered design and Usability testing*

2.2.1 *User centered design*

User centered design is defined as the "design processes in which end-users influence how a design takes shape" (Abras et. Al, 2004). The principle puts the focus on the end-user, in order to ensure that resulting design of the system is

one that is intuitive, usable and ultimately results in an overall better user experience.

The concept originated in the 1980s, when Norman & Draper (1986) published research that brought attention to the need to recognize the interests of the user and put focus on the usability of a system's design.

User-centered design may incorporate a variety of ways in which the user is involved in the design process. The user may be involved either in the beginning, during the requirements gathering phase, or after developing a prototype, in the form of usability testing.

As technology has evolved over the years, so has the field of human-computer interaction, making it increasingly easier to use computers and technology. One of the main barriers to the adoption of consumer health tools, such as personal health records (PHRs) is the reluctance to use and operate computers among patients (Lui et al., 2011). The reasons for this are as varied as the variance in patient demographics. Depending upon the condition, patients may have special needs, preventing use of a conventional computer system.

Additionally, lack of computer literacy poses another challenge to the use and adoption of information technology, especially among the elderly. Elderly population are especially faced with increased access, cognitive (memory impairment) or physical barriers (visual, hearing impairments) while using a personal health record (Lober et al., 2006).

Keeping up with new advances in computer technology, newer systems are being developed to make it easier than ever to be able to operate a computer system. While several voice-based systems are already in use, more recently, interfaces using computer vision are being developed that allow a user to control the system using facial expressions and hand gestures (Murthy et al., 2011).

In the United States, only seven million adult users currently use PHRs (Lardinois, 2009). For a personal health record system to be successful, it is thus imperative that a universal design approach is adopted, to address the issues arising from patients with special needs (Tzeng & Zhou, 2013; Fuji et al., 2014).

Learning from and understanding these barriers, a tool was redesigned for patients belonging to the Veterans Health Administration health system (Saleem et al., 2011), to remind them for periodic colorectal cancer screening. Evaluating the human-computer interaction, and thus improving upon the usability and workflow of the tool as well as various design enhancements resulted in an improved tool with better usability.

Better design principles, such as employing simple interfaces with bright colors, larger icons as well as limit the use of text have shown to improve overall usability and patient experience of a PHR (Liu et al., 2011). Similarly, limiting the use of complex medical jargon also help patients with lower health literacy by making it easier to interpret their health information.

Cell phones today are a ubiquitous tool and have completely changed the way we perform various tasks in our everyday lives. Various providers and developers have come up with patient-centric applications that allow users to keep track of their health conditions, using a mobile device. This has the added benefit of making pertinent health information accessible for patients who are frequent global travelers. By having a standardized personal health record template available on their mobile devices, patients are able to quickly and easily share this information with health care providers in another country (Li et al., 2011).

Having basic health information at hand, such as demographics, medication, medical history, test reports, travel history and family medical history available on hand could result in saving lives, in the event of an emergency abroad. Thus, it has been demonstrated how better design principles and focus on user-centered design can greatly improve patient experience and provide a boost to the mass-adoption and continued of a personal health record.

However, the convenience of a mobile device brings with it its own set of issues, such as privacy due to loss or theft. Smaller devices, such as cell phones generally tend to easy targets to loss or theft. This can have major privacy implications, due to the sensitive nature of the data contained within one's personal health record. Additionally, solely relying on a single source of personal health information such as a cell phone, can be problematic in time of disruption of service or non-availability.

2.2.2 *Usability Testing*

The ultimate reason for adopting a user-centered approach is to produce a system that is easy to use by the end users. It is therefore important to ascertain whether the system meets its intended goal of a high usability.

There are several ways of testing a system for its usability, depending on the system environment, resources and stage of system development. Some of the established methods of usability testing include heuristic evaluation, cognitive walkthroughs and task analysis (Holzinger, 2005).

Heuristic evaluation typically involves a group of experts individually evaluating the system to determine whether it each functional element follows established usability principles (Nielsen, 1993). While it is one of the most common usability testing methods, since this process requires a number of domain experts, it is not always feasible and cost-efficient.

A cognitive walkthrough is a task-based method wherein an analyst attempts to simulate step-by-step user behavior in order to accomplish a set of tasks. After completing each task, the analyst assesses whether the system accommodates any end-user issues such as cognition, learning and their overall thought process (Lewis, C. & Wharton, C., 1997). While this process doesn't need an already developed prototype, the major disadvantage is non-involvement of the end-user.

Finally, another widely used method for usability testing is the task-analysis method. While a task is any of the various end-user's work activities

involving the system, its analysis pertains to the understanding the end-users intuitions and their attempts at performing the tasks (Tucker, 2004). The concept of task analysis was founded in the field of Scientific Management (Taylor, 1911), with the intent in improving worker efficiency. This method involved the classic stop-watch method, wherein a user would be timed based on the duration of completing each assigned task. Since then, this method has been adopted in system design, even in consumer oriented health applications (Farzanfar et al., 2004); (Kushniruk et al., 1997). Since this method directly involves the end-user participation, important insights into the real-world usability of a system can be ascertained using this technique.

2.3 *Patient reported outcomes (PRO) and Observations of Daily Living (ODLs)*

According to the US-FDA, patient reported outcome is the reporting of the status of a patient's health condition, such that it originates directly from the patient, without a clinician interpreting the patient's response ("US-FDA," 2006).

PROs can be a very vital and rich source of information about a disease or treatment received, however, due to various constraints, they cannot be easily measured in a clinical environment. Some examples of this kind of data is shown below in Table 2.3.1 (Chin, R & Lee, BY, 2008).

- Various symptoms
  - Symptoms not obvious to observers
    e.g. fatigue, headache
  - Psychological symptoms
    e.g. depression, anxiety
  - Symptoms in absence of observer
    e.g. sleep disturbances
- Frequency of symptoms
  e.g. Does the headache occur daily or weekly or monthly?
- Severity of symptoms
  e.g. Headache is severe or moderate or mild?
- Nature and severity of disability of the patient
  e.g. How severe is the breathlessness?
- The impact if disease or condition on daily life of the patient
  e.g. Does rheumatoid arthritis interferes with the activities of daily living of the patient? If yes, how much is the impact?
- Perception or feeling of the patient towards the disease or the treatment given
  e.g. Is the patient satisfied with the treatment given?

Table 2.1: Examples of data that can only be obtained from the patient

PROs are a significant source of information of the patients' overall health condition, especially in situations where just the survival is not the ultimate goal, rather, it is important to monitor the quality of life, such as in breast cancer patients (Singh, 2010).

During each patient encounter, a physician usually only gets a brief moment to quickly make observations, ask questions and gather information to make a pertinent recommendation or diagnosis. Unfortunately, the symptoms or observations expressed by the patient when not at the physician's office may largely go unnoticed. Documenting this new source of information, when integrated with the data residing in the electronic medical record can prove to be a powerful tool in evaluating and managing the patient's condition, as well as encouraging shared decision making (Brennan et al., 2010).

Observations of Daily Living (ODLs) are personally meaningful cues to an individual's health condition. They further complement the more familiar symptoms the patients may already monitor. ODLs can be very diverse, depending on an individual's condition, and can range from personal moods to stress, changes in physical activity or eating patterns and so on. Documenting and analyzing these ODLs can reveal certain patterns or changes in one's health, allowing for further insight and change in treatment plans (Backonja et al., 2012).

There is strong evidence that suggests that overall, diverse patient populations express a positive attitude towards using electronic based methods while collecting patient reported data (Ruland et al., 2003). Such systems have also been demonstrated to be feasible and an effective means of capturing patient reported information for cancer patients (Abernethy et al., 2010). In a study involving 66 breast cancer patients, it was found that electronic tablets were a valid and acceptable method for collecting patient-reported outcomes in outpatient academic oncology (Abernathy et al., 2008). Furthermore, studies have also shown that patient reported outcome measures can effectively identify the most bothersome quality of life issues for cancer patients (Snyder et al., 2011).

2.4 *Expert Systems and personal decision support*

Founded on artificial intelligence principles, expert systems are specialized systems that try to emulate the judgement skills of a human expert, such as a physician. These systems can be trained using logic and algorithms, to enable them to perform complex computational tasks.

Expert systems attempt to replicate human reasoning, rather than computational problem solving, when solving problems in a specific domain (Mehdi, 1993). Supported by an underlying information system, expert systems may be applied towards various management tasks, such as strategic planning, management control or operation control (Anthony, 1965).

The increasing adoption of expert systems is bound to have an impact on the way we do several things. Substitution of face-to-face interaction by man-machine interaction has made it possible for people to perform medical or tax consultations from the comfort of their homes (Schefe, 1990).

Recently, expert systems are increasingly being used in order to promote patient self-testing and self-management. Patient self-testing and self-management has proven to be an effective means to improve conditions, such as thromboembolic events and has been shown to have a positive effect on patient outcomes, such as lower mortality and serious bleeding events, according to a

meta-analysis of various self-testing and management controlled trials (Bloomfield et al., 2011).

Atrial fibrillation patients being treated with warfarin are able to use portable devices that continually monitor the anti-coagulation effect of the medication (Nutescu et al., 2011). These portable devices use expert systems to determine the level of effect of the medication and provide personal decision support, thus saving the patient from continually visiting their physician for n-person testing, which may turn out to be not only inconvenient and time consuming, but also more expensive. Using intelligent devices such as these further empower the patient by allowing them to monitor their health more independently, from the comfort of their own home. This also offers the advantage of more frequent testing, wherein the patient can simply enter data, such as international normalized ratio (INR), which is a measure for anticoagulation effect, into a web-based system and the expert system displays and provides further dose and testing instructions (Ryan et al., 2008).

Another proven application of expert systems is in the management of asthma symptoms among patients. Asthmatic patients may especially benefit from continually monitoring their body condition, in relation to the current environment, which may trigger an attack. A rule-based expert system, developed using data gathered from interviewing physicians and from online

medical resources has been shown to assist asthmatic patients to better self-manage their condition, leading to a healthier lifestyle (Nee et al., 2010).

Several other chronic conditions, such as arthritis, hypertension and type 2 diabetes have also been shown to benefit from patient self-management, especially due to the easier availability of self-testing options at home (Bodenheimer et al., 2002).

A mobile health product developed by AT&T called Diabetes Manager allows patients to get real-time education, alerts, reminders and supports to manage blood glucose levels at home, based on processing home-test results using expert systems ("AT&T," 2012). An ideal solution such as this is one that promotes patient empowerment and independence, while also engaging caregivers and health care providers, when needed for added support.

This paves the way for expanding the use of expert systems in continually monitoring and processing data, as it is entered into the personal health record system and providing adequate feedback to the patient. Expert systems still being an emerging technology, especially in the field of medicine, is mired in its own set of problems. The knowledge is brittle and they are not able to handle correctly the scope of rules, while also not being able to learn and adapt to new knowledge. Additionally, while they may appear to work, any problems or inaccuracies in their working is not easily or quickly identifiable.

Chapter 3: Prototype design and development

This chapter describes the design and development process of the prototype as well as its core features and functions.

3.1 *Specific aims*

The prototype is aimed to make the traditional breast cancer survivorship plan more intelligent, comprehensive, interactive and portable, as compared to a traditional paper-based breast cancer survivorship care plan.

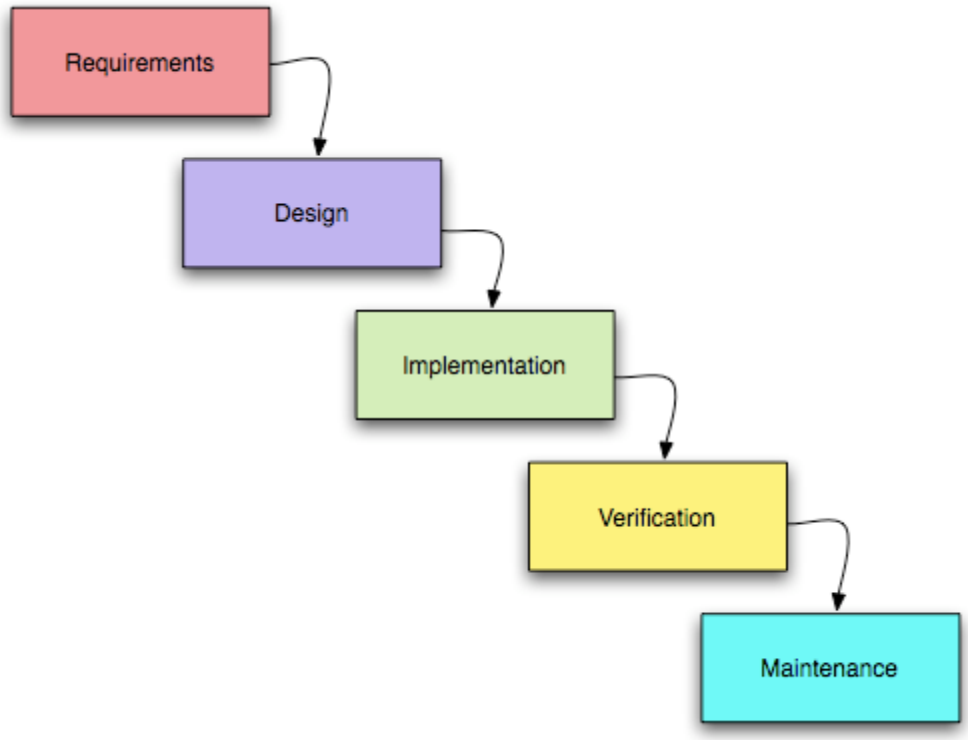

Figure 3.1: Traditional Waterfall Development Methodology (Royce, 1970)

Requirements for developing the system were gathered using a combination of surveying current literature to identify needs of breast cancer survivors as well as consultation with a breast cancer nurse. An iterative version of the development model, the waterfall model (Royce, W., 1970) was employed in the development process (Figure 3.1).

With iterative development methods increasingly becoming the standard in application development, the iterative waterfall model allows the design and implementation of efficient systems within the healthcare industry (Kushurik, 2002). Iterative evaluation methods further have been recognized to meet the designer's, users' as well as organization's expectations (Kushurik, 2002; McConnell, 1996).

3.2 *System architecture*

ACESO is implemented as a web based application, supported by Apache Web Server for web hosting, PHP for server side scripting and a MySQL Server database engine.

ACESO is designed to be a web application, so that it may be accessed independent of operating system platform (Linux, Windows, OSX), from any device (web-enabled smartphone, tablet, laptop or desktop) and a variety of web browsers (Firefox, Internet Explorer, Safari, Chrome). The web-based implementation of ACESO ensures it is available to all users who have a web-

enabled device, without the need for installation of any additional software.

Figure 3.2 shows the system architecture of ACESO.

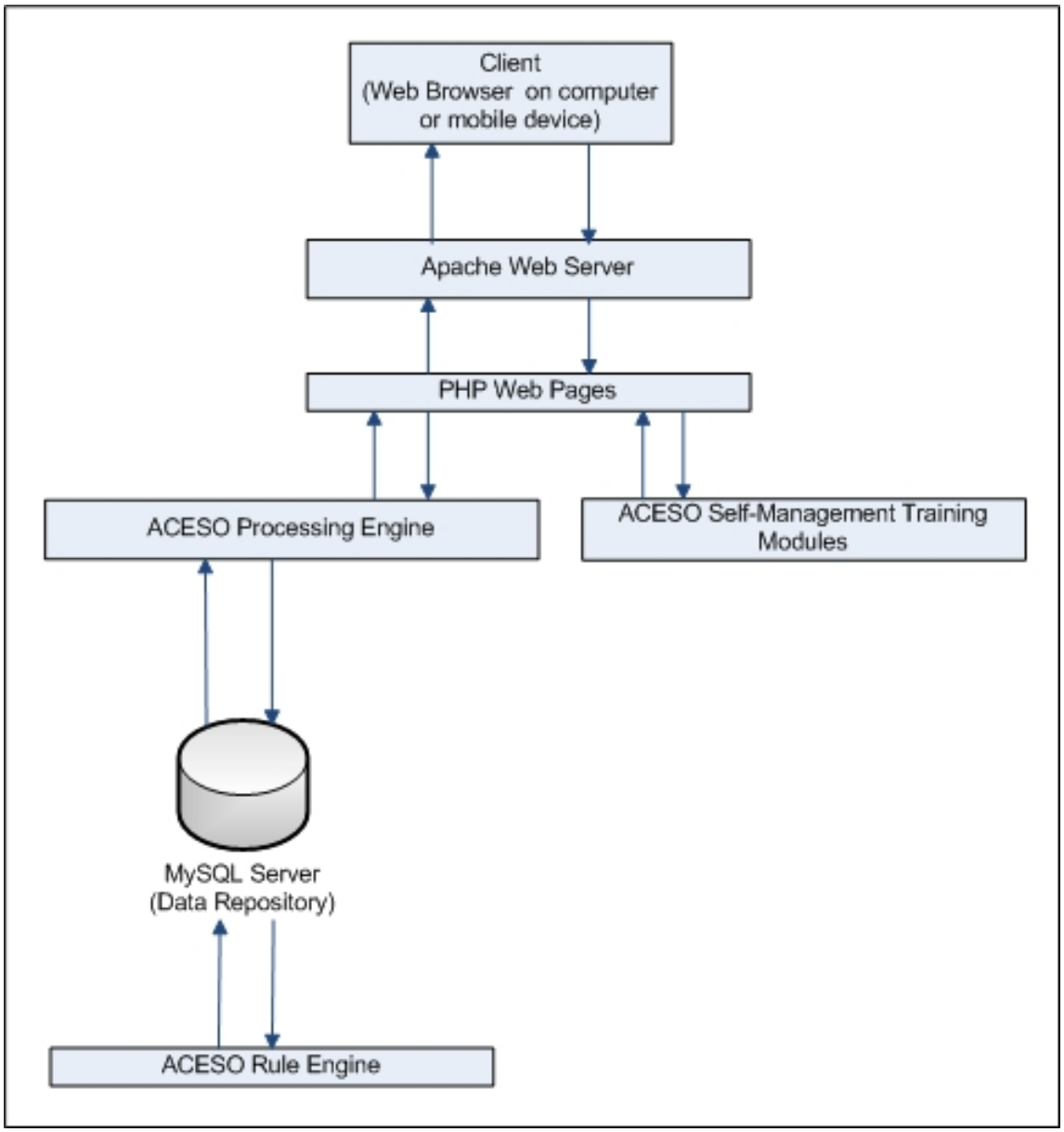

Figure 3.2: ACESO system architecture

The data repository utilizes MySQL Server at the backend. Both the raw data, as well as processed information will be stored in a database on the MySQL Server.

The ACESO rule engine actively analyzes the raw data in the data repository and processes it to usable, actionable information. The ACESO processing engine then pushes this information to the patient. The Apache Web Server will be used to present this information, to the client, via a web browser.

3.3 *Process Flow*

A typical user interaction with ACESO is described here. The user enters his/her login information and can view various elements of their personal cancer survivorship care plan as well as any relevant and upcoming alerts and reminders. This interaction is further described in Figure 3.3.

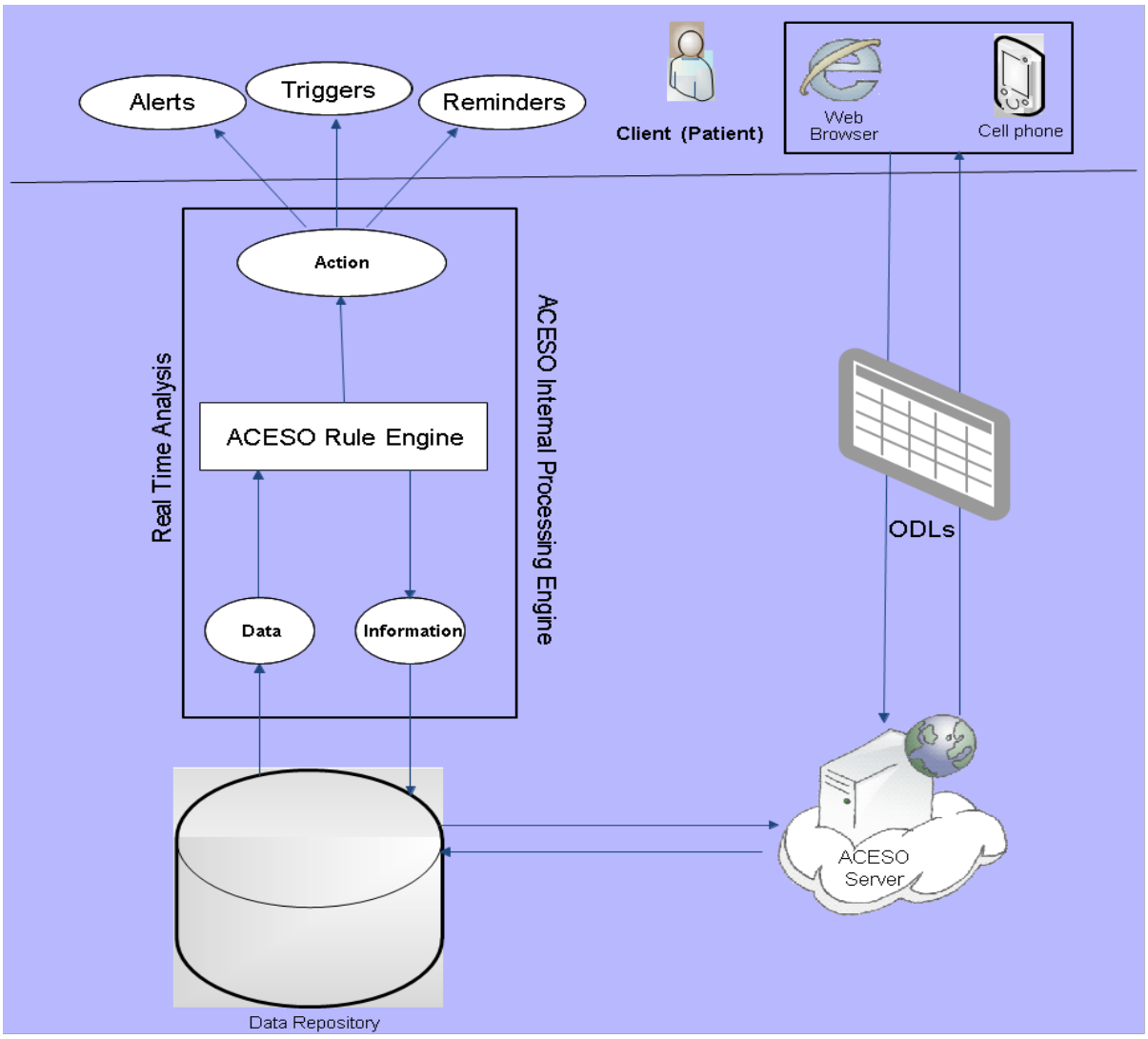

Figure 3.3: ACESO Process Flow

When the user logs in to ACESO, the user is presented with a view of their breast cancer related medical history, as well as any upcoming reminders for recording home observation, or upcoming follow-up visits, that they need to be aware of. If the user does not log in frequently, these reminders will still be pushed to the user in the form of an email, or reminder on their smartphone, depending on their alert preference. Being a web based system, it is technology

independent, however, installable cellphone applications could potentially be developed as well, in an effort to make it even easier to use.

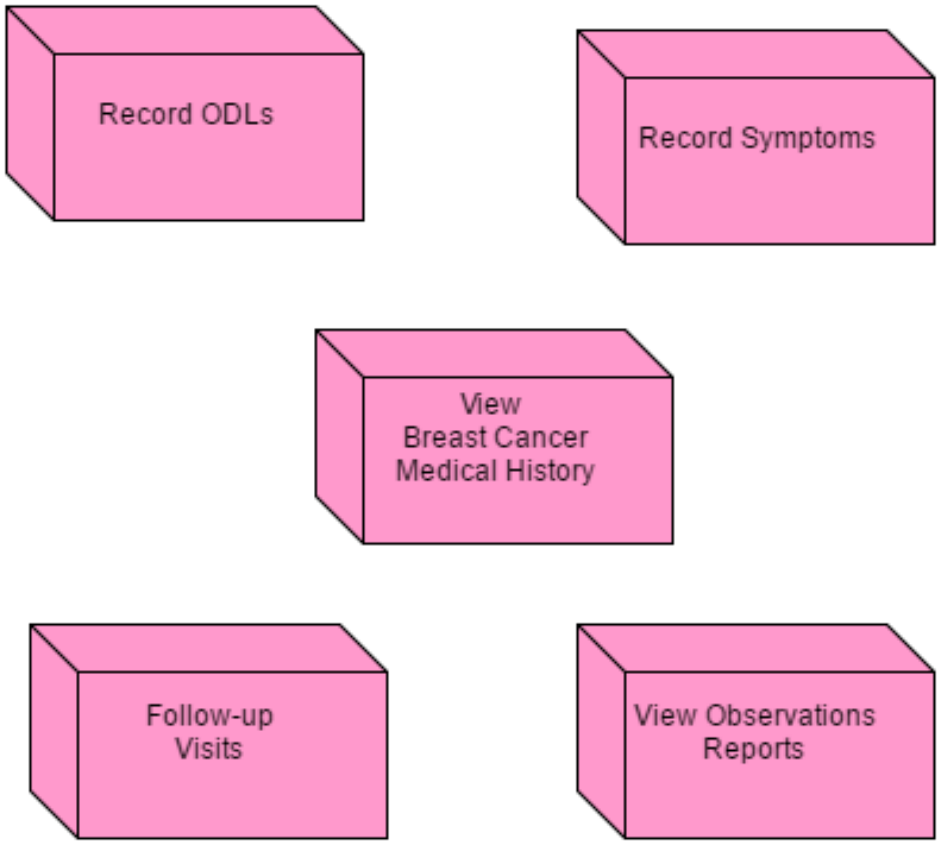

Figure 3.4: Various user functions of ACESO

Another important function of ACESO is the collection of patient reported observations of daily living (ODLs) that allows patients to record everyday activities, observations and occurrences, resulting in a chronological log of their self-reported health history. This may be useful to not only detect any health patterns, or significant changes in the state of health, but this information will also

be used to create timely alerts for patients, bringing to their attention the detection of any significant health patterns. Past recorded observations are presented to patients in the form of graphical reports to get a historical view of that particular observation. Patients may print and share these reports with their provider during their next follow-up visit. Identifying the presence or absence of any improvement in the observed symptoms, could also allow the physicians to modify treatment plans, leading to more effective treatment therapies.

3.4 *Data Model*

The back end of ACESO is supported by a MySQL database engine, which manages the database that hosts the raw data, as well as any derived information. The database design of ACESO follows a relational database model.

The relational database is used to store the primary, raw patient data as well as derived and processed information. Additionally, it also contains patient ODLs, their breast cancer related medical history, follow up visits, recorded symptoms as well as a knowledgebase of rules to interpret the raw data.

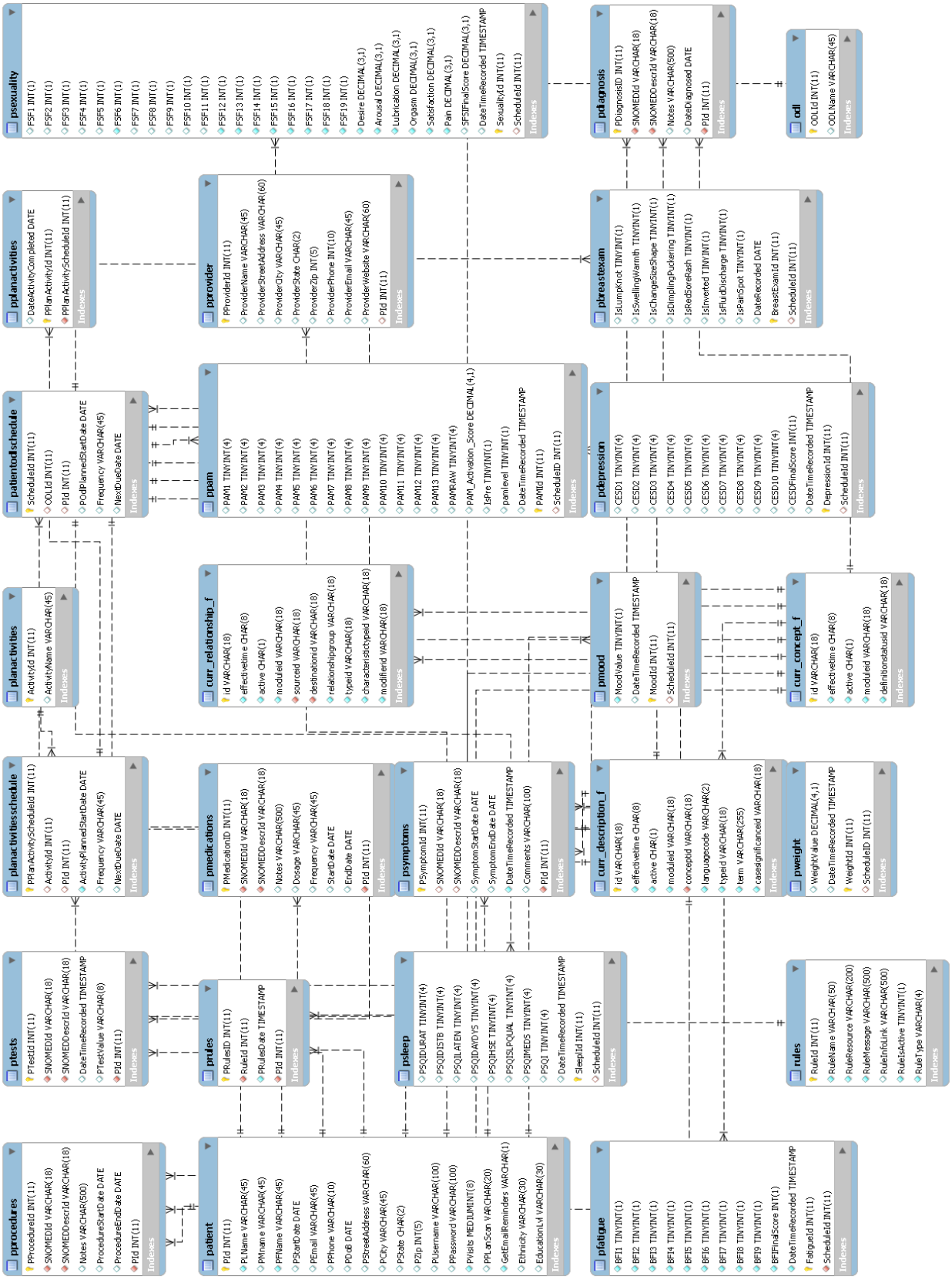

Figure 3.5: ACESO database physical model

3.5 *Data Sources*

A variety of data sources are utilized by ACESO, these include private, government, regulatory bodies or non-profit organizations.

As depicted below in Figure 3.6, patient data is sourced from breast cancer survivorship plans of breast cancer survivors. Upon completion of treatment (chemotherapy and/or radiation), each patient is provided this survivorship care plan document by their provider. The user enters information from this document into the system the first time that they set up their account. This data represents the raw data in the data repository, allowing the creation of personalized, custom action items (triggers, alerts, reminders) for each user patient.

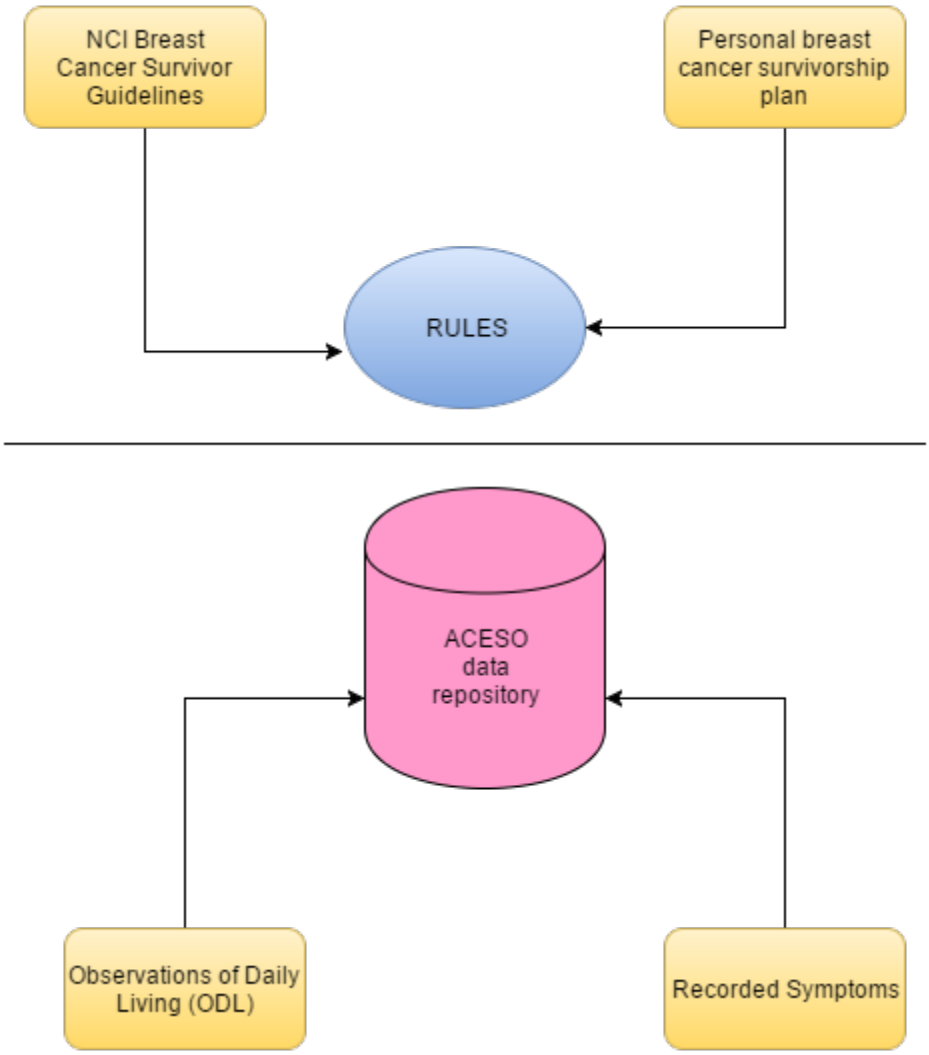

Figure 3.6: Data Sources of ACESO

Another vital source of data is the patient generated and originates from the users themselves. Patients may routinely enter data based on their observations at home, pertaining to their health and well-being. These observations of daily living (ODLs) are used to detect any changes in the health patterns of the patient in between physician visits. ODLs may collect

data on a variety of areas, such as fatigue, mood, sleep quality, etc. in addition to specific symptoms recorded by the patient.

There are various types of symptoms or observations a breast cancer survivor may expect to experience after discharge from hospital. There is a very broad range and scope of ODLs that encompass various quality of life determinants, which may range from sleep quality and fatigue to pain and adverse reactions (to procedures and/or medications). Some of the most common symptoms experienced by breast cancer survivors are shown below.

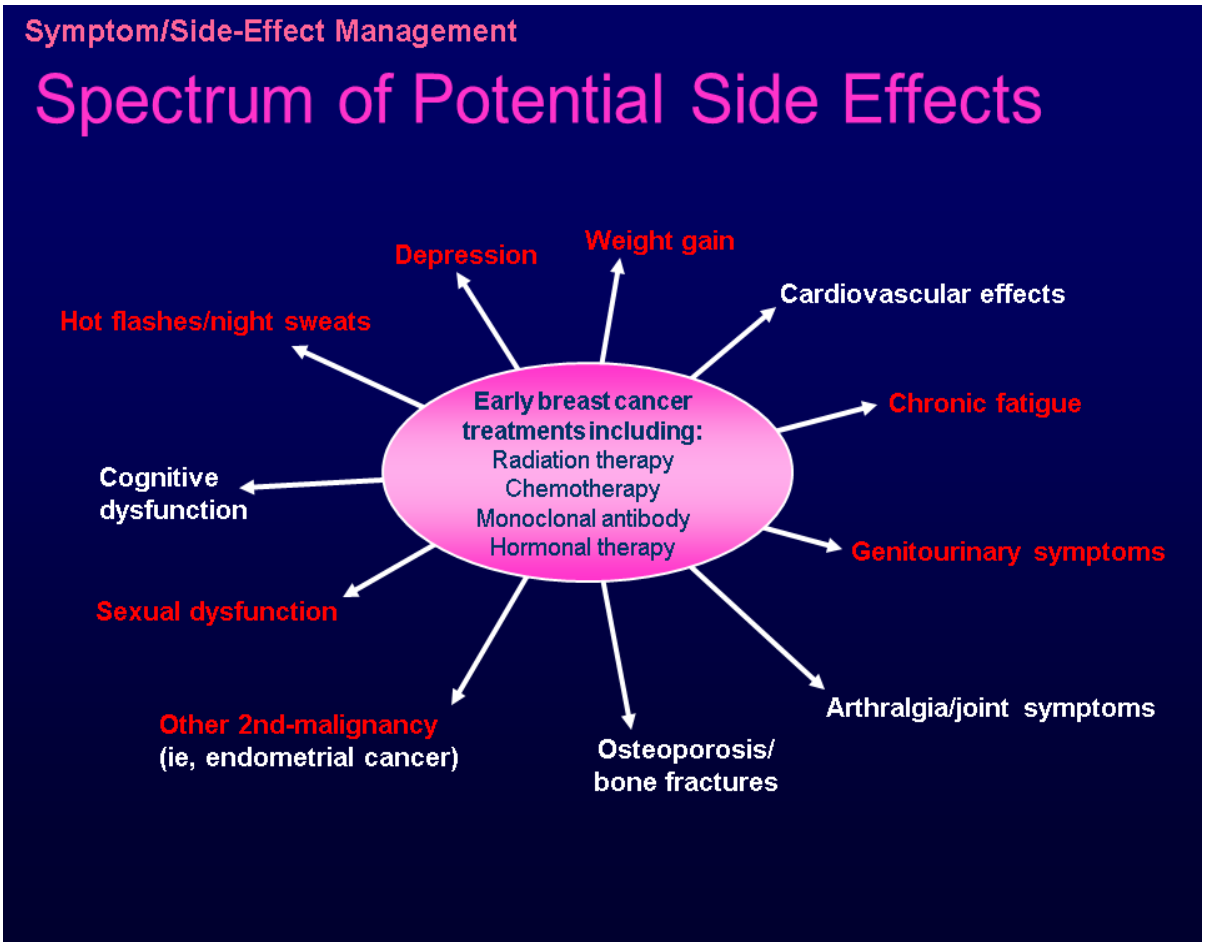

Figure 3.7: Spectrum of potential side effects experienced by breast cancer survivors (Hayes, 2007)

One of the most common side effects of cancer treatment that is symptom experienced by most breast cancer survivors is fatigue. Roughly as many as 70% of cancer patients receiving radiation therapy and chemotherapy experience fatigue. The rigorous courses of various medical procedures and strong medications have a debilitating effect on one's body, making it more prone to fatigue (Smets et al., 1993). In a study comprising 1957 breast cancer survivors, it was observed that while the rate of occurrence of fatigue among breast cancer survivors and similar aged women is quite similar, the cancer survivors experience a more severe level of fatigue, which is associated with higher levels of pain, depression and insomnia (Bower et al., 2000). The Brief Fatigue Inventory (BFI) was utilized to report fatigue from patients. This scale has been found to be an internally stable instrument, being easy to complete among cancer patients (Mendoza et al., 2000).

Depression is another common symptoms experienced by breast cancer survivors. Unfortunately, it is often goes unrecognized and thus untreated which further worsen their overall condition (Fann et al., 2008). Women undergoing invasive procedures such as mastectomy, lumpectomy and radiation therapy express high levels of depression as a result of dissatisfaction with body image (Lasry et al., 1987). Other side effects of treatment, such as hair loss from chemotherapy, weight gain, sexual functioning often result in a low self-esteem, leading to depression among breast cancer patients (Fobair et al., 2006). The CES-D scale is a commonly used short, self-report scale designed to measure

depressive symptomatology in the general population. It has been tested in various household surveys with high internal consistency, reliability and validity (Radloff, 1977). In order to reduce patient burden and lower refusal rate, a shorter form of the CES-D scale will be used in the study (Kohout et al., 1993).

Evidence suggests that an alarming 73% of breast cancer survivors experience poor sleep quality and sleep disturbance. Sleep duration is also found to be short among this group of patients (Carpenter et al., 2007). In a study comprising 300 breast cancer patients, it was found that 58% of the participants reported that cancer either caused or further aggravated their sleep issues and that insomnia complaints are more common among this group of patients in comparison to the general population (Savard et al., 2001). The study will make use of the Pittsburgh Sleep Quality Index (PSQI) to record patient observations regarding the quality of their sleep (Reynolds et al., 1989). It is a monthly self-administered questionnaire comprising nineteen individual items that score subjective sleep quality, sleep latency, sleep duration, sleep disturbances and several other parameters. Evidence supports the use of PSQI among cancer patients and its psychometric evaluation among this population has found it to be internally consistent, reliable and valid in two studies including a diverse set of cancer patients (Beck et al., 2004).

Another unfortunate side-effect to various cancer treatments and medications is that of weight gain. Women report that it is easier for them to gain weight and harder to lose weight in comparison to before diagnosis. In addition,

women also often experience changes in body composition and a difference in how their body distributes the additional weight (Capiello et al., 2007). Most importantly, the group of women who experienced weight gain mentioned they were not prepared for this possibility and would have preferred to have received more information and guidelines in advance regarding what they could do to minimize or prevent this from happening. For the purposes of this study, the patients will be expected to record self-reported weight measurements once, weekly.

In another research study involving 863 breast cancer survivors (Meyerowitz et al., 1999), one-third of the respondents reported a negative impact in their sex life. Most of these women experienced changes in hormonal status, relationship problems and vaginal dryness among other problems, all of which negatively impacted their sexual health. It has also been found that breast cancer survivors experience more frequent physical and menopausal symptoms than healthy women and sexual dysfunction was more common among women who had received chemotherapy (Ganz et al., 1998). The Watts Sexual Functioning Questionnaire (WSFQ) is a seventeen-item survey that evaluates the primary components of sexual function (Watts, R. J, 1982), will be utilized. The WSFQ has previously been used in studies to identify predictors of sexual health among two different samples representing 1134 breast cancer survivors (Ganz et al., 1999). A list of all ODLs that can be tracked via ACESO are shown in Table 3.1:

ODL Type	Capture Method	Frequency
Treatment After-Effects*	Multiple choice, check-boxes	As needed
Mood	Clickable Emoticons to describe mood	3x/ week
Fatigue	Brief Fatigue Inventory	1x / week
Weight	Self-reported	1x / week
Mental Health	CES-D Scale (short form)	1x / week
Sexual Function	Watts Sexual Function Questionnaire (WSFQ, Female version)	1x / week
Sleep	Pittsburgh Sleep Quality Index (PSQI)	1x / month

Table 3.1: List of some of the ODLs that will be collected via patient self-reporting. List of observed symptoms in Table 3.2.

Domain	Symptoms
Pain (intensity, location)	Abdominal pain, bone pain, chest pain

Lymphedema (Arm or Leg)	Arm/Leg swelling, heaviness, tightness, restricted motion, discomfort, hardening/thickening of skin
Respiratory	Shortness of breath or difficulty breathing
Menopausal	Hot flashes, botheration, night sweats/flashes
Sexual wellness	Decrease in libido, vaginal dryness
Cancer recurrence	swelling, lump(s) or pain in breast

Table 3.2: List of some after-effect symptoms a breast cancer survivor may expect to observe.

As with the nature of the course of treatment for breast cancer survivors, patients are required to periodically visit both an oncologist (to check for recurrence and monitor patient recovery) as well as a PCP (for general health issues and/or comorbidities). As a result, the patent health records are scattered across multiple health care providers, posing a challenge for the patient to maintain and view a comprehensive personal health record. Having a comprehensive patient record will also allow for the application of more accurate, individualized rules that take into account all aspects of the patient's health condition.

3.6 *Personal decision support*

The ACESO rule engine is based on a set of pre-compiled rules. The Breast Cancer Survivorship Care Plan recommendations, outlined by the National Cancer Institute (NCI, 2008) were used as the underlying knowledge and basis of these rules. The NCI plan is a comprehensive guideline of various follow-up care tests, recommendations, late effects and their corresponding interventions. The NCI plan is based on the guidelines issued by the American Society of Clinical Oncology (ASCO, 2006). Apart from these guidelines, the personalized survivor care plan given to each patient at discharge by their provider is used to create customized rules for them.

Each rule is constructed on the basis of three components: condition (various treatment related side-effects), context (breast cancer related medical history) and action (generation of an alert message or reminder).

Each of these three components are described by a variety of medical terms, such as symptoms, clinical findings, diagnoses, clinical tests, human anatomy and medical procedures. Since each provider may use a different terminology to describe the same medical concept, it poses a challenge to have the prototype function across a diverse set of breast cancer survivorship care plans.

In order to make the prototype semantically interoperable across various breast cancer survivorship plans from different providers, we adopted to use a standard medical terminology, called the Systemized Nomenclature of Medicine

– Clinical Terms (SNOMED-CT) (Wang et al., 2002). Originally released in 2002, the SNOMED-CT vocabulary today contains almost 350,000 clinical terms that provides comprehensive coverage on scientific medical corpora. The terminology has been scientifically validated, mapped to international standards and is currently in use in over 50 countries (ITHSDO, 2016). Semantically, since various terms may be used to describe the same concept, SNOMED-CT contains a primary set of unique concepts, denoted by a concept unique identifier (CUI), which are then mapped to other alternative or synonym terms. SNOMED-CT utilizes a hierarchical structure, wherein, various terms, or nodes may be connected to each other via an “is-a” relationship between the parent and child node (IHTSDO, 2016).

The 2014 Release 2 file of the U.S version of SNOMED-CT was used to implement the prototype. Incorporating the SNOMED-CT standard made it possible to enter information from a diverse set of breast cancer survivorship care plans (Figure 3.7), thus making the data more structured and machine interpretable, which further paved the way for implementation of the knowledgebase for personal decision support. A set-of pre-defined rules, built around SNOMED-CT concepts, were constructed based on the NCI standard survivorship plan.

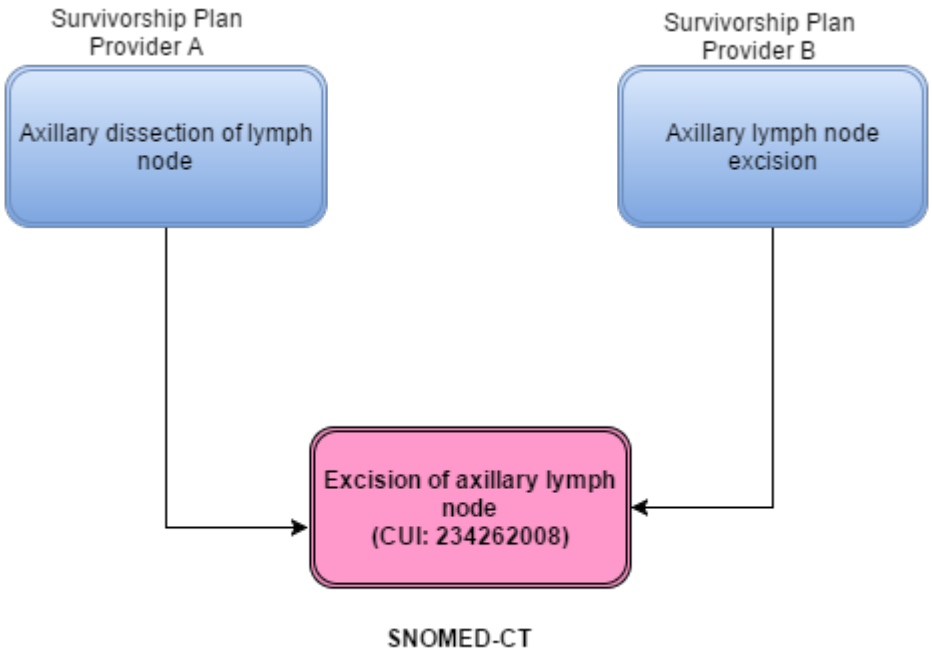

Figure 3.8: Mapping of two synonyms to a unique concept identifier in SNOMED-CT

As a result of interoperability challenges, while decision support is still in its novel stages among consumer applications, it has been used widely in robust, modern electronic medical record systems. SNOMED-CT has been utilized to successfully implement clinical decision support systems in modern electronic medical record applications (Maheronnaghsh, Nezareh, Sayyah, & Rahimi-Movaghar, 2013; Ciolko et al., 2010; Greibe, 2013; Mantena & Schadow, 2007; Cornet et al., 2015).

An advantage of using a set of pre-defined rules in this context is that they are relatively easy to modify and maintain to keep up with changes in guidelines. For instance, a rule has been compiled to help detect and warn patient about arm

lymphedema (Figure 3.8). Based on the information in the data repository derived from the patient's breast cancer survivorship care plan, the system will first check and verify if the patient is experiencing any symptoms of arm lymphedema, based on data collected via ODLs. The system will then check the patient received axillary dissection, and/or radiation treatments, which are known to be associated with arm lymphedema. In this manner, the system will help detect and monitor important observations and alert the patient in a timely manner, often preemptively, thus allowing them to take quick action as well as informing and educating them about what they are experiencing. The bringing together of data from personalized breast cancer survivorship care plan as well as the patient reported ODLs further enhances the early detection process.

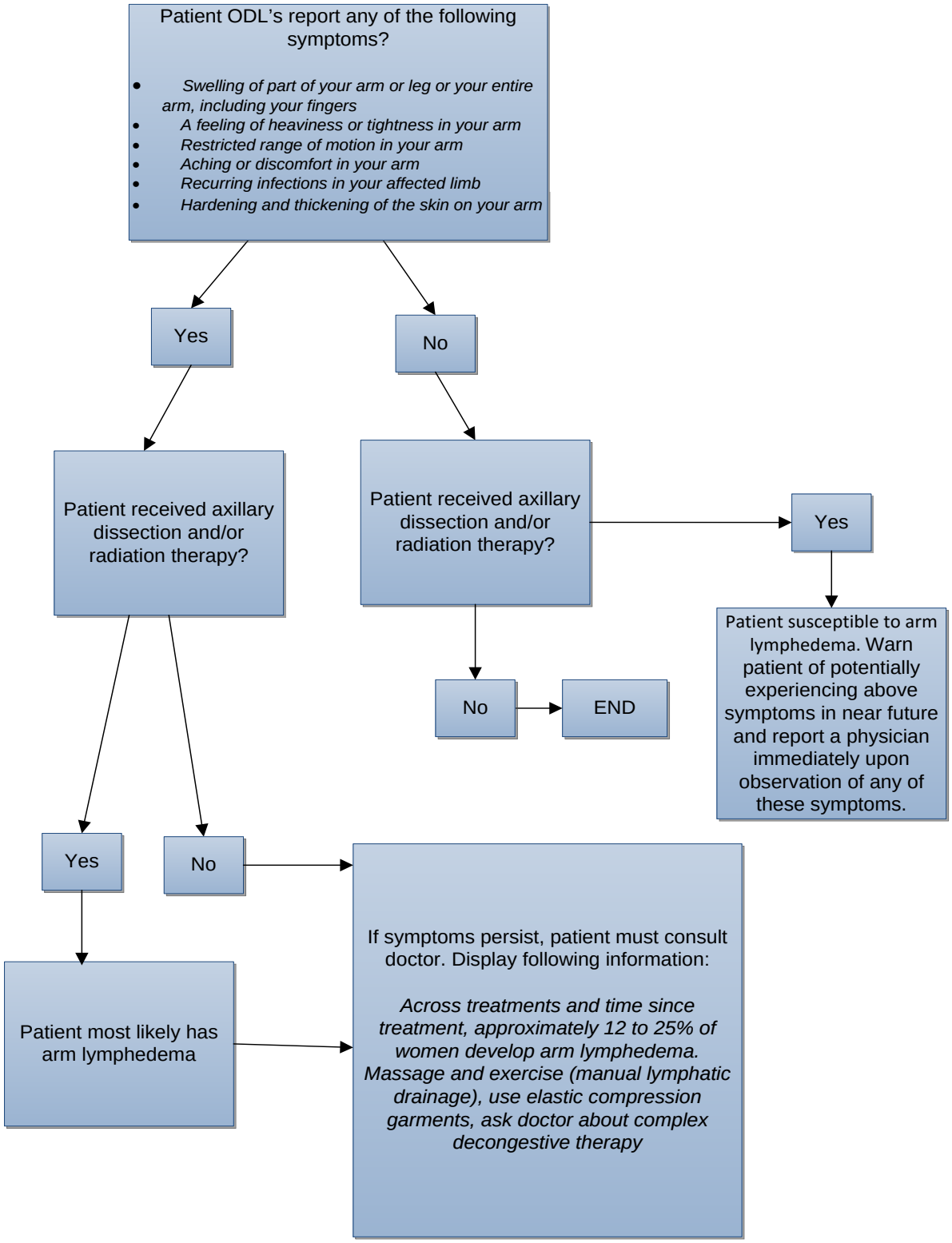

Figure 3.9: Decision tree for a rule to check for arm lymphedema

Chapter 4: Research Question and Conceptual Framework

One of the most important steps after prototype development is testing it with real users. As mentioned in previous chapters it is important to understand the perception of the application from the point of view of the end users. The primary outcome of interest is the acceptance, or adoption of ACESO among breast cancer survivors. Ultimately, the adoption of ACESO among breast cancer survivors for its intended use (self-management of treatment-related symptoms) will determine the success of the tool.

Davis et al. (1989) proposed a framework, for user acceptance of technology, called the Technology Acceptance Model (TAM), which indicates that

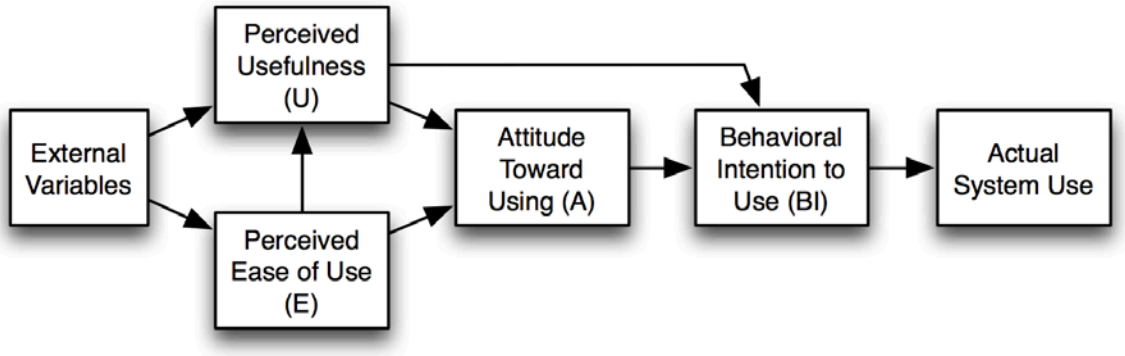

Figure 4.1: The Technology Acceptance Model (Davis, 1989).

actual system adoption is influenced by two primary predictors: perceived usefulness and perceived ease of use (usability).

Therefore, in order to evaluate the acceptability of ACESO, it is important to understand the perceptions of breast cancer survivors regarding both: the perceived usefulness as well as the usability of ACESO. The Technology Acceptance Model has been widely used to conduct usability and acceptance evaluation of several consumer health applications (Ozok et al., 2013; Osch et al., 2015).

User acceptance may be defined as “the demonstrable willingness within a user group to employ information technology for the tasks it is designed to support” (Dillon, 1996). Before the system is released and made available to a large audience of end-users, it is thus imperative to assess the attitude and willingness of the potential users to adopt and utilize the application. A system might have been shown to have a high usability via formal testing, however there is still no guarantee that the end-user will accept and adopt it.

Hence, the following research questions will be investigated: Q1: What is the perceived usefulness of an electronic self-management tool among breast cancer survivors?, Q2: How usable is the current prototype among lay users?, and Q3: How acceptable is the current prototype of ACESO among breast cancer survivors?

A combination of qualitative methodology using thematic analysis of semi-structured interviews, as well as quantitative usability measures will be employed to evaluate the prototype for its acceptability and usability. Thematic analysis may be described as a method that seeks to “uncover patterns of meaning in

respondent accounts of experience" (McLeod, 2001). Thematic analysis has widely been used to evaluate health applications in conjunction with other usability techniques (task analysis or cognitive walk-throughs). Mirkovic et al. (2014) employed a combination of thematic analysis of semi-structured interviews in combination with task analysis among a group of seven cancer patients to perform usability evaluation of a mobile app to support illness management in cancer patients. Similarly, Kim et al (2016) evaluated the usability of a mobile app for radiologists' decision making by employing a triangular method involving thematic analysis, task analysis and a system usability scale among a group of six radiologists. Osch et al., (2015) also used a combination of semi-structured interviews as well as task analysis, followed up with a survey to assess user preferences and usability of a smartphone app for home-based health monitoring. Several studies have adopted this methodology, combining qualitative methods, in addition to task analysis and follow-up survey questionnaires, in determining system acceptability in the domain of consumer health applications (Payne et al., 2015; Mirkovic et al., 2014; Hong et al., 2014; Joshi et al., 2013; Kim et al., 2016, Osch et al., 2015).

This research design is based on a similar approach in evaluating the prototype by combining task analysis, thematic analysis of personal interviews, as well as the Online User Experience Survey.

4.1 Perceived Usefulness

Perceived usefulness is the extent to which a breast cancer survivor believes that using the system would enhance self-management of their treatment related symptoms. As Davis (1989) defines it, perceived usefulness is "the degree to which a person believes that using a particular system would enhance his or her job performance". In the context of this study, the job pertains to the self-management of treatment related side effects.

Semi-structured interviews with open-ended questions will be employed, in order to assess perception of the respondents regarding the usefulness of ACESO. Talking points, or open-ended questions for the interviews were derived from the conceptual framework described in the Technology Acceptance Model (described in the previous section). Users were asked questions, such as: "Do you think having an app would help/have helped you navigate life after breast cancer any better?" and "Do you think more personalized tools (such as apps) to aid breast cancer survivors would be useful? Would you use such an app? Why?". User responses to these questions will highlight the perceived usefulness of new technologies and applications to support breast cancer survivors after treatment. In addition, to determine ACESO's general acceptability, respondents were also asked questions to determine their intent in adopting ACESO for use in their daily lives: "How willing would you be to use this app, if it were made available to you for free? Please

explain with reasons". The complete set of talking points used in the semi-structured interview are listed in Appendix C.

4.2 System usability

Davis (1989) defined usability as "the degree to which a person believes that using a particular system would be free from effort". A good, well designed and intuitive user interface will play a large role in improving the system's usability. The system's acceptability is concerned with the intent or willingness of the user to adopt the system for its intended purpose, which is influenced by the previous two factors (usefulness and usability).

Developing a high quality application, which is user-centric will maximize patient engagement and adoption of the tool. Thus, in order to ensure that the prototype is user-friendly, it is important to perform usability testing.

Usability studies have been conducted on various online self-management applications, in order to further refine the prototype. Payne et al. (2015) conducted a usability study on an e-counseling platform for patients with chronic heart failure. Mirkovic et al (2014) assessed the usability of a mobile app for cancer patients that supports illness management. Hong et al. (2014) tested the usability of a web application to promote physical activity among older adults. The above studies indicate that end-users can help identify current issues with the prototype in terms of its design and functionalities, which the application developer may have overlooked. The results of usability testing can help inform

the improvement of the current prototype and maximize its usability, before it is made available to larger groups of end users.

Usability studies usually adopt a multi-faceted approach, often involving a combination of two or more methods, which include personal interviews, task analysis as well as quantitative measures, such as user experience surveys (Payne et al., 2015; Mirkovic et al., 2014; Hong et al., 2014; Joshi et al., 2013; Kim et al., 2016; Osch et al., 2015). In this study, a similar approach was adopted in assessing the usability of the prototype, using a combination of personal interviews, task analysis as well as online user experience survey (includes usability dimension). The next section, outlines how the usability of the prototype will be measured and assessed.

First, the prototype will be assessed on its usability by using task analysis. A task pertains to any of the intended activities performed using the prototype, its analysis pertains to understanding end-user intuitions and their attempts to performing the tasks (Tucker, 2004). Task analysis has been used in the past to identify usability issues in various consumer health applications (Farzanfar et al., 2004; Kushniruk et al., 1997; Payne et al., 2015; Mirkovic et al., 2014; Hong et al., 2014; Joshi et al., 2013; Kim et al., 2016). Task analysis helps to assess how user-friendly the prototype is and how intuitive is the user-design. Having the end-user independently perform tasks on the prototype can pinpoint various issues in the user-interface of the prototype as well as identify any existing system errors. Task analysis includes observation of the end-user while they

complete a set of pre-assigned tasks. The task-administrator observes and makes notes based on the observations, pertaining to how the user interacts with the system interface and any issues or errors encountered by the user. In addition, it can also assess the prototype on the basis of various metrics, such as time taken to complete the task, number of errors made by the user while completing each task, and number of times the user sought help to complete the task. Several usability studies adopting the task-analysis method also measure the time taken for each user to complete each task. This measure is more suitable for business environments where efficiency is very important. However, in the case of personal health applications, such as ACESO, which is intended for home use, as needed, not much may be gleaned from this metric. Additionally, it was possible that openly timing the participants would create a sense of anxiety or hurriedness while performing the tasks and may make their interaction with the application more impetuous. Therefore, since user efficiency and speed is not paramount in the context of this application and rather, accuracy and ease-of-use is important, in this study, the time taken to complete the task is not measured. Hence, for task analysis, the measurements were (1) Observation notes on user interaction with the system interface, (2) The number of errors per task, and (3) The number of times the user sought help for each task?. A list of tasks was created (see Appendix C), based on purposive sampling, in order to capture all the activities a user may perform while accessing various functions of the system.

While task analysis would reveal the real life usability of ACESO, perceived usability of ACESO can be gleaned from personal interviews. This produces a firsthand account of the user's perception of the system, based on its usability. While the task analysis can pinpoint specific issues with the system interface, individual interviews allow the developer to gather user-input and suggestions on how the interface can be made user-friendly, which cannot be gathered using task-analysis alone. It also reflects the general perceived usability of the system, as indicated by the end-users.

Travers (2001) indicated that much can be learned from even a small number of respondents if open-ended questions are used in the interview process. This encourages generation of more and richer data, which, in turn helps in the generation of more codes, categories and concepts. Moreover, it has been suggested (Rubin, 1994) as best practice that usability studies include a minimum of 10 participants and that usability studies discover 80 percent of usability issues with as few as four to six participants.

Open ended questions for the interview were derived from the conceptual framework outlined in the Technology Acceptance Model. The respondents will be asked questions, such as "Can you describe how easy or difficult it was for you to use the app?". This will allow the respondents to answer in their own words, their perceived ease-of-use of the prototype. Other questions, such as "What are your thoughts on the visual appearance of the app?", and "What suggestions would you have to improve the app?" will allow the gathering of

user-input and feedback, based on their experience of the prototype. A complete list of talking points used for the usability interview are listed in Appendix C.

4.3 User Experience

Online user experience can be categorized into four dimensions, which are pragmatic, hedonic, usability and sociability (Nambisan 2010; Nambisan et al. 2010; Nambisan 2011; Nambisan et al. 2011). These dimensions are derived from knowledge in human psychology, communication science, consumer psychology, consumer behavior in online environments, human-computer interaction (HCI) as well as interaction and sociability and usability research.

a) Pragmatic experience encapsulates the practical or utilitarian view of users of an online experience. This measure is crucial when evaluating the user experience of ACESO, since the pragmatic experience often supersedes other experiences, since motivated users who perceives utility in the web application will continue to persevere and use it, even while other experience measures remain low.

b) Hedonic experience, based on research in human psychology, captures users' emotional feelings that result from interacting with an external environment (Nambisan, 2011). Hedonic experience is a pleasant and fun experience which influences the user's emotional state (Nambisan, 2011).

While breast cancer survivors have endured a rather unpleasant experience during the course of their treatment, ACESO will strive to make their experience such that it invokes positive, happy feelings even in the context of being reminded of their breast cancer. This will be a major challenge, and a huge achievement, if ACESO is successful in creating a hedonic experience among users.

c) Usability experience refers to the ease of use of the internet application. A user-friendly interface will result in a better usability experience. This measure draws on research in the field of human-computer interaction that lays a framework for how computer applications should be designed in order to make them easy to use.

d) Sociability experience refers to the socially engaging aspect of a web application. In order to achieve a high sociability experience, it is not imperative to include social networking or discussion forums on the website. An interactive interface that communicates with the user and engages them can be another means of offering the user a good sociability experience online.

The four user experience dimensions described above have been applied to assess user experience in a variety of web applications, irrespective of their context, such as online communities or web environment, consumable goods,

online classroom or in the context of health (Nambisan 2010; Nambisan et al 2010; Nambisan 2011; Nambisan et al 2011).

Nambisan (2010) indicates that the four dimensions may vary for a user within the same context. For instance, the pragmatic experience for a user may be high, however the hedonic or sociability experience for the same user may be low, for the same web application. For the purpose of this study, we assumed that being a breast cancer survivorship application, the hedonic dimension would not be applicable, and hence the remaining three dimensions are measured. The usability dimension of the online user experience will also be compared with the results of the usability assessment from task analysis and follow-up interview as confirmation of internal consistency. Similarly, the results of the pragmatic dimension will be compared to the perceived usefulness data gathered from the semi-structured interviews.

Chapter 5: Research method and design

5.1 *Specific aims*

The specific objective of this usability study is to understand the usability and acceptability analysis of a new interactive personal health management tool called 'After Cancer Education and Self-Management Operations' (ACESO).

5.2 *Cohort/Sample/Setting*

Participants self-referred to participate in the study, in response to recruitment via flyers located in various prominent locations across the University of Wisconsin-Milwaukee campus, as well as local breast cancer resource centers (eg. ABCD, etc.) in the South-Eastern Wisconsin area. All participants had received treatment for breast cancer, completed all treatment and were discharged from the hospital prior to the start of the study. Each eligible respondent who completed the entire study activities received a $20 Target gift card as compensation for their time to participate in the study. The following inclusion and exclusion criteria was used to screen participants:

(i) Having had a breast cancer diagnosis (initial stage 0, I, or II)

(ii) Having completed local and/or systemic adjuvant cancer therapy

(iii) Currently considered cancer free (for less than a year) and not receiving any cancer therapy other than tamoxifen (a drug used for the long term treatment and prevention of breast cancer)

(iv) Having no prior history of treatment of other cancers, with the exception of non-invasive skin cancer and cervical cancer

(v) Being able to read and write English

(vi) Having no other major disabling medical or psychiatric conditions that would confound evaluation of health-related quality of life

A notification email was sent out initially to all advisors at ABCD. Twelve participants responded individually to the email and scheduled a date/time for the session. An additional three participants responded to the flyers placed on campus and emailed to express their interest in participation. They were then followed up to schedule the time and venue for the study session.

5.3 *Procedure*

Prior approval from the University of Wisconsin-Milwaukee (UWM) Institutional Review Board (IRB) was obtained before conducting any research activities involving respondents. The study protocol was approved as minimal risk; expedited under Categories 6 and 7, as governed by 45 CFR 46.110. In addition, the protocol was also granted Level 3 confidentiality for Payments to Research Subjects per UWM Accounting Services Procedure: 2.4.6.

Upon completing an initial screening via email, a venue, date and time (according to the participant's preference) was arranged to personally meet each

participant, depending on their convenience and availability. Each respondent met with the investigator for an individual one-on-one session, lasting about 60-70 minutes. The session took place either at the University of Wisconsin-Milwaukee campus, a quieter public place, such as a study room in a local library, the participant's residence, or any other location depending on their preference and convenience. Offering the participants a choice in the meeting location ensured that they were comfortable to talk about their breast cancer condition and discuss various aspects of it freely, without any hindrance or encumbrance.

After completing the screening form, signed informed consent was obtained from each respondent prior to the beginning of the session and before proceeding any further with the rest of the study. Respondents were given an opportunity to address any personal concerns and ask any questions they had about the study, before consenting to participate. Prior consent to create audio-recordings of the interview sessions was obtained and included in the original consent form (Appendix A).

Each session began with a one-on-one interview on current practices for self-management and the perceived usefulness of a breast cancer web application. Respondents were asked questions such as "How useful did you find the breast cancer survivorship document given to you by your provider after you completed your cancer treatment?", "Do you think having an app would help/have helped you navigate life after breast cancer any better?" and "Do you

think more personalized tools (such as apps) to aid breast cancer survivors would be useful? Would you use such an app? Why?". The complete set of open ended questions used as talking points during this session are shown in Appendix C.

This round of the one-on-one acceptability interview was followed by a brief demonstration of the developed prototype (ACESO), to familiarize the respondent of the various functions and features of the prototype. Respondents were asked to "think-aloud" as they viewed the demonstration. Based on the work of Ericsson and Simon (1984), the think aloud technique allows the capture of one's cognitive process by having him/her verbalize it. This technique has been widely adopted as a standard in usability studies and to assess human-computer interaction (Bannon, 1992; Dix, Finlay, Abowd, & Beale, 1997; Nielsen, Clemmensen, & Yssing, 2002). The primary reason for breaking up the session and conducting the prototype demonstration after having completed the acceptability interview was to prevent any bias in the respondents' answers for questions pertaining specifically about the web application, such as what features they would like to see, and how they would like the application to appear.

Each respondent then participated in task-analysis using the prototype, in order to assess its overall usability. As mentioned in the previous section, a purposive sampling of possible tasks were developed based on all the features and functions of the prototype, keeping in mind the process flow (described in Section 3.3). In order to maintain participant confidentiality, no personal medical

information was captured while performing the tasks. The respondents were provided with hypothetical data to use while completing some of the tasks. The respondents were asked to complete each task independently, however they could seek my help and assistance if they were unsure about how to proceed. Each participant was observed as they completed each task notes were taken on how she found and accessed each component of the prototype's interface and how easy or hard it was to find. The number of times each participant sought help in completing the tasks, as well as if they made any errors while completing each task were recorded. Some of the tasks respondents were asked to perform included recording a symptom (upper arm swelling), retrieving dates they underwent chemotherapy, completing the brief fatigue survey (BFI) and entering dates of post treatment mammography. A list of tasks performed during the task-analysis are shown in Appendix C.

Having had a chance to use the prototype to perform various tasks and having been exposed to the features and functions of ACESO, respondents participated in a second round of one-on-one personal interviews to gather their individual opinion on the prototype's usability and acceptability, based on their experience while performing the tasks. Participants were also encouraged to offer their suggestions on how to further improve the prototype, or any changes they would like to be made. Some of the questions respondents were asked included "After having used the app, can you talk more on the usefulness of such an app?", "Can you talk about how easy or difficult was it for you to use the

app?", "What suggestions would you have to improve this app?" and "How willing would you be to use this app, if it were made available to you for free? Please explain with reasons". The complete set of talking points used for this one-on-one interview session are shown in in Appendix C.

Finally, respondents were provided instructions to complete the Online Experience Survey in order to assess the respondents' overall experience from using the web application. The Online Experience Survey used a seven-point semantic differential scale to measure the users' experience on three metrics: usability, sociability and pragmatism (see Section 4.3). Respondents rated the system on a scale of 1 (most positive) to 7 (most negative). A score of below 4 is considered to be a favorable user rating. Responses were self-reported and respondents were informed that this is an anonymous survey, which they completed independently and anonymously. The online survey was compiled utilizing the University of Wisconsin-Milwaukee's Qualtrics website, which has been designed specifically for distributing surveys for research purposes. Respondents were asked to rate their experience of ACESO on the three dimensions: Pragmatic (productive, practical, relevant, informative, worthwhile, productive and useful); Sociable (inviting, friendly, polite, personal and social) and Usability (easy, confusing, tiring, consistent and stressful). The online survey also included three demographic questions: age, race and education level. The questionnaire utilized for the survey is shown in Appendix C.

In order to limit any bias in the responses, respondents were not explicitly informed about who developed the web application. Furthermore, since assessing the usability of the prototype is the primary motive of this research, the overall usability was measured using three different approaches: task analysis, the one-on-one usability interview and the online experience survey. Cross-tabulating and comparing results from all three approaches would reveal discrepancies, if any or the possibility of any bias. The online experience survey was an anonymous survey, which the respondents completed in private, which further limited the potential for bias.

5.4 *Data analysis*

Thematic analysis was performed to analyze the qualitative data obtained from personal interviews and observation notes. Audio recordings from the interview sessions were transcribed to text, then read through entirely, to familiarize and orient myself with the overall theme of the interview. Subsequently in the unitizing stage, codes (or labels) were then tagged to describe interesting ideas that appeared in a word, phrase or sentence. Initially, a deductive approach was adopted, based on the two pre-determined high level themes (perceived usefulness and usability) of the conceptual framework described in Chapter 4. Inductive analysis was then carried out on the data within these themes, from which a number of sub-themes emerged.

Semantic themes that emerged from the analysis of the text that were representative of the respondents' experiences were identified. This process was repeated to revisit the categories and themes after transcribing each interview, until data saturation (no additional data to develop new categories) was achieved. The NVivo 11 software package was used to perform the thematic analysis.

The quantitative data that describes participant demographics, as well as from the task-analysis and the Online User Experience survey are tabulated and presented using descriptive statistics.

Responses to the personal interviews were compared and verified with results of the task analysis and the Online User Experience survey in order to identify any inconsistencies in the findings.

Chapter 6: Results

This chapter presents the results from the acceptability and usability testing of ACESO among the respondents.

6.1 Demographic data

Fifteen female breast cancer survivors who self-referred to participate comprised the sample for this study. 14 of the 15 of respondents identified themselves as Caucasian and 11 were over the age of 50, while 13 had at least a college degree. Table 6.1/Figure 6.1 outlines the data on age, race (Table 6.2/Figure 6.2) and education level (Table 6.3/Figure 6.3) of the respondents.

Age	***n***	***%***
18-24	0	0.00
25-29	0	0.00
30-39	1	6.67
40-49	3	20.00
50-59	4	26.67
Above 60	7	46.67
TOTAL	**15**	**100**

Table 6.1: Respondents by Age group

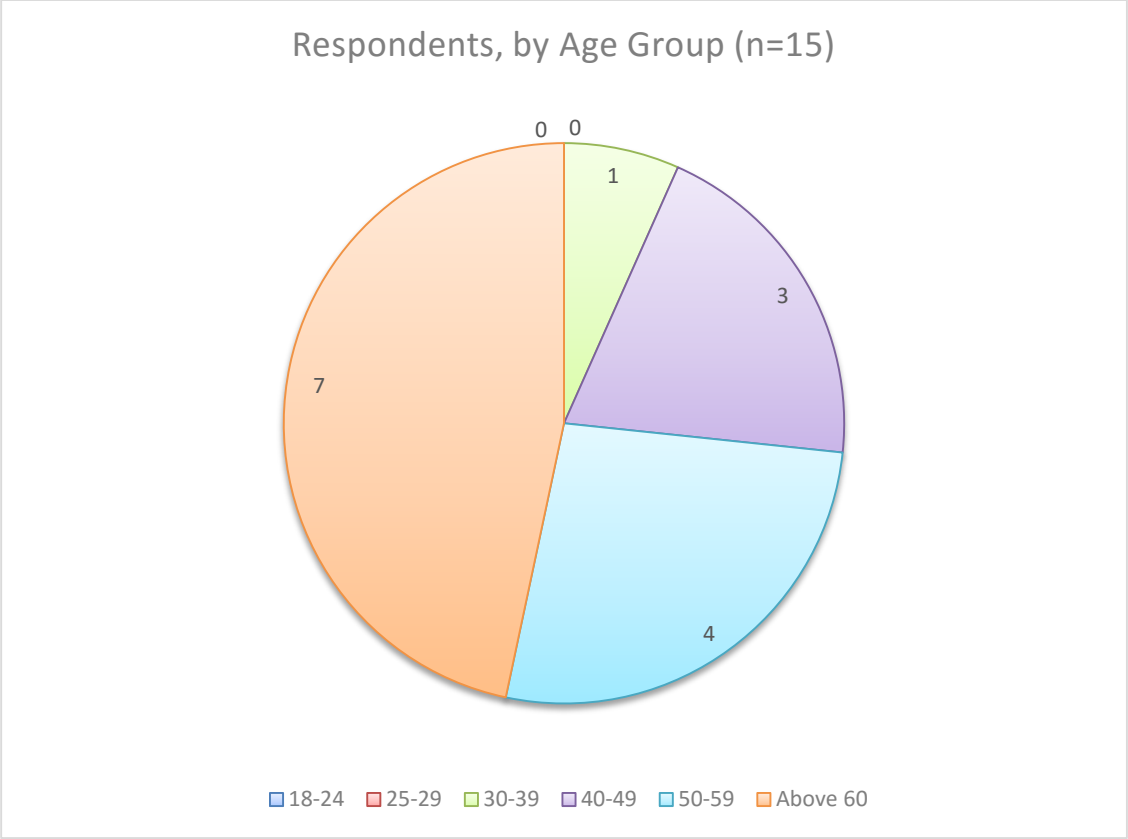

Figure 6.1: Respondents by Age group

Race/Ethnicity	n	%
African American	0	0.00
American Indian or Alaska Native	0	0.00
Asian	0	0.00
Caucasian	14	93.33
Hispanic or Latino	0	0.00
Multi Ethnic	0	0.00
Other	1	6.67
Unknown	0	0.00
TOTAL	**15**	**100**

Table 6.2: Respondents by Race/Ethnicity

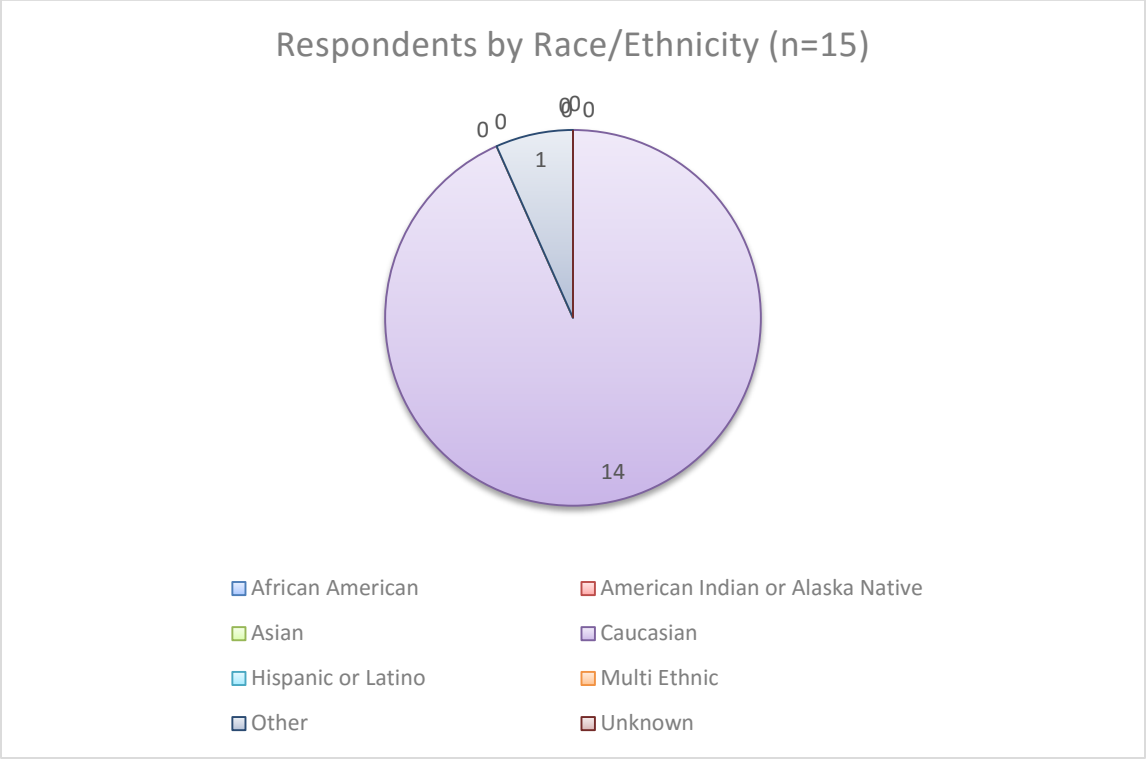

Figure 6.2: Respondents by Race/Ethnicity

Education (Highest level completed)	*n*	*%*
Haven't completed High School	0	0.00
High School	2	13.33
Associates/Technical degree	3	20.00
Bachelors degree (BA/BS, etc.)	7	46.67
Masters degree (MA/MS/MBA, etc.)	3	20.00
Doctorate degree (Ph.D, etc.)	0	0.00
Other professional degree	0	0.00
TOTAL	**15**	**100**

Table 6.3: Respondents by Education Level

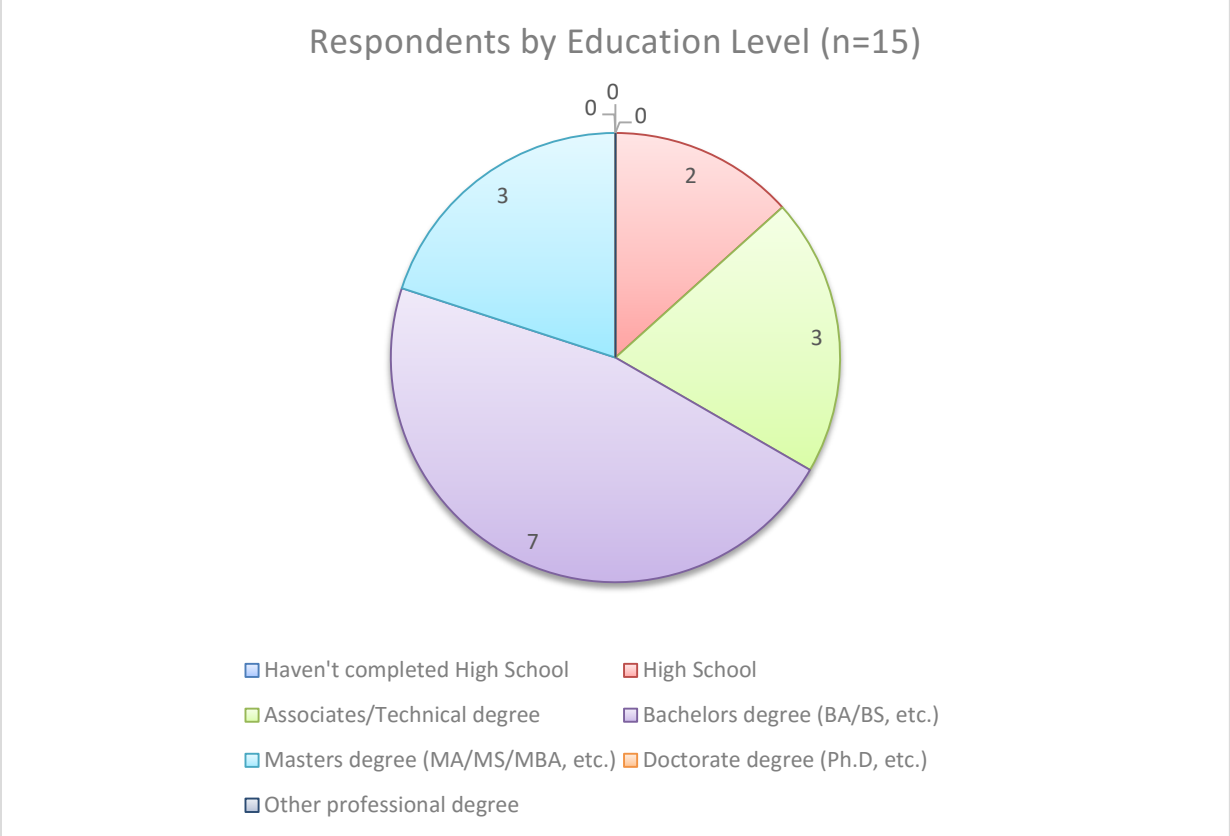

Figure 6.3: Respondents by Education Level

6.2 Perceived Usefulness and Patient Acceptance

This section describes the dominant themes that emerged from the analysis of the semi-structured interviews, in terms of ACESO's perceived usefulness and general acceptability.

As described previously, patient acceptance is largely influenced by perceived usefulness of the technology. This section describes results from the user feedback on their perceived usefulness as well as their general acceptability of ACESO. The overarching research questions were: "What is the perceived usefulness of an electronic self-management tool among breast cancer survivors?", and "How acceptable is the current prototype of ACESO among breast cancer survivors?". Following are some questions posed to the respondents in terms of their perceived usefulness of a breast cancer survivorship app, as well as their willingness to use ACESO for self-management.

Respondents were asked the question *"After completing your cancer treatment, how well prepared did you feel in terms of taking care of yourself and follow up treatments?"* One of the respondents mentioned *"I felt very prepared, yes"*. Another respondent stated *"I was quite prepared. Being involved with ABCD, I had access to an advisor who I could ask any questions I had"*. Most of the respondents (11/15) seemed to have felt quite prepared after the completion of their treatment in terms. While a significant number of respondents represented a convenience sample who self-referred from the After

Breast Cancer Diagnosis (ABCD) center in Milwaukee, WI, they had received one-on-one mentoring services and support provided by the center. As a result, respondents had access to peers to answer various questions pertaining to their breast cancer treatment. Participation in breast cancer support groups has been shown to have a positive psychosocial impact on the patients as well as improvement in their treatment related side-effects and overall prognosis (Montazeri et al., 2001; Goodwin et al., 2001; Geiger et al., 1999). As a result, while most respondents said they felt prepared in terms of taking care of treatment related side effects, there were some respondents (3/15) who mentioned that prior to them having access to a mentor, they felt unprepared and were not sure what to expect. *Respondent A* mentioned *"I had a really great medical team, so I didn't have much to worry about, but I was in such a state where I didn't always know everything that was going on"*. Another respondent mentioned that she had people in the family (her mother) who had breast cancer, but even still, when she was asked if she felt prepared in terms of knowing what treatment-related side effects to expect, her response was "*Not at all. Not at all*." These findings are consistent with prior research that states that in general, cancer patients feel unprepared in terms of taking care of treatment-related symptoms (Lubberding et al., 2015).

Respondents were asked the question *"How open are you towards using technology to help self-manage your medical condition(s)?"* One of the respondents answered "*I am very open. I use the Internet to Google stuff all the*

time." Another respondent stated *"I am very open to it. In the past, I have used the patient portal to send any questions I have to my doctor and she usually responds right away"*. The prevalent message in the interview responses was the respondents' being very open to using technology and often use it for information seeking online about their medical condition (12/15). Since the participants self-referred to participate in the study, there might be the presumption that they already look favorably towards using apps and technology, therefore it cannot be assumed that this is representative of the general population of breast cancer survivors. However, these findings are consistent as indicated by Satterlund, McCaul, & Sandgren (2003) who indicate that Internet is the top source of information for breast cancer survivors, even sixteen months after their treatment ended. Similarly, Mayer et al. (2007) also state that many breast cancer patients use the Internet "as an extension of and enhancement to their interactions" (with their providers). Several respondents (6/15) however were not satisfied with using the Internet as a source of medical information seeking, due to the generic information they find online. These respondents mentioned that they could not always identify what piece of information pertains specifically to them. A respondent mentioned "*I use the internet to look up stuff all the time…I use it a lot, but often end up reading so much, that I think Oh, I could have this and that and it ends up scaring me more*". Another respondent stated "*I often go to WebMD to do my own research, but I find it hard to understand if what I'm reading applies to me or not*." A third respondent stated "*You see things in the*

news online all the time, and a lot of time they are conflicting each other. I just don't know which one to believe."

Respondents were also asked about the perceived usefulness of a survivorship app *"Do you think having an app would help/have helped you navigate life after breast cancer any better?"* One respondent said *"Every time I go to the doctor I leave with so many documents. Look over there (as she pointed to her shelf above her work desk) at that thick binder. I always save everything, but I'm not sure if I ever needed to look for something that I will be able to find it".* Respondents revealed their current practices in terms of organizing their medical records and resources and having access to them. While they all had their own way of organizing information (post-it notes, receipts in wallet, binders, etc.), they were not always satisfied with their current practice. These findings are consistent with prior research on how lay people manage their personal health information at home (Brennan & Kwiatkowski, 2003), which indicates that several patients develop a style of storing their records in a common place, such as a drawer or file cabinet.

After getting a chance to view and use the app, respondents were posed a question "What did you like the most about the app?" in order to assess their perceived usefulness of the app. As one respondent stated *"I like that you can see everything in one place"*. Respondents (8/15) revealed that they find the portability aspect of an app very useful. Having access to a comprehensive online application would mean that they are able to access their own breast

cancer survivorship care plan no matter where they might be, especially when travelling.

Another of the features the respondents seem to find valuable was the ability to record observations (ODLs), such as sleep quality, fatigue and weight at home, and being able to view them later (7/15). As one respondent stated *"The visuals and the charts were really nice"*. Another respondent stated *"I like being able to track things at home."* Talking about the graphical observation charts, a respondent stated "*This could be really helpful. Is this something I can send to my doctor?*" Respondents also pointed out that *"I like being able to see the past measurements. That way I can tell if it's getting better or worse over time"*. These responses suggest that even though most respondents had initially stated that they felt prepared after completing their treatment, after getting a chance to view and use the app, they stated they would still like to have access these features, indicating that having ACESO could further improve their preparedness, especially in terms of tracking various quality of life indicators that impact breast cancer survivors.

In terms of general acceptability of ACESO, respondents were posed the question *"Do you have any concerns from using this app in real life?"*. One respondent answered. This response was reflective of the majority of the responses (9/15), stating that privacy and security of their personal health information was their only concern while using an app such as ACESO. If they were assured that their information would be kept secured and private, they did

not have any other concerns that would prevent them from using ACESO. Respondents were also asked *"How willing would you be to use this app, if it were made available to you for free? Please explain with reasons"*. All of the respondents (15/15) stated that they would use ACESO, if it was made available to them free of charge. Some respondents expressed further interest (6/15) in the application by asking *"So when does it come out?"*, or *"Is it going to cost any money to use it?"* towards the end of the interview session.

These responses from the respondents indicate a high level of acceptability, primarily owing to perceived usefulness and uniqueness of an app such as ACESO, as well as its ease-of-use (discussed in the following sections).

6.3 System usability

6.3.1 Task analysis

Each of the 15 respondents participated in the task analysis. The observations for each task were categorized as *Successful*, *Successful with assistance*, or *Not successful*. None of the respondents had any prior access to the prototype, or prior experience with any other online breast cancer survivorship plan. Table 6.4 and Figure 6.4 below shows the success rates for each of the tasks completed.

	Task	*Successful (%)*	*Successful with assistance (%)*	*Unsuccessful (%)*
1	Log In	15 (100)	0 (0)	0 (0)
2	Record symptom	12 (80)	3 (20)	0 (0)
3	Observe alert message	15 (100)	0 (0)	0 (0)
4	Find and answer fatigue survey	13 (86)	1 (7)	1 (7)
5	Record mammography date	14 (93)	0 (0)	1 (7)
6	Retrieve chemotherapy dates	15 (100)	0 (0)	0 (0)
7	Retrieve fatigue observation report	6 (40)	6 (40)	3 (20)
8	Find and list one local breast cancer resource	14 (93)	1 (7)	0 (0)
9	Log Out	15 (100)	0 (0)	0 (0)

Table 6.4: Task analysis – completion rate

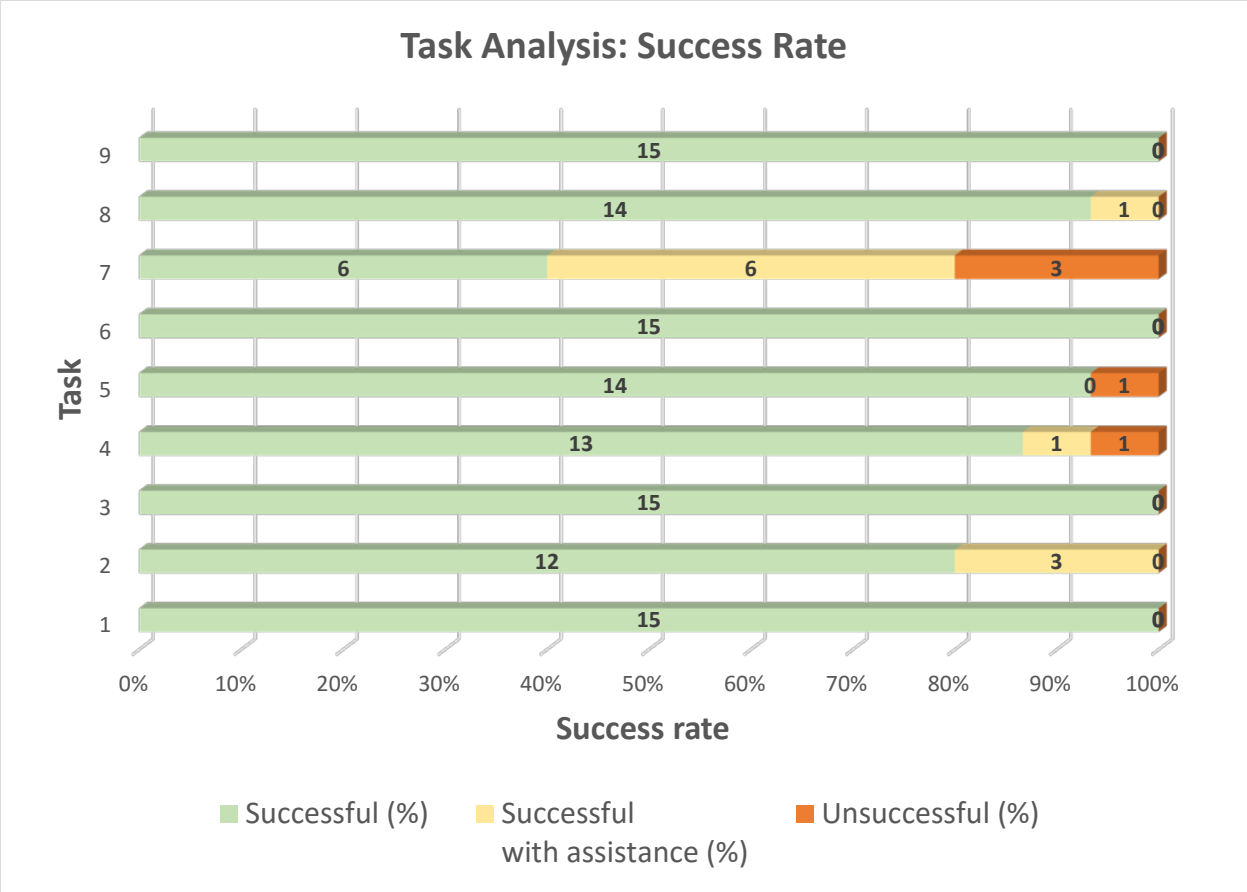

Figure 6.4: Task Analysis – Success rate

The task analysis revealed certain issues with the prototype's graphical user interface that affected its overall usability. The most apparent issue was with

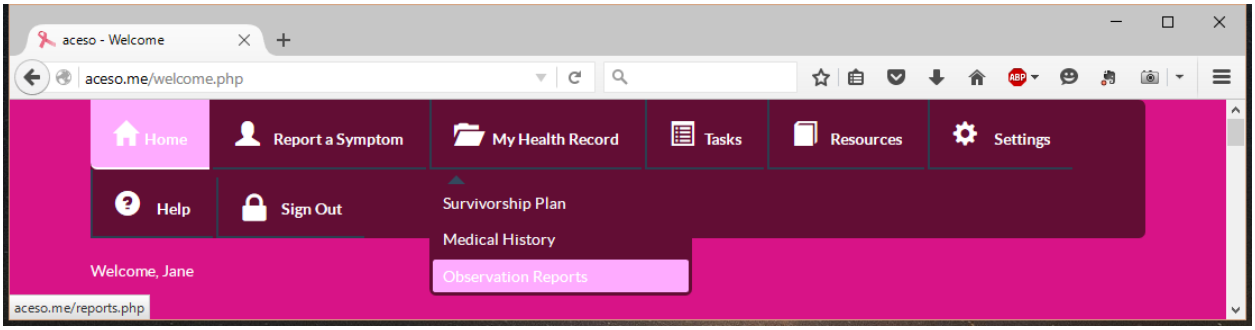

Figure 6.5: Sub-menu to access the Observations Report page

being able to access the observation reports (Task 6). This particular function requires the user to navigate through two levels of menus in the top navigation bar (Figure 6.5), thus affecting its visibility and making it harder to find and access. As many as six respondents asked for assistance in competing the task, while three were unable to successfully complete the task even with assistance. Certain respondents also had issues correctly using the *Record a Symptom* function of the prototype (Task 2). While all respondents successfully navigated to the required web page, three (of the fifteen) respondents were unsure how to proceed any further.

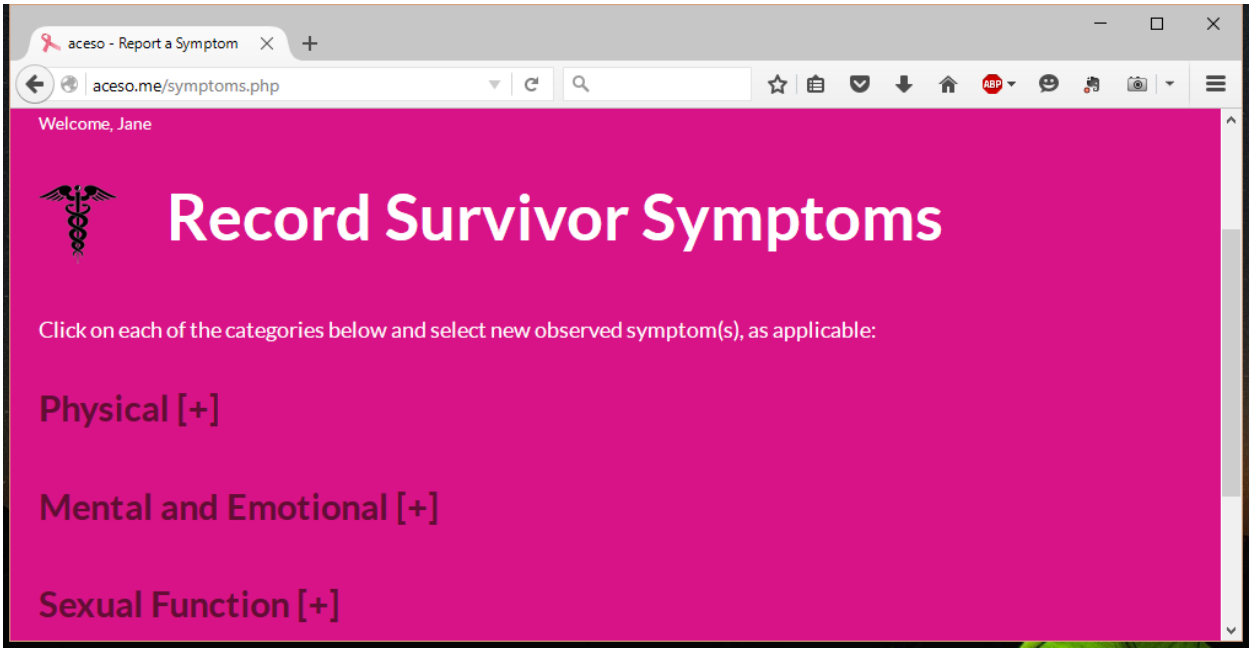

Figure 6.6: Top level symptom categories menu

The current interface requires the user to click on the '+' symbol (Figure 6.6) to expand or collapse the menu of top level categories of available symptoms in order to access the list of symptoms, which was confusing for these respondents. Another interface issue was observed with accessing the *Tasks* area of the

website to record ODLs (Task 4). The prototype's interface currently displays a

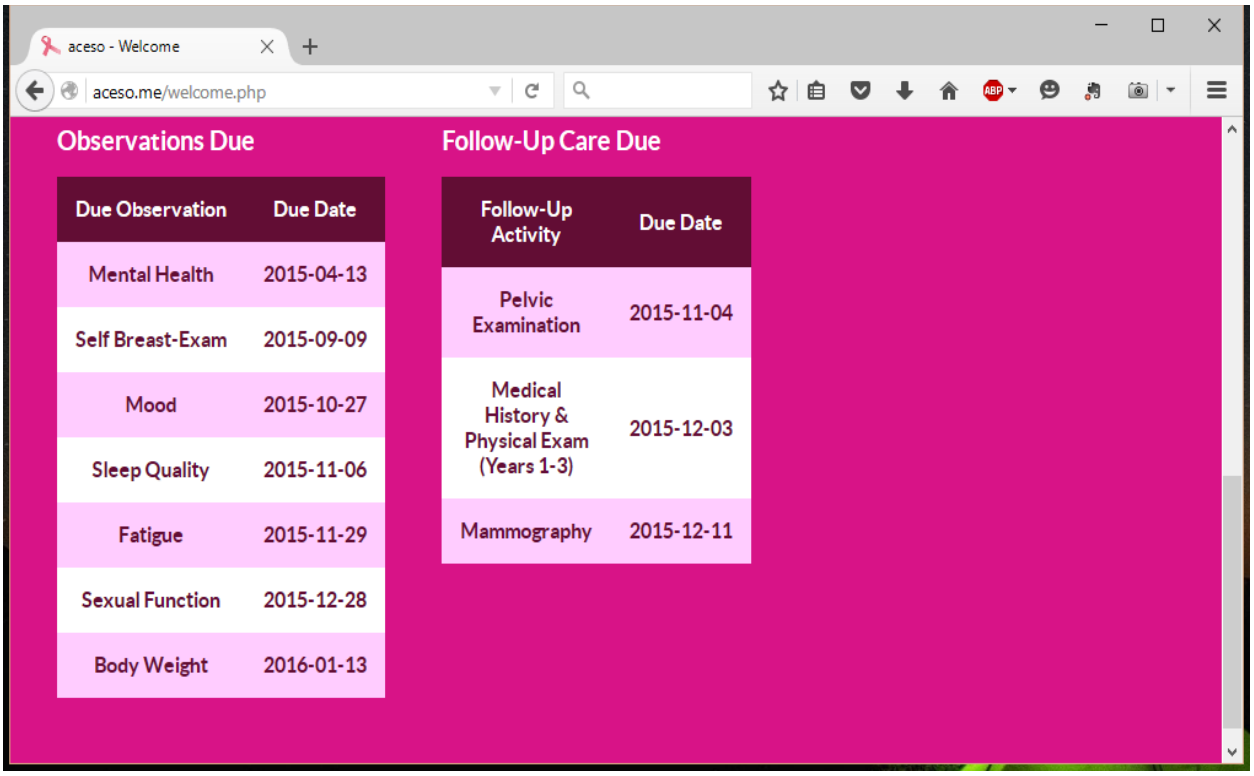

Figure 6.7: Observations Due list to record ODLs

list of observations that are past due for the user. The user may click on a particular task to proceed to the page where they would enter and record the specified observation. The current display scheme employs a table format to display this list of past due observations (Figure 6.7). However, to be able to click on a particular observation, the user would need to click on the text itself. Any other empty space within the same cell (besides the text) is not an active link, and there were three respondents who attempted to click on this empty space and were unable to proceed with the task without further assistance.

The prototype demonstrated an overall high usability among lay users. The graphical user-interface was found to be intuitive, however the study identified various issues (Table 7.1) which would need to be addressed to make the prototype even more easy to use.

1	On the Record a Symptom page, make the collapsible menu more intuitive by including a message describing how to access the sub-menu of symptoms.
2	Modify the table layout of the Observations Due and the Follow-Up Care due panels, such that the entire cell (not only the text) is an active link and clickable.
3	Change the date format used to record doctor visits from YYYY-MM-DD to MM-DD-YYYY, to make it less confusing and more user friendly.
4	Accessing the Observations reports page is currently requires accessing a sub-menu, making it hidden at first glance on the page. Giving this a more visibility and prominence on the page will make it more intuitive.
5	On the resources page, indicate the definition of 'Local' resources as 'South-Eastern WI'.

Table 6.5: Prototype usability issues identified via usability testing

6.3.2 Follow up interview

During the one-on-one interview session after the task analysis session, respondents were asked (see appendix C for interview questions) about their perception of the current prototype in terms of its overall usability as well as their opinion on the user interface in terms of its look and feel. The overarching research question was "How usable is the current prototype among lay users?"

Respondents were posed with the question: *"Can you talk about how easy or difficult was it for you to use the app?"*. While a respondent indicated *"It was quite easy. There are a lot of things you can do here, so if I spend more time using it, I will get used to it more"*. Consistent with the results of the task analysis, certain respondents (6/15) mentioned having difficulty accessing the *Observation Reports* area of the website. As one of the respondents mentioned *"I had to look around a lot to get to the Observations page, it was sort of hidden"*. Users suggested that making the link to the Observations Reports page more prominent would help resolve this issue.

Respondents were also asked the question *"What are your thoughts on the visual appearance of the app?"*. One of the respondents stated "*I like the colors that you used. It makes everything pop out*." Another respondent indicated "*The large white buttons (referring to the three navigation buttons on the main page) are nice. I was easily able to find where I needed to click*".

Overall, the participants responded favorably to their use of the prototype. In terms of the interface, respondents found the website to be well organized and found it easy to locate various areas of the website (11/15).

Respondents were also asked *"What suggestions would you have to improve this app?"*. As one respondent pointed out *"You know*, w*e become very sensitive after everything. Looking at this makes me somewhat anxious".* Another respondent stated "*I don't mind the alert messages but maybe make them more positive. I can't think of what you would use instead of 'Warning', right now…hmm…let me think about it for a while".* Another respondent suggested *"You have these warning messages, but I'd like to also see something positive, like 'Great work, Keep it up!', or something like that…just makes you feel better, you know?"* In particular, the presentation of the alert messages seemed to be the main point of issue. Each alert message appears at the top of the page, prefixed by the word *"Warning!"* The original intention was to make sure that the user does not miss these important alert messages, therefore they were given prominence on the web page, however, some respondents (8/15) found the use of the word *"Warning"* to be anxiety inducing. It must be pointed out that while respondents valued the alert messages function, they did not always agree with the way they were presented.

Apart from the alert messages, some respondents also pointed out that while the look and feel of the website is functional and efficient, it felt too clear-cut (3/15). As one respondent said "*It looks too clinical*." When further prompted

to describe what she meant by ‘clinical’, she explained *“Like something you’d see at the doctor’s office”*. When asked about any changes they would like see in the website, another respondent said “*Maybe make it more lively and fun*.”

The predominant theme that emerged from the personal interviews was that ACESO was fairly easy to use, however the *Observations Reports* page was somewhat difficult to find on the website. It was also found that applications need to accommodate for the sensitivities of the group of end users. Communicating positive re-enforcement messages via use of more pleasant and sociable language and incorporating more visuals would make the application more sociable for breast cancer survivors.

6.4 Online User Experience

All fifteen respondents completed the anonymous Online User Experience survey online. Based on their experience with the prototype while performing the tasks, respondents rated their experience with the prototype on the basis of three areas: pragmatic, sociable and usable. The survey utilizes a seven point bipolar scale, with a score of 1 being the most positive response and 7 being the most negative response. Results for each of the three categories are shown below.

Question	1	2	3	4	5	6	7	Total Responses	Mean
Informative:Not Informative	9	2	2	1	0	0	0	14	1.64
Worthwhile:Worthless	9	4	1	0	0	0	0	14	1.43
Productive:Not Productive	10	2	2	0	0	0	0	14	1.43
Relevant:Irrelevant	10	3	1	0	0	0	0	14	1.36
Valuable:Not valuable	11	4	0	0	0	0	0	15	1.27
Practical:Not practical	11	3	0	0	0	0	0	14	1.21
Useful:Not useful	13	1	0	0	0	0	0	14	1.07

Table 6.6: Pragmatic Online User Experience – Summary of responses

In the pragmatic category, the *informative* dimension was rated most negatively ($\bar{x}$=1.64), while *useful* received the most favorable response ($\bar{x}$=1.07).

Statistic	Valuable: Not valuable	Practical: Not practical	Relevant: Irrelevant	Informative: Not Informative	Worthwhile: Worthless	Productive: Not Productive	Useful: Not useful
Min Value	1	1	1	1	1	1	1
Max Value	2	2	3	4	3	3	2
Mean	1.27	1.21	1.36	1.64	1.43	1.43	1.07
Variance	0.21	0.18	0.40	1.02	0.42	0.57	0.07
Standard Deviation	0.46	0.43	0.63	1.01	0.65	0.76	0.27
# Responses	15	14	14	14	14	14	14

Table 6.7: Pragmatic Online User Experience - Descriptive statistics

The participants rated ACESO very favorably in terms of its pragmatic dimension. These results indicate a high level of perceived usefulness of ACESO, which subsequently contributes to its overall acceptability.

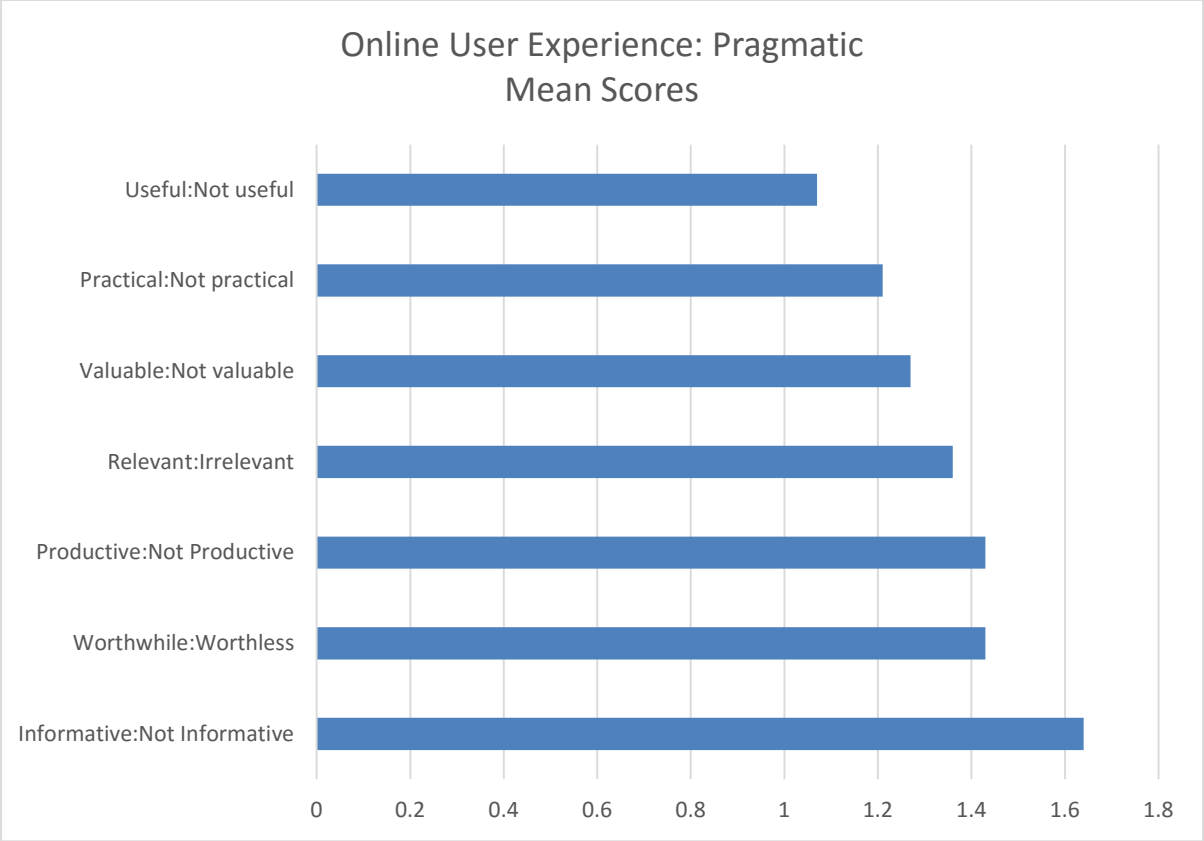

Figure 6.8: Pragmatic Online User Experience – Mean scores

In the sociability category, the *social* dimension received the most negative score ($\bar{x}$=2.14), while *inviting* and *friendly* had the most positive scores, as rated by respondents. While participants rated ACESO favorably in terms of sociability, the overall sociability score was lower, in comparison to the other dimensions (pragmatic and usability).

Question	1	2	3	4	5	6	7	Total Responses	Mean
Social:Unsocial	3	6	5	0	0	0	0	14	2.14
Polite:Impolite	8	5	1	0	0	0	0	14	1.50
Personal:Impersonal	9	4	1	0	0	0	0	14	1.43
Friendly:Unfriendly	12	1	1	1	0	0	0	15	1.40
Inviting:Uninviting	11	1	2	0	0	0	0	14	1.36

Table 6.8: Sociability Online User Experience – Summary of responses

Statistic	Inviting: Uninviting	Friendly: Unfriendly	Polite: Impolite	Personal: Impersonal	Social: Unsocial
Min Value	1	1	1	1	1
Max Value	3	4	3	3	3
Mean	1.36	1.40	1.50	1.43	2.14
Variance	0.55	0.83	0.42	0.42	0.59
Standard Deviation	0.74	0.91	0.65	0.65	0.77
Total Responses	14	15	14	14	14

Table 6.9: Sociability Online User Experience - Descriptive statistics

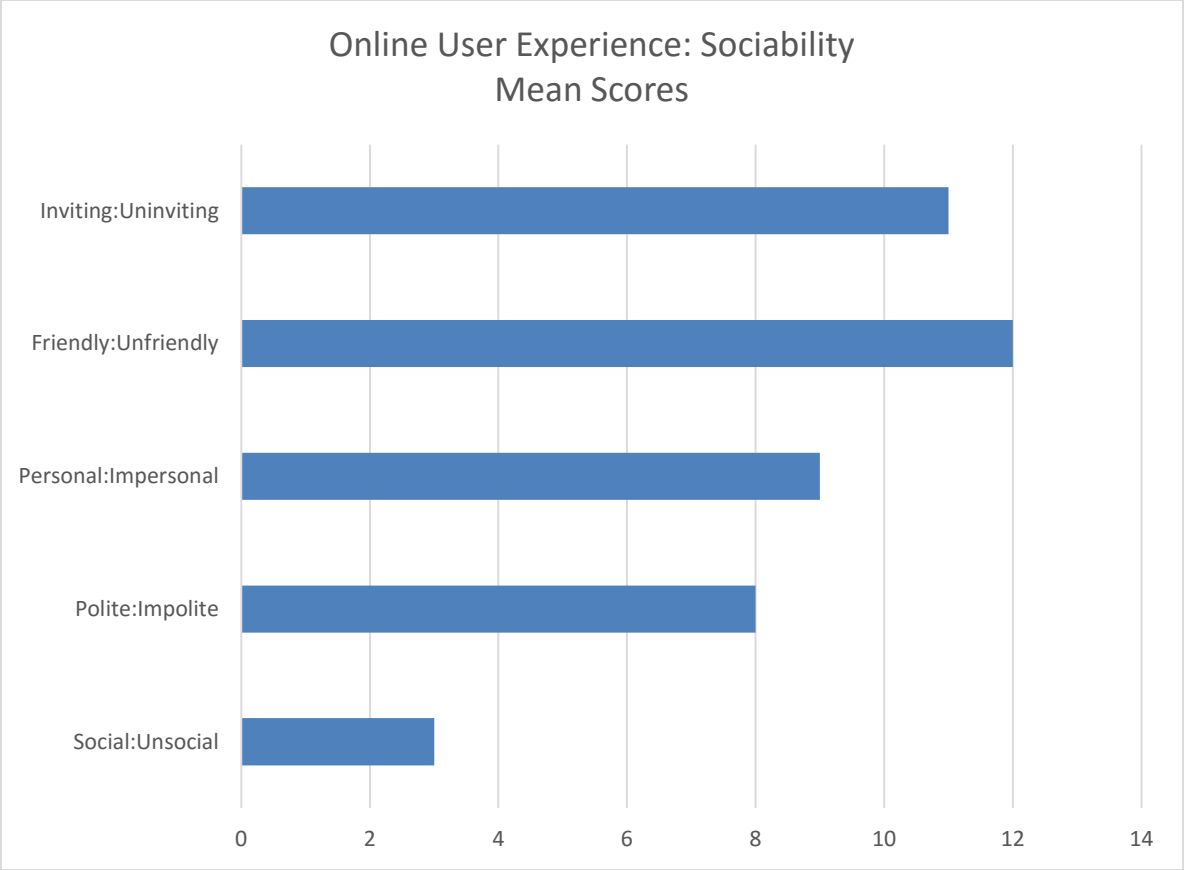

Figure 6.9: Sociability Online User Experience – Mean scores

Examining the Usability category, the respondents rated the *consistent* and *not stressful* items most favorably ($\bar{x}$=1.21). While the *simple* dimension still received a very positive score, it was rated most unfavorably ($\bar{x}$=1.47), in comparison to other dimensions in the category. Overall, the prototype demonstrated a high level of usability among the participants.

Question	1	2	3	4	5	6	7	Total Responses	Mean
Not confusing:Confusing	8	3	1	0	0	1	1	14	2.14
Simple:Complicated	9	5	1	0	0	0	0	15	1.47
Easy:Difficult	10	3	1	0	0	0	0	14	1.36
Not tiring:Tiring	10	4	0	0	0	0	0	14	1.29
Not stressful:Stressful	11	3	0	0	0	0	0	14	1.21
Consistent:Inconsistent	11	3	0	0	0	0	0	14	1.21

Table 6.10: Usability Online User Experience – Summary of responses

Statistic	Simple: Complicated	Easy: Difficult	Confusing: Not confusing	Not tiring: Tiring	Consistent: Inconsistent	Not stressful: Stressful
Min Value	1	1	1	1	1	1
Max Value	3	3	7	2	2	2
Mean	1.47	1.36	1.32	1.29	1.21	1.21
Variance	0.41	0.40	3.82	0.22	0.18	0.18
Standard Deviation	0.64	0.63	1.96	0.47	0.43	0.43
Total Responses	15	14	14	14	14	14

Table 6.11: Usability Online User Experience - Descriptive statistics

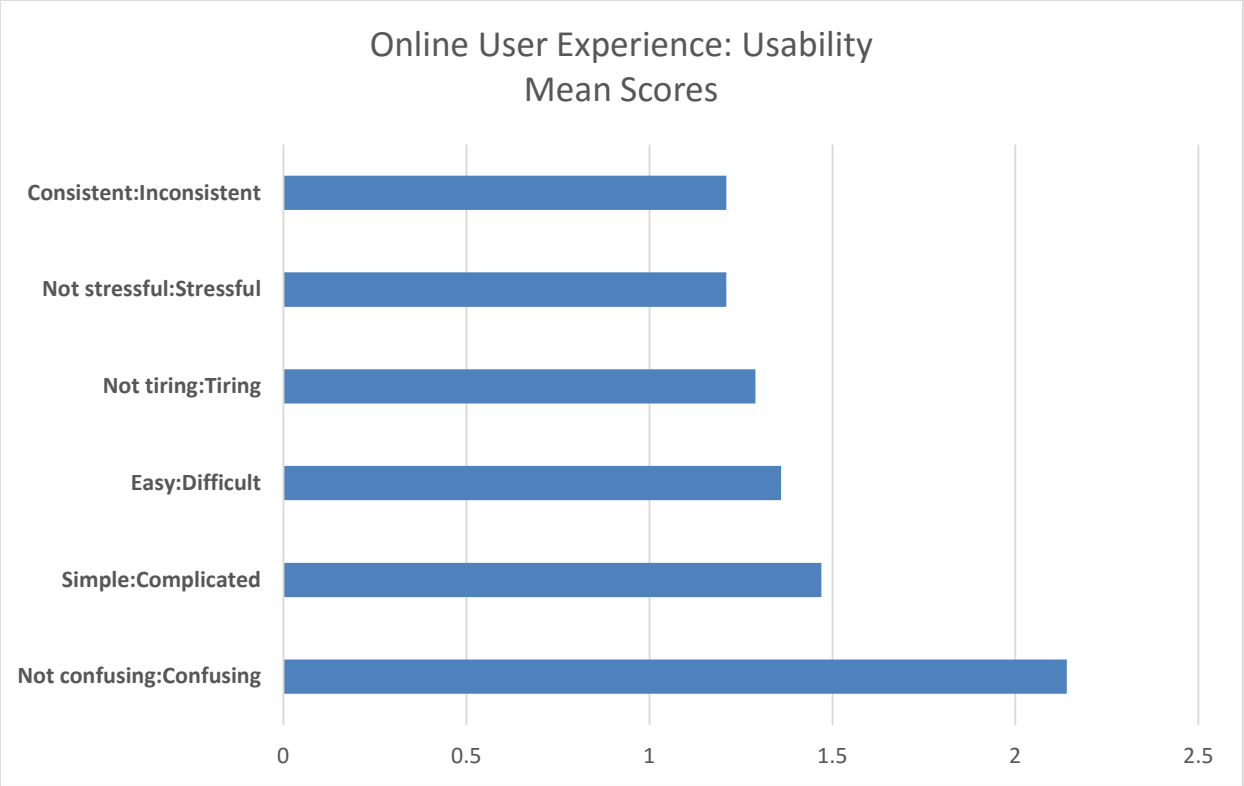

Figure 6.10: Usability Online User Experience – Mean scores

Chapter 7: Discussion and Conclusion

7.1 Discussion

The design of the prototype is accessible from any web-enabled mobile device or a computer system allows patients of varying levels of computer literacy to benefit from it. The prototype makes the cancer survivor plan, currently existing in the form of a paper document, more intelligent, smart and dynamic, thus bestowing new value to conventional cancer survivor care plans.

By tapping a severely underused source of patient data by capturing ODLs (Chin, R & Lee, BY, 2008), it is hoped that the system will help detect unusual changes in the patient's health and alert them in a timely manner. This could potentially also promote a better understanding of the patient's own medical condition, subsequently leading to better patient-provider communication and shared decision-making.

The developed prototype is unique in the way it not only incorporates personalized breast cancer survivorship plans, but also includes additional value added features, such as being able to track and record observations at home (ODLs) and personal decision support in the form of timely alerts regarding treatment related side-effects, and reminders for follow-up visits.

In order to assess the usability of the prototype, the study employed a combination of qualitative methodology, task analysis as well as an Online User

Experience survey. The overall usability results of each of these methods were found to be consistent with each other in the findings.

Overall, the respondents appeared to be very open and willing to use a web-application for managing their medical conditions post-treatment. There is however a need to improve upon the sociability aspect of the prototype. This was verified as a result of consistent results obtained from the usability interview session (described in section 4.4) and the Online Experience survey (Table 4.7).

The results of the study hold important implications for clinical practice. By utilizing a personalized tool that incorporates personal decision support, new guidelines for breast cancer survivors can be implemented more efficiently, simply by updating existing decision rules. Additionally, developing a tool that is both: usable as well as acceptable, could result in higher patient education and engagement, which, in turn, could improve patient-provider communication. Being well informed about their current state of health, patients would be in a position to share decision-making with their provider, and ask better, well-informed questions during their clinic/office visits.

The study also demonstrates how, by incorporating a standardized terminology, such as SNOMED-CT, diverse breast cancer survivorship care plans from different providers can be unified, paving the way for value added features, such as personal decision support. Moreover, the user feedback and opinions gathered through the study could inform the development of future self-

management applications, which target breast cancer survivors, or other chronic ailments that benefit from self-management.

7.2 Limitations

There are a few limitations that need to be mentioned. The volunteer nature of recruitment could imply that the respondents had an inclination for using technology in self-management, therefore these respondents may not be a representative sample of breast cancer survivors. However, the respondents in this study were similar to other breast cancer survivors in that their voices echoed similar themes found in the literature conveying habits of breast cancer survivors regarding their use of the Internet and technology (Satterlund, McCaul, & Sandgren, 2003; Mayer et al., 2007). Furthermore, since all respondents self-referred, it is possible that they have a particular inclination to participate in research studies. The sample was also not representative of minority and other under-represented categories. While every effort was made to put fliers where minorities would notice, there were no calls from that group. Future studies would need to incorporate other means to enroll participants from the minority population. Qualitative studies such as observations and note taking are also often subject to researcher bias. A mixed-methods approach was therefore adopted in the study to account for any inconsistencies in the results. This methodology has been widely used to assess the usability and acceptability of consumer health applications (Payne et al., 2015; Mirkovic et al., 2014; Hong et

al., 2014; Joshi et al., 2013; Kim et al., 2016; Ozok et al., 2013; Osch et al., 2015).

7.3 Implications and Future Directions

With the increasing use of technology in the field of consumer health, various applications have gone beyond what the traditional provider online portal offers and have made self-management of various medical conditions such as cancer and other chronic ailments more accessible (Hong et al., 2014; Mirkovic et al., 2014; Hong et al., 2014; Joshi et al., 2013). The major contribution of this research is the development of an intelligent resource tool, specifically designed for survivors of breast cancer. To the best of my knowledge, a tool such as this will be the first of its kind. While there do exist generic questionnaire based systems, they are a one size fits all solution and are not customized to the specific unique needs of an individual. Using the developed prototype, the patients will be able to not only keep a log of their daily health related activities, but will also be provided with timely information in the form of alerts, triggers or reminders of various tasks or items that need attention. Additionally, it will also serve as a training tool and resource, providing these patients with pertinent information about the various aspects of their long term health, such as physical activity, sleep quality and mental health, while educating them about any related side effects and symptoms. All participants agreed that ACESO is useful and that they would use it in the future for managing their health conditions, if it was made

available to them for free. The results of the study support the notion that patient support systems for breast cancer survivors, such as ACESO, should be made more accessible via the Internet.

7.3.1 Implications for clinical practice

The development of a breast cancer survivorship application that incorporates a standard terminology like SNOMED-CT has the potential to unify different breast cancer survivorship plans from a diverse group of providers. This paves the way for offering the patients value added features, such as personal decision support. In addition, alerts and reminders in the form of messages delivered dynamically to the patients offer a quick and efficient way to implement clinical guidelines, especially as they get revised and updated (Kapoor, A. & Nambisan, P., 2016).

This system demonstrates the potential role that more personalized and specialized online tools can play in filling the existing gap in the healthcare industry today. ACESO transforms the passive paper-format of breast cancer survivorship plans into a more interactive, smart and dynamic tool. As patient engagement continues to become a vital component of Meaningful Use Stage 2, healthcare providers should look at alternative means to more effectively engage patients in taking an active role in managing their health in a more interactive manner (Kruse et al., 2015; Kapoor, A. & Nambisan, P., 2015).

ACESO also has the potential to educate breast cancer survivors on various survivorship topics. Using the application, survivors can read about

various treatment related side-effects, their causes and suggested ways to resolve them. Educating survivors in the manner can play a role in enhancing patient-provider communication, with the provider being able to communicate information to the patient more easily, in a manner that it is well understood by the patient. Improved patient-provider communication has been shown to be linked to improved patient health outcomes (Stewart, 1995).

7.3.2 Implications for breast cancer survivors

Most patient portals in their current state, are a missed opportunity due to their nature of being very generic and aim to serve the entire patient population using a one size fits all approach. There are however special patient groups that could greatly benefit from portals that provide specialized functions. Moreover, it has been shown that incorporating more personalized and interactive content results in more sustained use (Ross et al., 2006).

Breast cancer survivors can expect to experience several treatment-related side effects, several weeks after treatment. By employing a clinical decision support systems approach and incorporating feedback in the form of warnings, alerts and reminders for the patient, the system explores making the patient experience more interactive for breast cancer survivors. Having easy access to their own personal health information allows the patients to share some responsibility in managing their health condition with their provider (Ross & Lin, 2003). Subsequently, self-management of treatment related side effects can

foster patient empowerment and a sense of being in control of one's own health. Being better informed about their health condition can lead to a more meaningful interaction with one's physician, thus encouraging shared decision making (Roberts, Cox, Reintgen, Baile, & Gibertini, 1994). It is hoped that this tool will empower these patients, enabling them to take charge of their health on their own hands, participate in shared-decision making and ask better, informed questions from their provider.

7.3.3 Future Directions

A major contribution of this study lies in the valuable experience gained from the development of the prototype. All the input received from patients will contribute in the development of better, more enhanced systems, which may even be applied to other areas, in future.

Based on the user feedback received and the identification of usability issues from this study, the prototype will be further refined to make it more user-friendly. Future plans include Phase II of this study which involves making ACESO available to a much larger group of breast cancer survivors, with the aim to assess impact of the app on various patient health outcomes using quantitative measures. The tools and methods have received IRB approval and most respondents from this research study have expressed interest and willingness to participate in the next study phase.

This larger group of survivors will have access to use ACESO over a period of two months and Individual patient usage of the application will be investigated during this period. Upon the completion of this period, the impact of ACESO on various health outcomes, which are described as follows, will be assessed:

Patient-provider communication

One of the goals of ACESO is to improve patient-provider communication. Most studies and instruments developed so far have focused on measuring the providers' quality and level of interaction with their patients. We hope to study the impact of ACESO on the patient in their communication with their provider, such as being able to ask better, well-informed questions, better comprehending what the doctor says, etc.

Attitude towards provider services

Patient attitude towards the service provider is greatly influenced by the variety and quality of products or services they offer. We intend to study the impact of ACESO on influencing the patients' attitude towards their provider. Any consequent change in users' attitude from using ACESO will help guide future projects by providers and inform them of the need and impact of tools, such as ACESO.

Patient-engagement

One of the primary goals of ACESO is to improve patient engagement by providing them the tools (ACESO) required by them to manage their own health so they can claim part ownership in the responsibility of taking care of their own health, instead of the entire responsibility resting with the physicians or care providers. While the study will measure patient activation (individual's confidence, knowledge and skills for self-management), it is also important to understand more specifically, the role of ACESO in bringing about patient engagement.

Perceived quality of life

While ACESO will help the patients monitor various aspects of their quality of life which are specific to breast cancer patients, such as fatigue, weight, sexual function, mental health and sleep quality, it is also important to understand the patient's perception of the role of ACESO in helping them maintain their quality of life. This will help in understanding the patients' perceived utility of ACESO in helping them manage various quality of life indicators.

Compliance with follow-up

One of the goals of ACESO is to help the users stay on track with their follow up schedule by using timely reminders of upcoming follow p activities via email as well as on the website. Patient compliance with follow up can be measured by

logs of each follow up visit (patient self-reported), which may be further verified with the patient's follow up care plan, as described in their breast cancer survivorship plan.

It is hoped that this technology would make a positive and significant impact on the patient's life in the form of an active and useful resource, in the absence of a similar alternative, for recent breast cancer survivors.

BIBLIOGRAPHY

Abernethy, A. P., Ahmad, A., Zafar, S. Y., Wheeler, J. L., Reese, J. B., & Lyerly, H. K. (2010). Electronic Patient-Reported Data Capture as a Foundation of Rapid Learning Cancer Care. *Medical Care*, *48*, S32–S38. http://doi.org/10.1097/MLR.0b013e3181db53a4

Abernethy, A. P., Herndon, J. E., Wheeler, J. L., Patwardhan, M., Shaw, H., Lyerly, H. K., & Weinfurt, K. (2008). Improving health care efficiency and quality using tablet personal computers to collect research-quality, patient-reported data. *Health Serv Res*, *43*, 1975–91. http://doi.org/10.1111/j.1475-6773.2008.00887.x

Abras, C., Maloney-Krichmar, D., & Preece, J. (2004). User-Centered Design. In *Encyclopedia of Human-Computer Interaction*. Thousand Oaks: Sage Publications.

Alsos, O. A., Das, A., & Svanæs, D. (2012). Mobile health IT: The effect of user interface and form factor on doctor–patient communication. *International Journal of Medical Informatics*, *81*(1), 12–28. http://doi.org/10.1016/j.ijmedinf.2011.09.004

Am, G., Es, M., Pa, S., Bw, E., & Db, P. (1999). Evaluation of a breast cancer patient information and support program. *Effective Clinical Practice : ECP*, *3*(4), 157–165.

Ant Ozok, A., Wu, H., Garrido, M., Pronovost, P. J., & Gurses, A. P. (2014). Usability and perceived usefulness of Personal Health Records for preventive health care:

a case study focusing on patients' and primary care providers' perspectives. Applied Ergonomics, 45(3), 613–628. http://doi.org/10.1016/j.apergo.2013.09.005

Anthony, R. N. (1965). *Planning and Control Systems: A Framework for Analysis*. Harvard University Press.

AT&T: mHealth Diabetes Pilot Shows Promise. (2012, August 28). Retrieved April 2, 2016, from http://www.rcrwireless.com/20120828/wireless/att-mobile-diabetes-management-shows-success

Backonja, U., Kim, K., Casper, G., Patton, T., Ramly, E., & Brennan, P. F. (2012). *Observations of Daily Living: Putting the "Personal" in Personal Health Record*. Presented at the 11th National Congress on Nursing Informatics.

Ball, M. J., Smith, C., & Bakalar, R. S. (2007). Personal health records: empowering consumers. *J Healthc Inf Manag*, *21*, 76–86.

Bannon, L. (1992). Design at Work. In J. Greenbaum & M. Kyng (Eds.), (pp. 25–44). Hillsdale, NJ, USA: L. Erlbaum Associates Inc. Retrieved from http://dl.acm.org/citation.cfm?id=125470.125458

Beck, S. L., Schwartz, A. L., Towsley, G., Dudley, W., & Andrea Barsevick, A. (2004). Psychometric evaluation of the Pittsburgh sleep quality index in cancer patients. *Journal of Pain and Symptom Management*, *27*, 140–148.

Bensing, J. (1991). Doctor-patient communication and the quality of care. *Social Science & Medicine*, *32*(11), 1301–1310. http://doi.org/10.1016/0277-9536(91)90047-G

Bensing, J. M., Brink-Muinen, A. van den, Boerma, W., & Dulmen, S. van. (2013). The manifestation of job satisfaction in doctor-patient communication; a ten-country European study. *52*. Retrieved from http://repository.ubn.ru.nl/handle/2066/126141

Bloomfield, H. E., Krause, A., Greer, N., Taylor, B. C., MacDonald, R., Rutks, I., … Wilt, T. J. (2011). Meta-analysis: effect of patient self-testing and self-management of long-term anticoagulation on major clinical outcomes. *Ann Intern Med*, *154*, 472–82. http://doi.org/10.1059/0003-4819-154-7-201104050-00005

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *JAMA*, *288*, 2469–75.

Bower, J. E., Ganz, P. A., Desmond, K. A., Rowland, J. H., Meyerowitz, B. E., & Belin, T. R. (2000). Fatigue in Breast Cancer Survivors: Occurrence, Correlates, and Impact on Quality of Life. *Journal of Clinical Oncology*, *18*, 743–753.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. http://doi.org/10.1191/1478088706qp063oa

Brennan, P. F., Downs, S., & Casper, G. (2010). Project HealthDesign: rethinking the power and potential of personal health records. *J Biomed Inform*, *43*, S3–5. http://doi.org/10.1016/j.jbi.2010.09.001

Brennan, P. F., & Kwiatkowski, K. (2003). How do lay people manage health information in the home. *Proceedings, 8th International Congress in Nursing Informatics. New York: Elsevier.*

Buysse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh Sleep Quality Index (PSQI): A new instrument for psychiatric research and practice. *Psychiatry Research*, *28*, 193–213.

Cappiello, M., Cunningham, R. S., Knobf, M. T., & Erdos, D. (2007). Breast cancer survivors: information and support after treatment. *Clin Nurs Res*, *16*, 278–93; discussion 294–301. http://doi.org/10.1177/1054773807306553

Cappiello, M., Cunningham, R. S., Knobf, M. T., & Erdos, D. (2007). Breast Cancer Survivors Information and Support After Treatment. *Clinical Nursing Research*, *16*(4), 278–293. http://doi.org/10.1177/1054773807306553

Carpenter, J. S., Elam, J. L., Ridner, S. H., Carney, P. H., Cherry, G. J., & Cucullu, H. L. (2007). Sleep, Fatigue, and Depressive Symptoms in Breast Cancer Survivors and Matched Healthy Women Experiencing Hot Flashes. *Oncology Nursing Forum*, *31*, 591–598. http://doi.org/10.1188/04.ONF.591-598

Chin, R, & Lee, BY. (2008). *Economics and patient reported outcomes, Principles and practice of clinical trial medicine*. Elsevier.

Cimprich, B., Janz, N. K., Northouse, L., Wren, P. A., Given, B., & Given, C. W. (2005). Taking CHARGE: A self-management program for women following breast cancer treatment. *Psychooncology*, *14*, 704–17. http://doi.org/10.1002/pon.891

Ciolko, E., Lu, F., & Joshi, A. (2010). Intelligent clinical decision support systems based on SNOMED CT. *Conference Proceedings: ... Annual International Conference of the IEEE Engineering in Medicine and Biology Society. IEEE*

Engineering in Medicine and Biology Society. Annual Conference, *2010*, 6781–6784. http://doi.org/10.1109/IEMBS.2010.5625982

Civan, A., Skeels, M. M., Stolyar, A., & Pratt, W. (2006). Personal health information management: consumers' perspectives. *AMIA Annu Symp Proc*, 156–60.

Cornet, R., Stoicu-Tivadar, L., & Hörbst, A. (2015). *Digital Healthcare Empowering Europeans: Proceedings of MIE2015*. IOS Press.

Davis, F. D. (1989). Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology. *MIS Q.*, *13*(3), 319–340. http://doi.org/10.2307/249008

Davis, R. E., Jacklin, R., Sevdalis, N., & Vincent, C. A. (2007). Patient involvement in patient safety: what factors influence patient participation and engagement? *Health Expectations*, *10*(3), 259–267. http://doi.org/10.1111/j.1369-7625.2007.00450.x

Deshpande, P. R., Rajan, S., Sudeepthi, B. L., & Abdul Nazir, C. P. (2011). Patient-reported outcomes: A new era in clinical research. *Perspectives in Clinical Research*, *2*(4), 137–144. http://doi.org/10.4103/2229-3485.86879

Dillon, A., & Morris, M. G. (1996). User Acceptance of Information Technology: Theories and Models. *Annual Review of Information Science and Technology (ARIST)*, *31*, 3–32.

Dix, A., Finlay, J., Abowd, G., & Beale, R. (1997). *Human-computer Interaction*. Upper Saddle River, NJ, USA: Prentice-Hall, Inc.

Do, Nhan VBarnhill, RickHeermann-Do, Kimberly ASalzman, Keith LGimbel, Ronald WJ Am Med Inform Assoc. 2011 Mar-Apr;18(2). (n.d.).

Do, N. V., Barnhill, R., Heermann-Do, K. A., Salzman, K. L., & Gimbel, R. W. (2011). The military health system's personal health record pilot with Microsoft HealthVault and Google Health. *J Am Med Inform Assoc*, *18*, 118–24. http://doi.org/10.1136/jamia.2010.004671

Dow, K. H., Ferrell, B. R., Leigh, S., Ly, J., & Gulasekaram, P. (1996). An evaluation of the quality of life among long-term survivors of breast cancer. *Breast Cancer Research and Treatment*, *39*(3), 261–273. http://doi.org/10.1007/BF01806154

Ericsson KA, & Simon, H. (1984). How to study thinking in everyday life: Contrasting think-aloud protocols with descriptions and explanations of thinking. *Mind, Culture and Activity*, *5*(3), 178–186.

Eveleigh, R. M., Muskens, E., van Ravesteijn, H., van Dijk, I., van Rijswijk, E., & Lucassen, P. (2012). An overview of 19 instruments assessing the doctor-patient relationship: different models or concepts are used. *Journal of Clinical Epidemiology*, *65*(1), 10–15. http://doi.org/10.1016/j.jclinepi.2011.05.011

Fann, J. R., Thomas-Rich, A. M., Katon, W. J., Cowley, D., Pepping, M., McGregor, B. A., & Gralow, J. (2008a). Major depression after breast cancer: a review of epidemiology and treatment. *Gen Hosp Psychiatry*, *30*, 112–26. http://doi.org/10.1016/j.genhosppsych.2007.10.008

Fann, J. R., Thomas-Rich, A. M., Katon, W. J., Cowley, D., Pepping, M., McGregor, B. A., & Gralow, J. (2008b). Major depression after breast cancer: a review of

epidemiology and treatment. *Gen Hosp Psychiatry*, *30*, 112–26. http://doi.org/10.1016/j.genhosppsych.2007.10.008

Farzanfar, R., Finkelstein, J., & Friedman, R. H. (2004). Testing the Usability of Two Automated Home-Based Patient-Management Systems. *Journal of Medical Systems*, *28*(2), 143–153. http://doi.org/10.1023/B:JOMS.0000023297.50379.3c

Ferguson, G., Quinn, J., Horwitz, C., Swift, M., Allen, J., & Galescu, L. (2010). Towards a Personal Health Management Assistant. *Journal of Biomedical Informatics*, *43*(5, Supplement), S13–S16. http://doi.org/10.1016/j.jbi.2010.05.014

Fillon, M. (2015). New Tool Improves Doctor–Patient Communication. *Journal of the National Cancer Institute*, *107*(4), djv116. http://doi.org/10.1093/jnci/djv116

Fobair, P., Stewart, S. L., Chang, S., D'Onofrio, C., Banks, P. J., & Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psychooncology*, *15*, 579–94. http://doi.org/10.1002/pon.991

Fuji, K. T., Abbott, A. A., & Galt, K. A. (2014). Personal Health Record Design: Qualitative Exploration of Issues Inhibiting Optimal Use. *Diabetes Care*, *37*(1), e13–e14. http://doi.org/10.2337/dc13-1630

Full Text PDF. (n.d.). Retrieved from http://jamia.oxfordjournals.org/content/jaminfo/16/5/683.full.pdf

Ganz, P. A., Desmond, K. A., Belin, T. R., Meyerowitz, B. E., & Rowland, J. H. (1999). Predictors of sexual health in women after a breast cancer diagnosis. *J Clin Oncol*, *17*, 2371–80.

Ganz, P. A., Kwan, L., Stanton, A. L., Krupnick, J. L., Rowland, J. H., Meyerowitz, B. E., … Belin, T. R. (2004). Quality of Life at the End of Primary Treatment of Breast Cancer: First Results From the Moving Beyond Cancer Randomized Trial. *Journal of the National Cancer Institute*, *96*(5), 376–387. http://doi.org/10.1093/jnci/djh060

Ganz, P. A., Rowland, J. H., Desmond, K., Meyerowitz, B. E., & Wyatt, G. E. (1998). Life after breast cancer: understanding women's health-related quality of life and sexual functioning. *Journal of Clinical Oncology*, *16*, 501–514.

Goel, M. S., Brown, T. L., Williams, A., Hasnain-Wynia, R., Thompson, J. A., & Baker, D. W. (2011). Disparities in Enrollment and Use of an Electronic Patient Portal. *Journal of General Internal Medicine*, *26*(10), 1112–1116. http://doi.org/10.1007/s11606-011-1728-3

Goh Kim, N., Syafiq, M. A., Sugathan, S. K., Chen Yoke, Y., & Akhir, E. A. P. (2010). The development of a rule-based asthma system (Vol. 3, pp. 1104–1108). Presented at the Information Technology (ITSim), 2010 International Symposium in. http://doi.org/10.1109/itsim.2010.5561614

Goldzweig, C. L., Orshansky, G., Paige, N. M., Towfigh, A. A., Haggstrom, D. A., Miake-Lye, I., … Shekelle, P. G. (2013). Electronic Patient Portals: Evidence on Health Outcomes, Satisfaction, Efficiency, and AttitudesA Systematic Review. *Annals of Internal Medicine*, *159*(10), 677–687. http://doi.org/10.7326/0003-4819-159-10-201311190-00006

Goodwin, P. J., Leszcz, M., Ennis, M., Koopmans, J., Vincent, L., Guther, H., … Hunter, J. (2001). The Effect of Group Psychosocial Support on Survival in Metastatic Breast Cancer. *New England Journal of Medicine*, *345*(24), 1719–1726. http://doi.org/10.1056/NEJMoa011871

Greibe, K. (2013). Development of a SNOMED CT based national medication decision support system. *Studies in Health Technology and Informatics*, *192*, 1147.

Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. (2006). *Health and Quality of Life Outcomes*, *4*, 79. http://doi.org/10.1186/1477-7525-4-79

Gysels, M., Richardson, A., & Higginson, I. J. (2007). Does the patient-held record improve continuity and related outcomes in cancer care: a systematic review. *Health Expectations*, *10*(1), 75–91. http://doi.org/10.1111/j.1369-7625.2006.00415.x

Hayes, D. F. (2007). Follow-up of Patients with Early Breast Cancer. *New England Journal of Medicine*, *356*(24), 2505–2513. http://doi.org/10.1056/NEJMcp067260

Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res*, *39*, 1005–26. http://doi.org/10.1111/j.1475-6773.2004.00269.x

Holzinger, A. (2005). Usability Engineering Methods for Software Developers. *Commun. ACM*, *48*(1), 71–74. http://doi.org/10.1145/1039539.1039541

Hong, Y., Goldberg, D., Dahlke, D. V., Ory, M. G., Cargill, J. S., Coughlin, R., … Peres, S. C. (2014). Testing Usability and Acceptability of a Web Application to Promote Physical Activity (iCanFit) Among Older Adults. *JMIR Human Factors*, *1*(1), e2. http://doi.org/10.2196/humanfactors.3787

ihtsdo.org -. (n.d.). Retrieved April 3, 2016, from http://www.ihtsdo.org/snomed-ct/what-is-snomed-ct

Irizarry, T., DeVito Dabbs, A., & Curran, C. R. (2015). Patient Portals and Patient Engagement: A State of the Science Review. *Journal of Medical Internet Research*, *17*(6), e148. http://doi.org/10.2196/jmir.4255

Jan-Benedict E. M Steenkamp, M. G. de J. (2010). Socially Desirable Response Tendencies in Survey Research. *Journal of Marketing Research - J MARKET RES-CHICAGO*, *47*(2), 199–214. http://doi.org/10.1509/jmkr.47.2.199

Joshi, A., Wilhelm, S., Aguirre, T., Trout, K., & Amadi, C. (2013). An interactive, bilingual touch screen program to promote breastfeeding among Hispanic rural women: usability study. *JMIR Research Protocols*, *2*(2), e47. http://doi.org/10.2196/resprot.2872

Kapoor, A., & Nambisan, P. (2016). Implementing Clinical Guidelines: An Online Breast Cancer Survivorship Tool for Education and Knowledge Representation. Presented at the IEEE International Conference on Biomedical and Health Informatics (BHI), Las Vegas, NV: IEEE. Retrieved from http://emb.citengine.com/event/bhi-2016/paper-details?pdID=7636

Kapoor, A., & Nambisan, P. (2015). ACESO (After Cancer Education and Support Operations): a clinical decision support system approach for engaging breast cancer survivors. Presented at the American Medical Informatics Association Annual Symposium, San Francisco, CA, USA. Retrieved from https://knowledge.amia.org/59310-amia-1.2741865/t005-1.2744350/f005-1.2744351/2248784-1.2745076/2248784-1.2745077?timeStamp=1460612790311

Khatcheressian, J. L., Wolff, A. C., Smith, T. J., Grunfeld, E., Muss, H. B., Vogel, V. G., … Davidson, N. E. (2006). American Society of Clinical Oncology 2006 update of the breast cancer follow-up and management guidelines in the adjuvant setting. *J Clin Oncol*, *24*, 5091–7. http://doi.org/10.1200/JCO.2006.08.8575

Kim, E., Wang, M., Lau, C., & Kim, Y. (2004). Application and Evaluation of Personal Health Information Management System. *Proceedings of the 26th Annual International Conference of the IEEE EMBS*.

Kim, J., Park, J., Kim, H., & Lee, C. (2007). HCI (Human Computer Interaction) Using Multi-touch Tabletop Display.

Kim, M. S., Aro, M. R., Lage, K. J., Ingalls, K. L., Sindhwani, V., & Markey, M. K. (2016a). Exploring the Usability of Mobile Apps Supporting Radiologists' Training in Diagnostic Decision Making. *Journal of the American College of Radiology: JACR*, *13*(3), 335–343. http://doi.org/10.1016/j.jacr.2015.07.021

Kim, M. S., Aro, M. R., Lage, K. J., Ingalls, K. L., Sindhwani, V., & Markey, M. K. (2016b). Exploring the Usability of Mobile Apps Supporting Radiologists' Training in Diagnostic Decision Making. *Journal of the American College of Radiology: JACR*, *13*(3), 335–343. http://doi.org/10.1016/j.jacr.2015.07.021

Kohout, F. J., Berkman, L. F., Evans, D. A., & Cornoni-Huntley, J. (1993). Two Shorter Forms of the CES-D Depression Symptoms Index. *Journal of Aging and Health*, *5*, 179–193.

Kreps, G. L., & Neuhauser, L. (2010). New directions in eHealth communication: opportunities and challenges. *Patient Education and Counseling*, *78*(3), 329–336. http://doi.org/10.1016/j.pec.2010.01.013

Kruse, C. S., Bolton, K., & Freriks, G. (2015). The Effect of Patient Portals on Quality Outcomes and Its Implications to Meaningful Use: A Systematic Review. Journal of Medical Internet Research, 17(2). http://doi.org/10.2196/jmir.3171

Kushniruk, A. W., Patel, V. L., & Cimino, J. J. (1997). Usability testing in medical informatics: cognitive approaches to evaluation of information systems and user interfaces. *Proceedings of the AMIA Annual Fall Symposium*, 218–222.

Lardinois, F. (2009). Personal Health Records: Lots of Interest, but Few Users.

Lasry, J. M., Margolese, R. G., Poisson, R., Shibata H, Fleischer, D., Lafleur, D., … Taillefer, S. (1987). Depression and body image following mastectomy and lumpectomy. *Journal of Chronic Diseases*, *40*, 529–534.

Leedham, B., & Ganz, P. A. (1999). Psychosocial Concerns and Quality of Life in Breast Cancer Survivors. *Cancer Investigation*, *17*(5), 342–348. http://doi.org/10.3109/07357909909032876

Lee KA, Hicks G, & Nino-Murcia G. (1991). Validity and reliability of a scale to assess fatigue. *Psychiatry Research*, *36*, 291–298.

Lenore Sawyer Radloff. (1977). The CES-D Scale A Self-Report Depression Scale for Research in the General Population. *Applied Psychological Measurement*, *1*, 385–401.

Lerdal, A., Kottorp, A., Gay, C. L., & Lee, K. A. (2012). Development of a short version of the Lee Visual Analogue Fatigue Scale in a sample of women with HIV/AIDS: a Rasch analysis application. *Qual Life Res*. http://doi.org/10.1007/s11136-012-0279-3

Lewis, C., & Wharton, C. (1997). *Cognitive Walkthroughs. Handbook of Human-Computer Interaction* (2nd ed.). Elsevier.

Li, Y. C., Detmer, D. E., Shabbir, S. A., Nguyen, P. A., Jian, W. S., Mihalas, G. I., … Kimura, M. (2012). A global travelers' electronic health record template standard for personal health records. *J Am Med Inform Assoc*, *19*, 134–6. http://doi.org/10.1136/amiajnl-2011-000323

Li, Yu-ChuanDetmer, Don EShabbir, Syed-AbdulNguyen, Phung AnhJian, Wen-ShanMihalas, George IShortliffe, Edward HTang, Pa. (n.d.).

Lober, W. B., Zierler, B., Herbaugh, A., Shinstrom, S. E., Stolyar, A., Kim, E. H., & Kim, Y. (2006). Barriers to the use of a Personal Health Record by an Elderly Population. *AIMA 2006 Symposium Proceedings*, *514-518*.

Lubberding, S., van Uden-Kraan, C. F., Te Velde, E. A., Cuijpers, P., Leemans, C. R., & Verdonck-de Leeuw, I. M. (2015). Improving access to supportive cancer care through an eHealth application: a qualitative needs assessment among cancer survivors. Journal of Clinical Nursing, 24(9-10), 1367–1379. http://doi.org/10.1111/jocn.12753

Lui, L., Shih, P. C., & Hayes, G. R. (2011). Barriers to the Adoption and Use of Personal Health Record Systems.

Luo, G., Tang, C., & Thomas, S. B. (2010). Intelligent Personal Health Record: Experience and Open Issues.

Maheronnaghsh, R., Nezareh, S., Sayyah, M.-K., & Rahimi-Movaghar, V. (2013). Developing SNOMED-CT for decision making and data gathering: a software prototype for low back pain. *Acta Medica Iranica*, *51*(8), 548–553.

Mantena, S., & Schadow, G. (2007). Evaluation of the VA/KP problem list subset of SNOMED as a clinical terminology for electronic prescription clinical decision support. *AMIA ... Annual Symposium Proceedings / AMIA Symposium. AMIA Symposium*, 498–502.

Markle Foundation. (2003). *Connecting for Health. The personal health working group final report.* Markle Foundation.

Mary Rucklos Hampton, I. F. (2000). Women's Experience of Traumatic Stress in Cancer Treatment. *Health Care for Women International*, *21*(1), 67–76. http://doi.org/10.1080/073993300245410

Matusitz, J., & Spear, J. (2014). Effective Doctor–Patient Communication: An Updated Examination. *Social Work in Public Health*, *29*(3), 252–266. http://doi.org/10.1080/19371918.2013.776416

Mayer, D. K., Terrin, N. C., Kreps, G. L., Menon, U., McCance, K., Parsons, S. K., & Mooney, K. H. (2007). Cancer survivors information seeking behaviors: A comparison of survivors who do and do not seek information about cancer. *Patient Education and Counseling*, *65*(3), 342–350. http://doi.org/10.1016/j.pec.2006.08.015

McConnell, S. (1996). *Rapid Development: Taming Wild Software Schedules* (1st ed.). Redmond, WA, USA: Microsoft Press.

McLeod, J. (2001). *Qualitative Research in Counselling and Psychotherapy*. SAGE.

Mehdi Sagheb-Tehrani. (1993). The Technology of Expert Systems: Some Social Impacts. *Computers & Society*, *23*.

Mendoza, T. R., Wang, X. S., Cleeland, C. S., Morrissey, M., Johnson, B. A., Wendt, J. K., & Huber, S. L. (1999). The rapid assessment of fatigue severity in cancer patients. *Cancer*, *85*(5), 1186–1196. http://doi.org/10.1002/(SICI)1097-0142(19990301)85:5<1186::AID-CNCR24>3.0.CO;2-N

Meyerowitz, B. E., Desmond, K. A., Rowland, J. H., Wyatt, G. E., & Ganz, P. A. (1999). Sexuality following breast cancer. *J Sex Marital Ther*, *25*, 237–50. http://doi.org/10.1080/00926239908403998

Mirkovic, J., Kaufman, D. R., & Ruland, C. M. (2014a). Supporting cancer patients in illness management: usability evaluation of a mobile app. *JMIR mHealth and uHealth*, *2*(3), e33. http://doi.org/10.2196/mhealth.3359

Mirkovic, J., Kaufman, D. R., & Ruland, C. M. (2014b). Supporting cancer patients in illness management: usability evaluation of a mobile app. *JMIR mHealth and uHealth*, *2*(3), e33. http://doi.org/10.2196/mhealth.3359

Molaee Zadeh, M., Shahandeh, K., Bigdeli, S., & Basseri, H. R. (2014). Conflict in Neighboring Countries, a Great Risk for Malaria Elimination in Southwestern Iran: Narrative Review Article. *Iranian Journal of Public Health*, *43*(12), 1627–1634.

Montazeri, A., Jarvandi, S., Haghighat, S., Vahdani, M., Sajadian, A., Ebrahimi, M., & Haji-Mahmoodi, M. (2001). Anxiety and depression in breast cancer patients before and after participation in a cancer support group. *Patient Education and Counseling*, *45*(3), 195–198. http://doi.org/10.1016/S0738-3991(01)00121-5

Murthy, G. R. S., & Jadon R. S. (2011). Computer Vision Based Human Computer Interaction. *Journal of Artificial Intelligence*, *4*, 245–256.

Nambisan, P. (2010). Online public health preparedness training programs: an evaluation of user experience with the technological environment. *Online Journal of Public Health Informatics*, *2*(3). http://doi.org/10.5210/ojphi.v2i3.3012

Nambisan, P. (2011). Evaluating patient experience in online health communities: Implications for health care organizations. *Health Care Management Review*, *36*(2), 124–133. http://doi.org/10.1097/HMR.0b013e3182099f82

Nambisan, P., Gustafson, D., Pingree, S., & Hawkins, R. (2010). Patients' sociability and usability experience in online health communities: impact on attitudes towards the healthcare organisation and its services. *International Journal of Web Based Communities*, *6*(4), 395–409.

Nambisan, P., & Watt, J. H. (2011). Managing customer experiences in online product communities. *Journal of Business Research*, *64*(8), 889–895.

Nazi, K. M., Hogan, T. P., Wagner, T. H., McInnes, D. K., Smith, B. M., Haggstrom, D., … Weaver, F. M. (2010). Embracing a health services research perspective on personal health records: lessons learned from the VA My HealtheVet system. *J Gen Intern Med*, *25 Suppl 1*, 62–7. http://doi.org/10.1007/s11606-009-1114-6

NCI Community Cancer Centers Program. (2008, 08). Breast Cancer Survivorship Care Plan. National Cancer Institute.

Nielsen, J. (1993). *Usability Engineering*. San Francisco, CA, USA: Morgan Kaufmann Publishers Inc.

Nielsen, J., Clemmensen, T., & Yssing, C. (2002). Getting Access to What Goes on in People's Heads?: Reflections on the Think-aloud Technique. In *Proceedings of the Second Nordic Conference on Human-computer Interaction* (pp. 101–110). New York, NY, USA: ACM. http://doi.org/10.1145/572020.572033

Noblin, A. M., Wan, T. T. H., & Fottler, M. (2012). The Impact of Health Literacy on a Patient's Decision to Adopt a Personal Health Record. *Perspectives in Health Information Management / AHIMA, American Health Information Management Association*, *9*(Fall). Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3510648/

Norman, D. A., & Draper, S. W. (1986). *User Centered System Design; New Perspectives on Human-Computer Interaction*. Hillsdale, NJ, USA: L. Erlbaum Associates Inc.

Nutescu, E. A., Bathija, S., Sharp, L. K., Gerber, B. S., Schumock, G. T., & Fitzgibbon, M. L. (2011). Anticoagulation patient self-monitoring in the United States: considerations for clinical practice adoption. *Pharmacotherapy*, *31*, 1161–74. http://doi.org/10.1592/phco.31.12.1161

van Osch, M., Rövekamp, A., Bergman-Agteres, S. N., Wijsman, L. W., Ooms, S. J., Mooijaart, S. P., & Vermeulen, J. (2015). User preferences and usability of iVitality: optimizing an innovative online research platform for home-based health monitoring. Patient Preference and Adherence, 9, 857–867. http://doi.org/10.2147/PPA.S82510

Ross, S. E., & Lin, C.-T. (2003). The Effects of Promoting Patient Access to Medical Records: A Review. Journal of the American Medical Informatics Association, 10(2), 129–138. http://doi.org/10.1197/jamia.M1147

Palen, T. E., Bayliss, E. A., & Steiner, J. F. (2013). Are patient portals one key to unlocking the door for engaging patients in their healthcare? *Journal of Comparative Effectiveness Research*, *2*(2), 99–101. http://doi.org/10.2217/cer.13.8

Paskett, E. D., & Stark, N. (2000). Lymphedema: Knowledge, Treatment, and Impact Among Breast Cancer Survivors. *The Breast Journal*, *6*(6), 373–378. http://doi.org/10.1046/j.1524-4741.2000.99072.x

Payne, A. Y., Surikova, J., Liu, S., Ross, H., Mechetiuc, T., & Nolan, R. P. (2015). Usability Testing of an Internet-Based e-Counseling Platform for Adults With Chronic Heart Failure. *JMIR Human Factors*, *2*(1), e7. http://doi.org/10.2196/humanfactors.4125

PubMed entry. (n.d.). Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19567790

Radloff, L. S. (1977). The CES-D Scale A Self-Report Depression Scale for Research in the General Population. *Applied Psychological Measurement*, *1*(3), 385–401. http://doi.org/10.1177/014662167700100306

Roberts, C. S., Cox, C. E., Reintgen, D. S., Baile, W. F., & Gibertini, M. (1994). Influence of physician communication on newly diagnosed breast patients' psychologic adjustment and decision-making. Cancer, 74(S1), 336–341. http://doi.org/10.1002/cncr.2820741319

Roblin, D. W., Houston, T. K., Allison, J. J., Joski, P. J., & Becker, E. R. (2009). Disparities in Use of a Personal Health Record in a Managed Care Organization.

Journal of the American Medical Informatics Association, *16*(5), 683–689. http://doi.org/10.1197/jamia.M3169

Ross, S. E., Haverhals, L. M., Main, D. S., Bull, S. S., Pratte, K., & Lin, C.-T. (2006). Adoption and Use of an Online Patient Portal for Diabetes (Diabetes-STAR). AMIA Annual Symposium Proceedings, 2006, 1080.

Ross, S. E., & Lin, C.-T. (2003). The Effects of Promoting Patient Access to Medical Records: A Review. Journal of the American Medical Informatics Association, 10(2), 129–138. http://doi.org/10.1197/jamia.M1147

Royce, Winston W. (1970). Managing the Development of Large Software Systems. In *Technical Papers of Western Electronic Show and Convention (WesCon)* (pp. 25–28). Los Angeles, USA.

Rubin, J. (1994). *Handbook of Usability Testing: How to Plan, Design, and Conduct Effective Tests* (1st ed.). New York, NY, USA: John Wiley & Sons, Inc.

Ruland, C. M., White, T., Stevens, M., Fanciullo, G., & Khilani, S. M. (2003). Effects of a computerized system to support shared decision making in symptom management of cancer patients: preliminary results. *J Am Med Inform Assoc*, *10*, 573–9. http://doi.org/10.1197/jamia.M1365

Ruland, Cornelia MWhite, ThomasStevens, MargueriteFanciullo, GilbertKhilani, Samir MJ Am Med Inform Assoc. 2003 Nov-Dec; (n.d.).

Ryan, F., Byrne, S., & O'Shea, S. (2008). Managing oral anticoagulation therapy: improving clinical outcomes. A review. *J Clin Pharm Ther*, *33*, 581–90. http://doi.org/10.1111/j.1365-2710.2008.00959.x

Saleem, J. J., Haggstrom, D. A., Militello, L. G., Flanagan, M., Kiess, C. L., Arbuckle, N., & Doebbeling, B. N. (2011). Redesign of a computerized clinical reminder for colorectal cancer screening: a human-computer interaction evaluation. *BMC Med Inform Decis Mak*, *11*, 74. http://doi.org/10.1186/1472-6947-11-74

Satterlund, M. J., McCaul, K. D., & Sandgren, A. K. (2003). Information Gathering Over Time by Breast Cancer Patients. *Journal of Medical Internet Research*, *5*(3), e15. http://doi.org/10.2196/jmir.5.3.e15

Savard, J., Simard, S., Blanchet, J., Ivers, H., & Morin, C. M. (2001). Prevalence, Clinical Characteristics, and Risk Factors for Insomnia in the Context of Breast Cancer. *SLEEP*, *24*, 583–590.

Schefe, P. (1990). Impacts of expert systems on working life: an assessment. *AI Soc.*, *4*, 183–195. http://doi.org/10.1007/bf01889939

Shalom, M. M., Hahn, E. E., Casillas, J., & Ganz, P. A. (2011). Do Survivorship Care Plans Make a Difference? A Primary Care Provider Perspective. *Journal of Oncology Practice*, *7*(5), 314–318. http://doi.org/10.1200/JOP.2010.000208

Shaw, B. R., Han, J. Y., Baker, T., Witherly, J., Hawkins, R. P., McTavish, F., & Gustafson, D. H. (2007). How women with breast cancer learn using interactive cancer communication systems. *Health Education Research*, *22*(1), 108–119. http://doi.org/10.1093/her/cyl051

Sheila LaFortune Fredette. (2016, March 7). Breast cancer survivors: concerns and coping. : Cancer Nursing. Retrieved March 7, 2016, from

http://journals.lww.com/cancernursingonline/Fulltext/1995/02000/Breast_cancer_survivors__concerns_and_coping_.6.aspx

Simard, S., Thewes, B., Humphris, G., Dixon, M., Hayden, C., Mireskandari, S., & Ozakinci, G. (2013). Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. *Journal of Cancer Survivorship*, *7*(3), 300–322. http://doi.org/10.1007/s11764-013-0272-z

Singh, D. P. (2010). Quality of life in cancer patients receiving palliative care. *Indian Journal of Palliative Care*, *16*(1), 36–43. http://doi.org/10.4103/0973-1075.63133

Smets, E. M., Garssen, B., Schuster-Uitterhoeve, A. L., & de Haes, J. C. (1993). Fatigue in cancer patients. *British Journal of Cancer*, *68*, 220–224.

Snapshot. (n.d.). Retrieved from http://jamia.oxfordjournals.org/content/16/5/683.long

Snyder, C. F., Blackford, A. L., Aaronson, N. K., Detmar, S. B., Carducci, M. A., Brundage, M. D., & Wu, A. W. (2011). Can patient-reported outcome measures identify cancer patients' most bothersome issues? *J Clin Oncol*, *29*, 1216–20. http://doi.org/10.1200/JCO.2010.33.2080

Steenkamp, J.-B. E. ., de Jong, M. G., & Baumgartner, H. (2010). Socially Desirable Response Tendencies in Survey Research. *Journal of Marketing Research*, *47*(2), 199–214. http://doi.org/10.1509/jmkr.47.2.199

Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: a review. CMAJ: Canadian Medical Association Journal = Journal de l'Association Medicale Canadienne, 152(9), 1423–1433.

Tang, Paul CAsh, Joan SBates, David WOverhage, J MarcSands, Daniel ZJ Am Med Inform Assoc. 2006 Mar-Apr;13(2):121-6. Epu. (n.d.).

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc*, *13*, 121–6. http://doi.org/10.1197/jamia.M2025

Taylor, F. W. (1911). *The principles of scientific management*. New York, London, Harper & Brothers. Retrieved from http://archive.org/details/principlesofscie00taylrich

Travers, M. (2001). *Qualitative Research through Case Studies*. SAGE.

Tucker, A. B. (2004). *Computer Science Handbook, Second Edition*. CRC Press.

Tzeng, S.-W., & Zhou, Y. (2013). Design Guidelines for an Integrated PHR System: An Approach for UI Designers to Break Down Individual-Level Barriers to PHR Adoption. In C. Stephanidis & M. Antona (Eds.), *Universal Access in Human-Computer Interaction. Applications and Services for Quality of Life* (pp. 553–562). Springer Berlin Heidelberg. Retrieved from http://link.springer.com/chapter/10.1007/978-3-642-39194-1_64

Wang, A. Y., Sable, J. H., & Spackman, K. A. (2002). The SNOMED clinical terms development process: refinement and analysis of content. *Proceedings / AMIA ... Annual Symposium. AMIA Symposium*, 845–849.

Watts, R. J. (1982). Sexual functioning, health beliefs, and compliance with high blood pressure medications. *Nursing Research*, *31*, 278–282.

Weingart, Saul NRind, DavidTofias, ZacharySands, Daniel Z1 K08 HS 11644/HS/AHRQ HHS/J Am Med Inform Assoc. 2006 Jan-Feb; (n.d.).

Weingart, S. N., Rind, D., Tofias, Z., & Sands, D. Z. (2006). Who uses the patient internet portal? The PatientSite experience. *J Am Med Inform Assoc*, *13*, 91–5. http://doi.org/10.1197/jamia.M1833

Wen, K.-Y., Kreps, G., Zhu, F., & Miller, S. (2010). Consumers' perceptions about and use of the internet for personal health records and health information exchange: analysis of the 2007 Health Information National Trends Survey. *Journal of Medical Internet Research*, *12*(4), e73. http://doi.org/10.2196/jmir.1668

Yamin, C. K., Emani, S., Williams, D. H., Lipsitz, S. R., Karson, A. S., Wald, J. S., & Bates, D. W. (2011). The digital divide in adoption and use of a personal health record. *Archives of Internal Medicine*, *171*(6), 568–574. http://doi.org/10.1001/archinternmed.2011.34

Zarcadoolas, C., Vaughon, W. L., Czaja, S. J., Levy, J., & Rockoff, M. L. (2013). Consumers' Perceptions of Patient-Accessible Electronic Medical Records. *Journal of Medical Internet Research*, *15*(8). http://doi.org/10.2196/jmir.2507

APPENDICES

Appendix A: Institutional Review Board (IRB) Documents

UNIVERSITY of WISCONSIN
UWMILWAUKEE
Department of University Safety & Assurances

Melissa Spadanuda
IRB Manager
Institutional Review Board
Engelmann 270
P. O. Box 413
Milwaukee, WI 53201-0413
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spadanud@uwm.edu

New Study - Notice of IRB Expedited Approval

Date: August 27, 2015

To: Priya Nambisan, PhD
Dept: Health Informatics and Administration

CC: Akshat Kapoor

IRB#: 16.049
Title: Patient acceptance and usability testing of an online breast cancer survivorship tool

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been approved as minimal risk Expedited under Category 6 and 7 as governed by 45 CFR 46.110.

In addition, your protocol has been granted **Level 3** confidentiality for Payments to Research Subjects per UWM Accounting Services Procedure: 2.4.6.

This protocol has been approved on **August 27, 2015** for one year. IRB approval will expire on **August 26, 2016**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, a continuation for IRB approval must be filed by the submission deadline. If the study is closed or completed before the IRB expiration date, please notify the IRB by completing and submitting the Continuing Review form found in IRBManager.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. It is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the UWM IRB, maintain proper documentation of study records and promptly report to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project.

Respectfully,
[redacted]
Melissa C. Spadanuda
IRB Manager

UNIVERSITY OF WISCONSIN – MILWAUKEE
CONSENT TO PARTICIPATE IN RESEARCH

THIS CONSENT FORM HAS BEEN APPROVED BY THE IRB FOR A ONE YEAR PERIOD

1. General Information

Study title:
Patient acceptance and usability testing of an online breast cancer survivorship tool

Person in Charge of Study (Principal Investigator):
Dr. Priya Nambisan, Ph.D, Assistant Professor, Department of Health Care and Administration, UWM

2. Study Description

You are being asked to participate in a research study. Your participation is completely voluntary. You do not have to participate if you do not want to.

Study description:
The purpose of this study is to understand the user's attitude and usability experience from testing an online breast cancer survivorship tool. The goal of the study is to gather patient experience and opinions to guide the development of a user friendly, effective and intuitive prototype of the app. The study will consist of a single one-on-one session approximately 90 minutes.

3. Study Procedures

What will I be asked to do if I participate in the study?
If you agree to participate you will be asked to meet with a member of the research team once, for a an individual/one-on-one session to help test the app and answer a few questions regarding your attitude towards using such apps and your experience from testing the app provided to you during the session.

You will only need to meet with a member of the research team once, at a place of your convenience: either at the UWM campus, or your residence, or a public meeting place, depending on your preference.

The session will consist of the following activities (in order):

1) In-depth interview: Your general opinion towards the availability and use of such an app will be gathered via a set of questions you will answer orally. (~20 minutes)
2) Prototype demo: You will be given a quick demo of the prototype of the app and its functions and features. (~10 minutes)

3) Usability testing: You will be given a short list of small tasks to perform on the app. You will be provided instructions and will use test data to perform the tasks. No personal health information will be collected. We will record the time taken by you to complete each of the tasks. Instructions will be provided to complete the tasks and you may ask for assistance at any time. (~20 minutes)
4) In-depth interview: Your opinion and experience based on the demo and your testing of the app will be recorded. (~20 minutes)
5) Online anonymous survey: You will be asked to complete an anonymous online survey to assess your online experience while testing the app. (~10 minutes)

Your responses to the interview questions as well as your opinions during the prototype demo will be audio taped in order to record your responses for further analysis. Recording these responses are vital to the research goals and thus is required for participation. All data collected, including audio recordings will be de-identified and will not be published in whole, or with any accompanying identifying information.

4. Risks and Minimizing Risks

What risks will I face by participating in this study?
There are no foreseeable risks for participating in this research study. All data collected will be de-identified and used anonymously for research purposes.

5. Benefits

Will I receive any benefit from my participation in this study?
While there will be no direct benefit to you, the results of the study will further contribute to the knowledge of developing more intuitive and useful personal health applications. The findings of the study will inform the development of a more streamlined, user friendly and effective app that is intended to help breast cancer survivors as they assume the role of managing their own health after treatment ends.

6. Study Costs and Compensation

Will I be charged anything for participating in this study?
You will not be responsible for any of the costs from taking part in this research study.

Are subjects paid or given anything for being in the study?
Upon successful completion of the study, you will be paid a $20 Target gift card. Please note that UWM employees are not eligible for this compensation.

7. Confidentiality

What happens to the information collected?
All information collected about you during the course of this study will be kept confidential to the extent permitted by law. We may decide to present what we find to others, or publish our results

in scientific journals or at scientific conferences. Only the PI and student PI will have access to the information. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records.

This document is the only place that contains any of your personal identifying information. In order to protect your confidentiality, this document will be stored securely in a locked cabinet until the completion of the study and will subsequently be destroyed after a period of two years.

8. Alternatives

Are there alternatives to participating in the study?
There are no known alternatives available to you other than not taking part in this study.

9. Voluntary Participation and Withdrawal

What happens if I decide not to be in this study?
Your participation in this study is entirely voluntary. You may choose not to take part in this study. If you decide to take part, you can change your mind later and withdraw from the study. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with the University of Wisconsin Milwaukee.

If you choose to withdraw from the study, we will use the information collected to that point.

10. Questions

Who do I contact for questions about this study?
For more information about the study or the study procedures or treatments, or to withdraw from the study, contact:

Dr. Priya Nambisan
Assistant Professor
Department of Health Informatics and Administration
College of Health Sciences
University of Wisconsin – Milwaukee
Northwest Quadrant Building B, Rm #6410
2400 East Hartford Avenue
Milwaukee, WI 53201-0413
Ph: (414) 229-7136; Fax: (414) 229-3373
Email: nambisap@uwm.edu

Who do I contact for questions about my rights or complaints towards my treatment as a research subject?
The Institutional Review Board may ask your name, but all complaints are kept in confidence.

Institutional Review Board
Human Research Protection Program
Department of University Safety and Assurances
University of Wisconsin – Milwaukee
P.O. Box 413
Milwaukee, WI 53201
(414) 229-3173

11. Signatures

Research Subject's Consent to Participate in Research:
To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study, you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read or had read to you this entire consent form, including the risks and benefits, and have had all of your questions answered, and that you are 18 years of age or older.

_____
Printed Name of Subject/ Legally Authorized Representative

_____ _____
Signature of Subject/Legally Authorized Representative Date

Research Subject's Consent to Audio Recording:

It is okay to audiotape me while I am in this study and use my audiotaped data in the research.

Please initial: ____Yes ____No

Principal Investigator (or Designee)
I have given this research subject information on the study that is accurate and sufficient for the subject to fully understand the nature, risks and benefits of the study.

_____ _____
Printed Name of Person Obtaining Consent Study Role

_____ _____
Signature of Person Obtaining Consent Date

Appendix B: Recruitment Materials

Opportunity to participate in study to test a new web app for breast cancer survivors

You are invited to participate in an IRB approved study (# 16.049-UWM) being conducted by researchers at the **University of Wisconsin**.

The study evaluates the acceptability and usability of an online breast cancer survivorship application. The study will be completed during an individual one-on-one session, which will be about an hour to an hour and a half.

Who is eligible?

- Breast Cancer Survivor (must have completed primary treatment (radiation, surgery and/or chemotherapy).
- Should be able to read, speak and understand English.

What do you have to do to participate?

You will be asked to help test a new web app for breast cancer survivors and give your opinions based on your experience with the app. All you have to do is to test the app by completing a few small tasks on the app and tell us about your experience after you have used it. The app will use test data and no personal health information will be collected.

Compensation

As a token of appreciation for participating in this study, you will receive a $20 Target gift card upon completion of the study.

If you have any questions or are interested in participating, contact:

Akshat Kapoor at email: akapoor@uwm.edu

Breast Cancer Survivor Research Study akapoor@uwm.edu
Breast Cancer Survivor Research Study akapoor@uwm.edu
Breast Cancer Survivor Research Study akapoor@uwm.edu
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Breast Cancer Survivor Research Study akapoor@uwm.edu
Breast Cancer Survivor Research Study akapoor@uwm.edu

Get Timely Alerts

Be informed. Take timely action.

Based on information collected from the survivor care plan, their medical history and any reported symptoms and observations, **aceso.me** issues customized, timely alerts to users, bringing to their attention the detection of any significant health patterns.

Resources

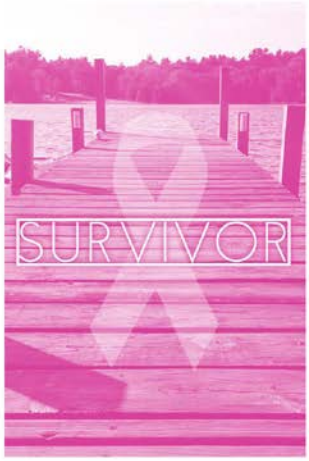
Learn, educate and empower yourself on various topics concerning breast cancer survivorship.

aceso.me will also include a resources module that will serve to educate and empower users about various aspects of their health condition and help improve their overall quality of life.

www.aceso.me
support@aceso.me

aceso.me

Healing Begins NOW



Report a symptom

Record any observed changes to your body, usually resulting from side-effects of treatment and medication.

Usually, the symptoms or observations expressed by the patient when not at the physician's office may largely go unnoticed.

Users may pick to report symptoms which are broadly divided into four categories: physical, mental and emotional, sexual function and other, which become part of their medical history. This recorded log of observed symptoms adds to the patient's medical history, enriching it further.

Named after the Greek goddess of healing, aceso (pronounced 'ah-kee-so') or, After Cancer Education and Self-management Operations is an active, intelligent tool that supports breast cancer survivors as they transition from hospital to home and begin to take charge of heir own health. Traditionally handed a paper document containing their survivorship plan, aceso.me works as an active tool to make the survivor experience somewhat more manageable.

My Health Record

Access your breast cancer related medical history: diagnosis, tests, procedures and medications. View recorded symptoms & your survivorship plan.

Having your breast cancer related health record accessible anytime, anywhere is not only valuable but also very convenient. A user is able to view various aspects of their breast cancer related medical history, such as diagnosis, tests, procedures, medications

Users are also able to access and view the paper version of their survivorship care plan provided by their provider.

"Yesterday I dared to struggle.
Today I dare to win."
– Bernadette Devlin

Tasks and Reminders

Stay on track! View list of pending observations of daily living and get appointment reminders for upcoming follow-up visits.

Making your passive paper survivorship plan into an active, actionable list of tasks, **aceso.me** takes all the guesswork out your care plan and reminds you when you need to record an observation of daily living , or visit your doctor for a follow up visit.

Observations of daily living (ODL) are personally meaningful cues to an individual's health condition. They further complement the more familiar symptoms the patients may already monitor. **aceso.me** tracks several such observations, such as fatigue, sleep quality, mood, sexual function, mental health, weight and self-breast exams.

Documenting and analyzing these ODLs can reveal certain patterns or changes in one's health, allowing for further insight and change in treatment plans.

Appendix C:

User testing questionnaires

Breast Cancer Online App: Usability and Acceptability User Screening Form

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Eliigibility

To see if you qualify for this study, we need to ask you some questions about your health history, present condition and access to various resources. Some of these questions may be sensitive and you do not have to answer any questions you do not wish to answer. If you do not qualify for this study, the information you provided here will be destroyed immediately and will never be used for any purpose:

I have completed primary breast cancer treatment (chemotherapy, surgery and/or radiation therapy)

- ❑ Yes
- ❑ No

I am able to read and understand 8th grade level English

- ❑ Yes
- ❑ No

I possess basic internet skills (accessing websites and navigating web pages)

- ❑ Yes
- ❑ No

I have a history or am currently being treated for a mental health condition

- ❑ Yes
- ❑ No

I have prior experience (or currently use) an online breast cancer survivorship plan

- ❑ Yes
- ❑ No

Online User Experience Survey

Based on your use of ACESO, please rate your online experience based on the parameters listed below on the scale provided:		
Valuable	○ ○ ○ ○ ○ ○ ○	Not valuable
Practical	○ ○ ○ ○ ○ ○ ○	Not practical
Relevant	○ ○ ○ ○ ○ ○ ○	Irrelevant
Informative	○ ○ ○ ○ ○ ○ ○	Not Informative
Worthwhile	○ ○ ○ ○ ○ ○ ○	Worthless
Productive	○ ○ ○ ○ ○ ○ ○	Not Productive
Useful	○ ○ ○ ○ ○ ○ ○	Not useful

Based on your use of ACESO, please rate your online experience based on the parameters listed below on the scale provided:		
Inviting	○ ○ ○ ○ ○ ○ ○	Uninviting
Friendly	○ ○ ○ ○ ○ ○ ○	Unfriendly
Polite	○ ○ ○ ○ ○ ○ ○	Impolite
Personal	○ ○ ○ ○ ○ ○ ○	Impersonal
Social	○ ○ ○ ○ ○ ○ ○	Unsocial

Based on your use of ACESO, please rate your online experience based on the parameters listed below on the scale provided:

Simple	○ ○ ○ ○ ○ ○ ○	Complicated
Easy	○ ○ ○ ○ ○ ○ ○	Difficult
Confusing	○ ○ ○ ○ ○ ○ ○	Not confusing
Not tiring	○ ○ ○ ○ ○ ○ ○	Tiring
Consistent	○ ○ ○ ○ ○ ○ ○	Inconsistent
Not stressful	○ ○ ○ ○ ○ ○ ○	Stressful

Please select your age group from the options below:

- ○ 18-24
- ○ 25-29
- ○ 30-39
- ○ 40-49
- ○ 50-59
- ○ 60+

Race/Ethnicity (Please select an option):

- ○ African American
- ○ American Indian or Alaska Native
- ○ Asian

- Caucasian
- Hispanic or Latino
- Multi Ethnic
- Other
- Unknown

Please indicate your HIGHEST education level completed:

- Haven't completed High School
- High School
- Associates or technical degree
- Bachelors degree (BA/BS, etc.)
- Masters degree (MA/MS/MBA, etc.)
- Doctorate degree (Ph.D.)
- Other professional degree

Current practices and perceived usefulness interview: Talking points

Q1	After completing your cancer treatment, how well prepared did you feel in terms of taking care of yourself and follow up treatments?
Q2	How open are you towards using technology to help self-manage your medical condition(s)?
Q3	How useful did you find the breast cancer survivorship document given to you by your provider after you completed your cancer treatment?
Q4	Do you think having an app would help/have helped you navigate life after breast cancer any better? Why?
Q5	Do you think more personalized tools (such as apps) to aid breast cancer survivors would be useful? Would you use such an app? Why?
Q6	What features would you like to see in such an app? What would it look like?
Q7	Do you have any concerns from using such an app? If yes, what are they?
Q8	Any other comments for me?

Task Analysis: User Instructions

Below is a list of tasks to perform using the online app provided. Brief instructions are provided for you to perform on the website. You may ask for assistance or clarification at any time, as needed.	
Task 1	1) Log In a)Open browser and the following website: [redacted] b) Use the following username and password to log in: Username: [redacted] Password: [redacted]
Task 2	Find the 'Report a Symptom' function and report the following physical symptom: "Upper Arm Swelling". (You may leave the date fields blank)
Task 3	1) Do you see any alert message appear on top of the home page now? Check below. a. No b. Yes
Task 4	Find and answer the Fatigue survey. Pretend that you are *Jane Doe* while answering the survey (instead of actually answering the survey as it pertains to you).
Task 5	On the Home page, find the 'Follow-Up Care Due' section, and record the date for last visit for Mammography as 09/01/2015.
Task 6	On the home page, find the 'My Health Record' panel and under 'Procedures', note the Start and End date for the chemotherapy treatment below: a. Start Date _____ b. End Date _____
Task 7	Navigate to the *Observation Reports* page. Observe the graph/chart and locate the last recorded fatigue observation (last data point in chart). What fatigue severity level (color) does it fall under? a. Severe (red) b. Moderate (yellow) c. Mild (green)

Task 8	On the Home page, find the Resources panel to access the Resources page. Name any one local breast cancer resource from the list you see on the page: _____
Task 9	Sign Out

Task Analysis: Administrator Sheet

	Task	# Help Requests	# Errors
1	Log In		
2	Report Symptom: Upper Arm Swelling		
3	Observe alert message		
4	Find and answer Fatigue survey		
5	Record date of mammography follow-up		
6	Retrieve dates of chemotherapy treatment		
7	Retrieve last recorded fatigue observation		
8	Name one local resource for breast cancer from the list of resources		
9	Log Out		

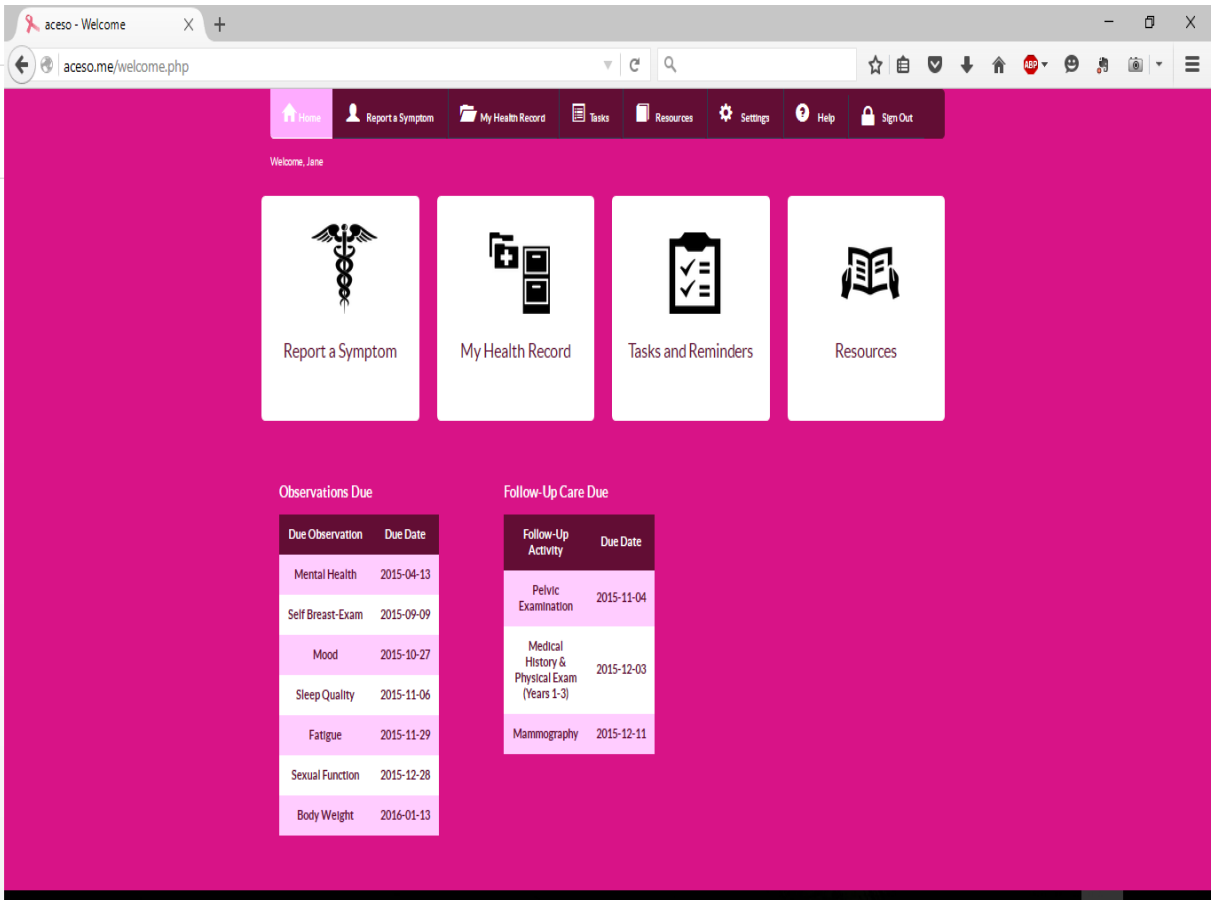
Notes:

Usability and Acceptability Interview: Talking points

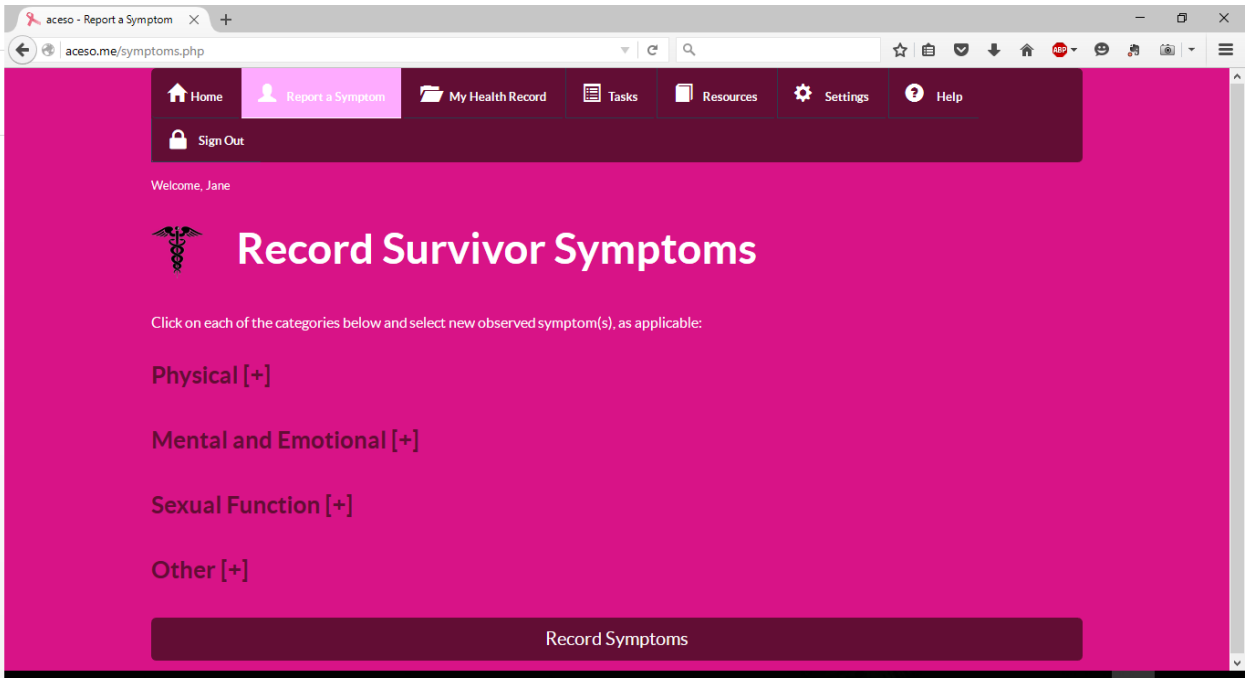
Q1	After having used the app, can you talk more on the usefulness of such an app?
Q2	Can you describe how easy or difficult was it for you to use the app?
Q3	What are your thoughts on the visual appearance of the app?
Q4	What did you like the most about the app?
Q5	What did you like the least about the app?
Q6	What features would you like to see in such an app? What would it look like?
Q7	What suggestions would you have to improve this app?
Q8	Would you have any concerns from using this app in real life?
Q9	How willing would you be to use this app, if it were made available to you for free? Please explain with reasons.
Q10	Any other comments for me?

Appendix D:

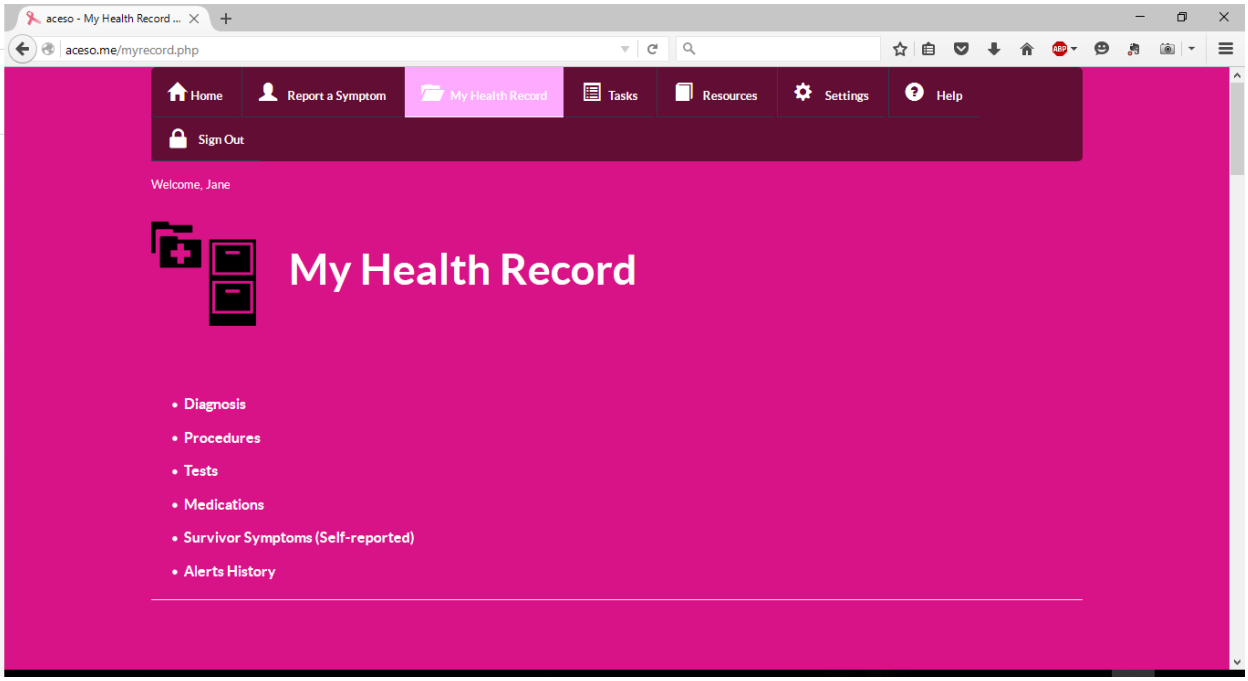
ACESO User Interface



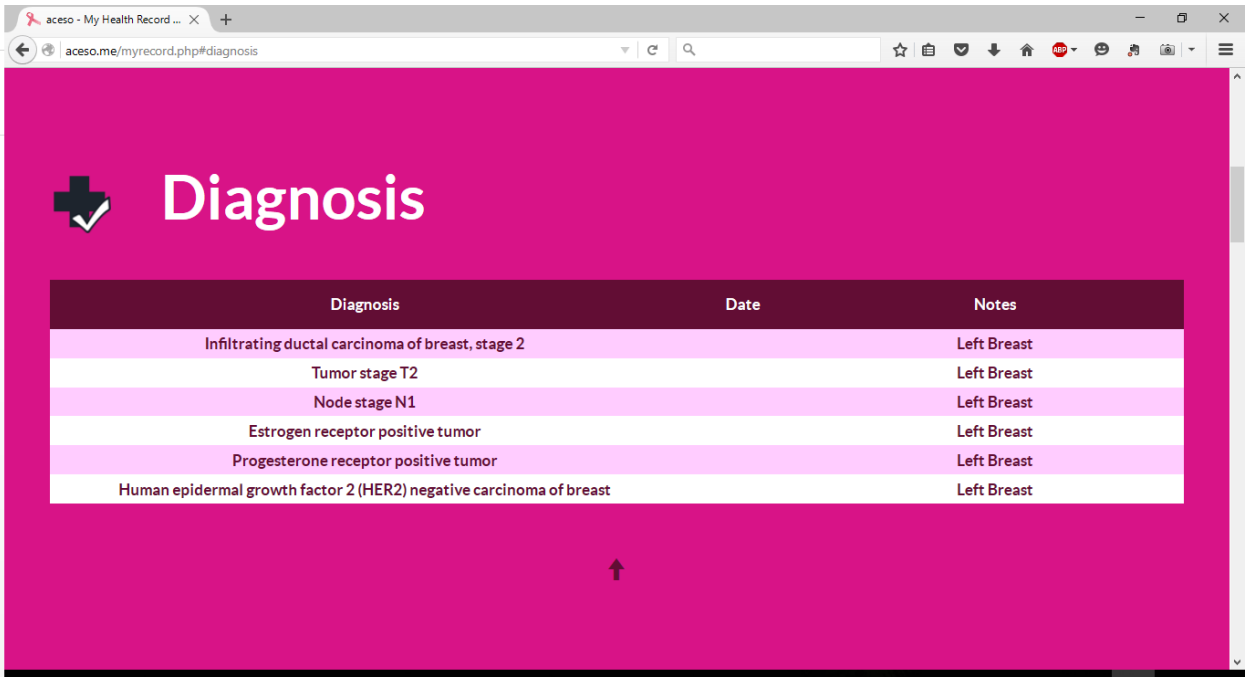
Home page



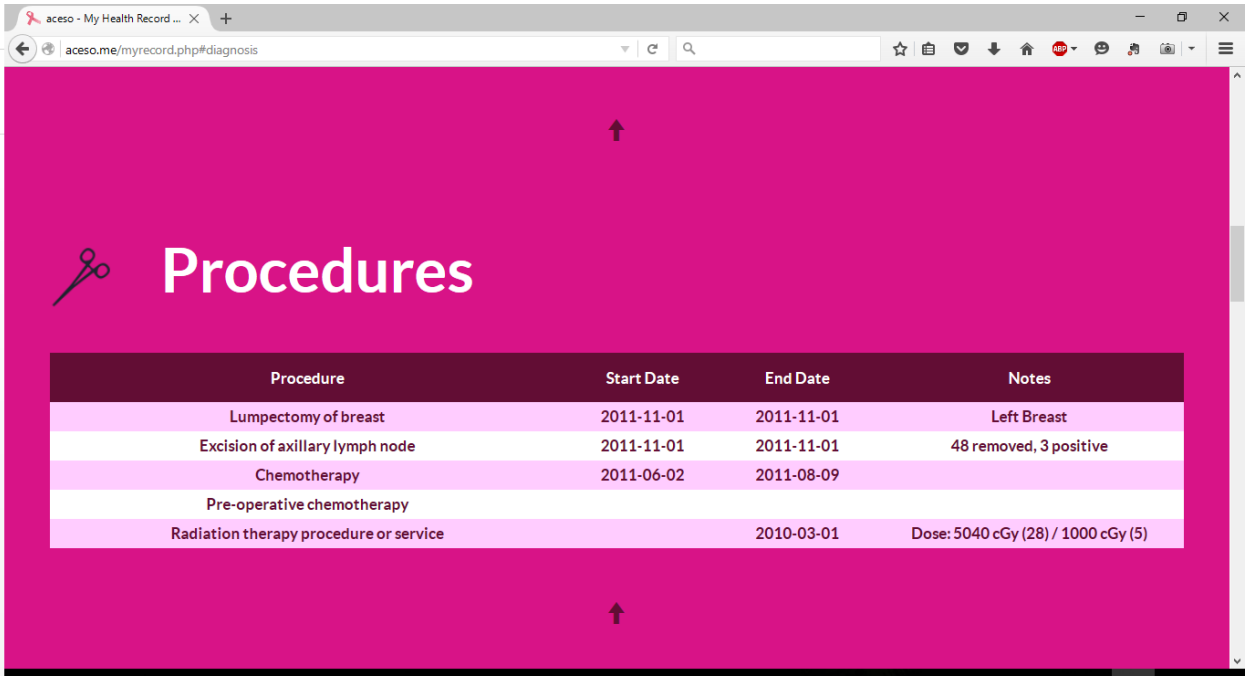
Record Survivor symptoms page



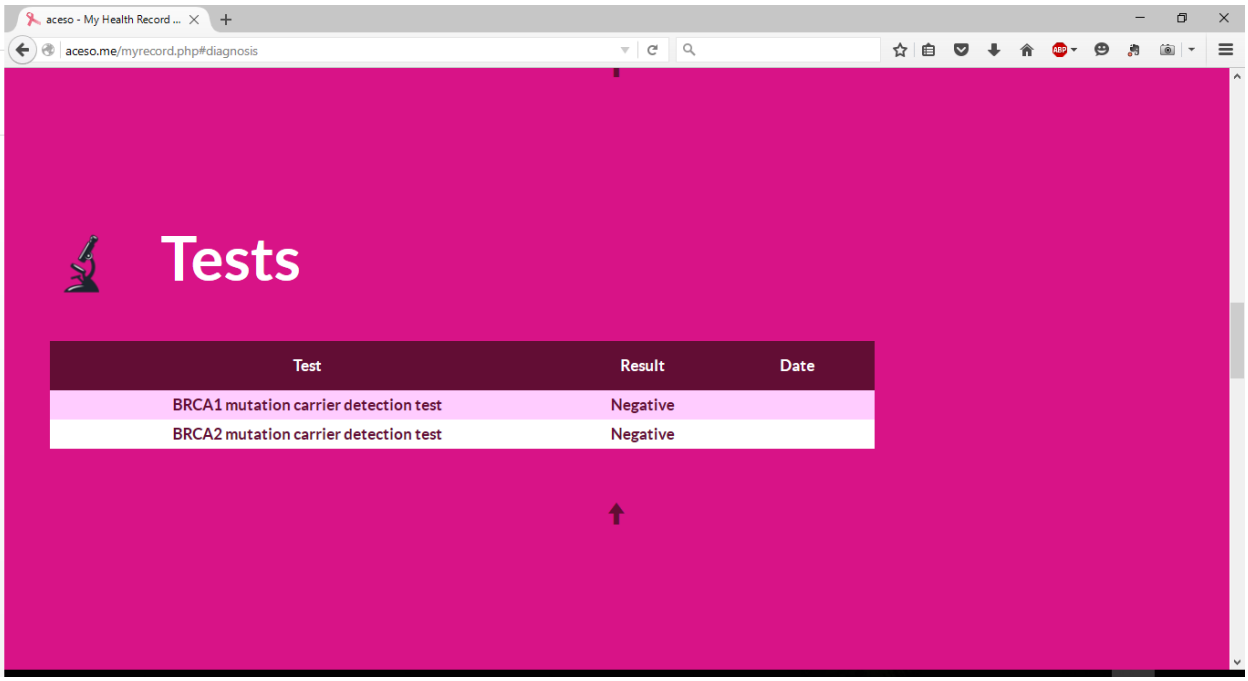
My Health Record page



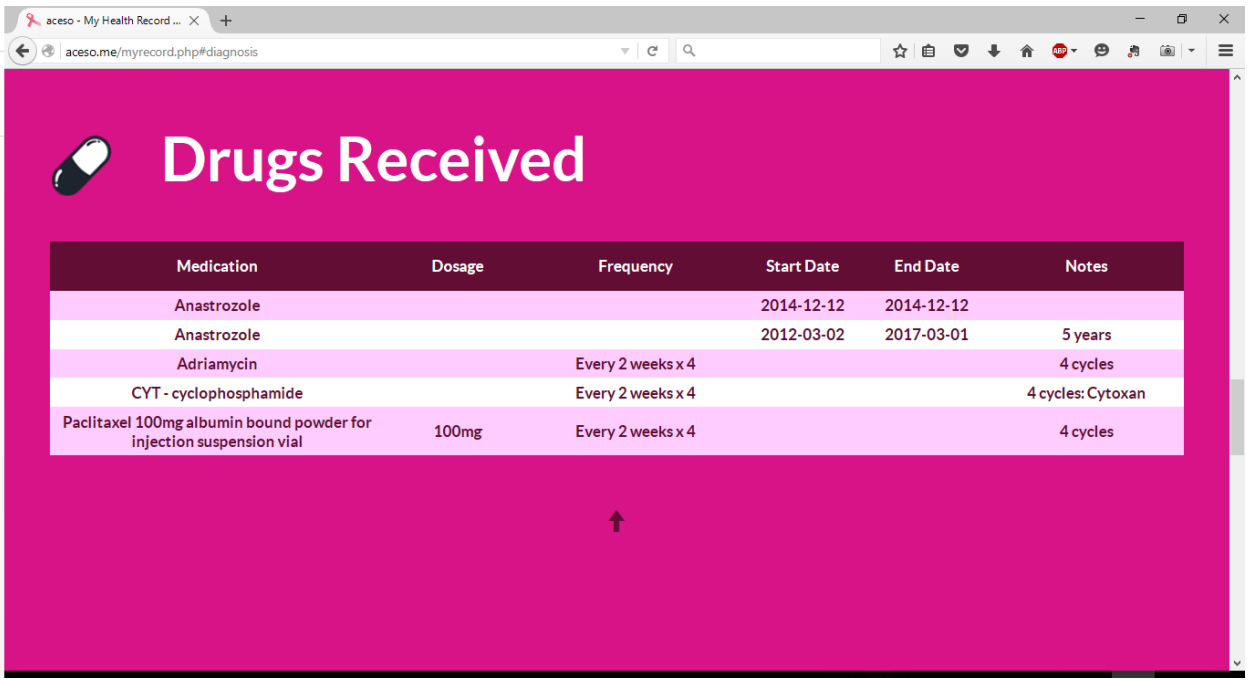
My Health Record page: Diagnosis



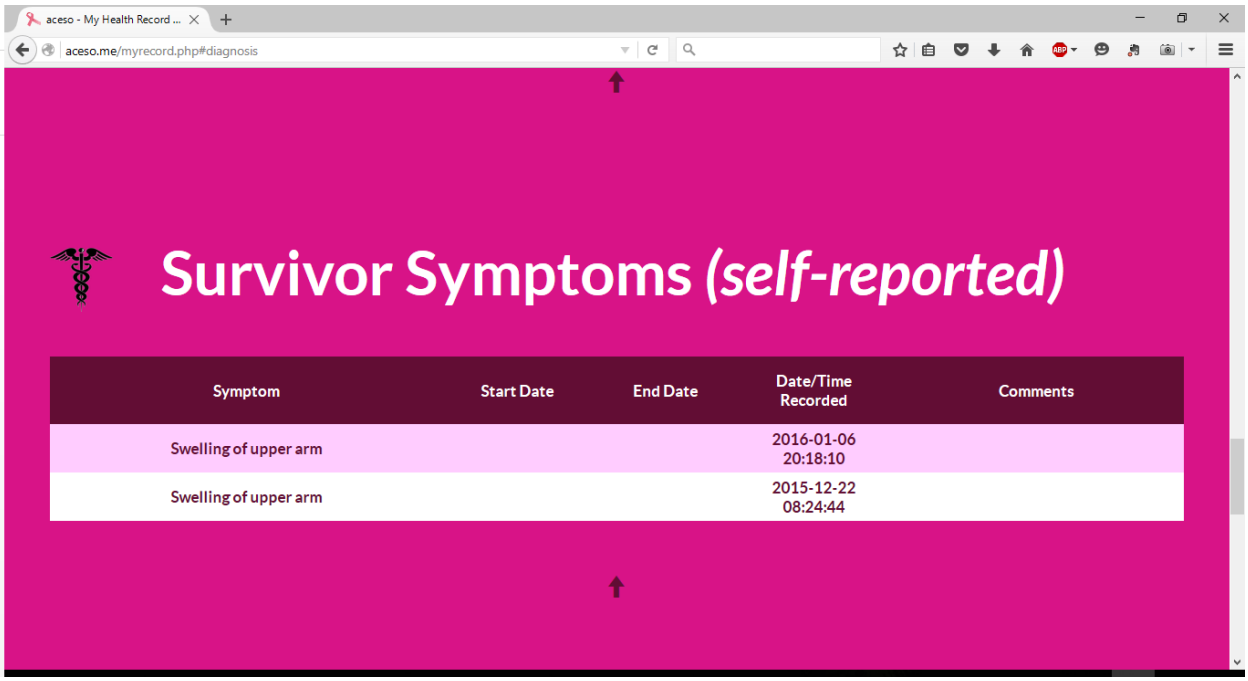
My Health Record page: Procedures



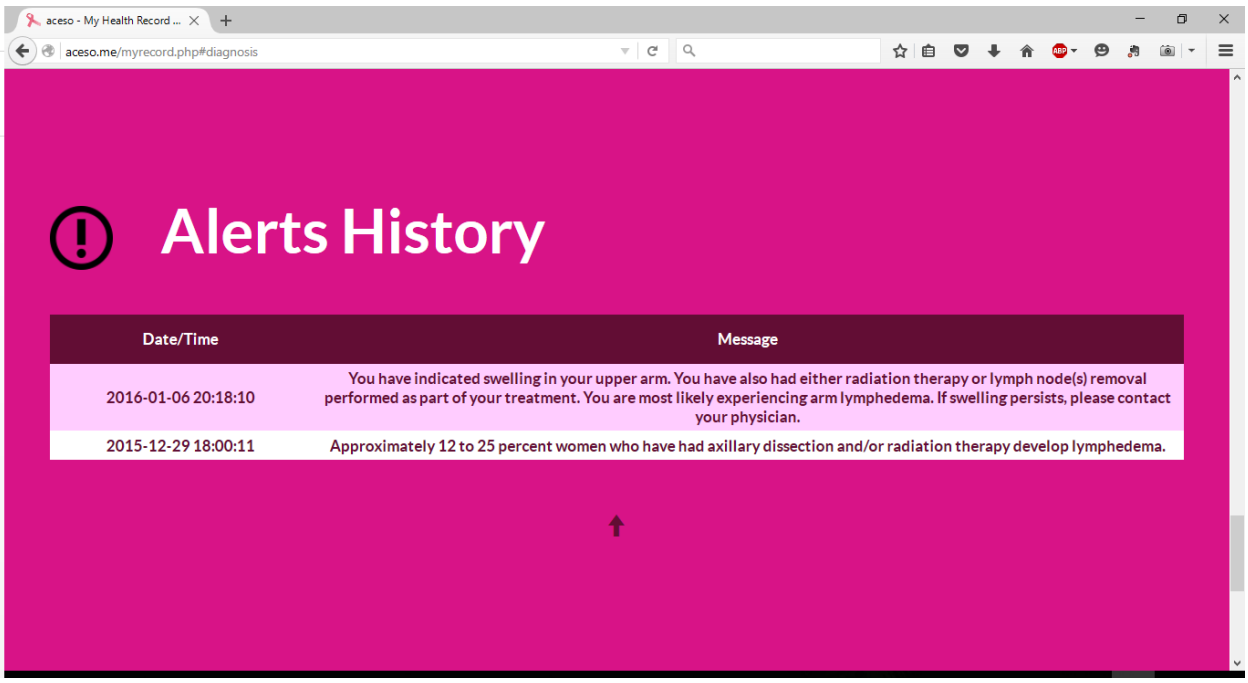
My Health Record page: Tests



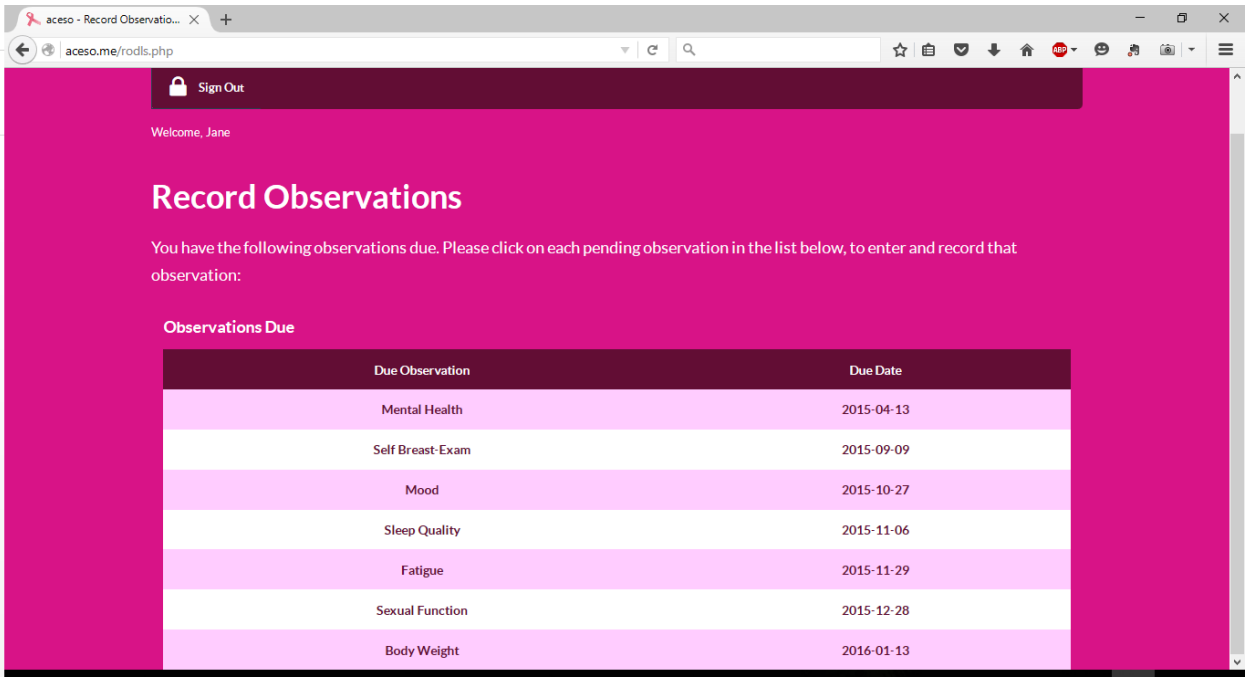
My Health Record page: Drugs Received



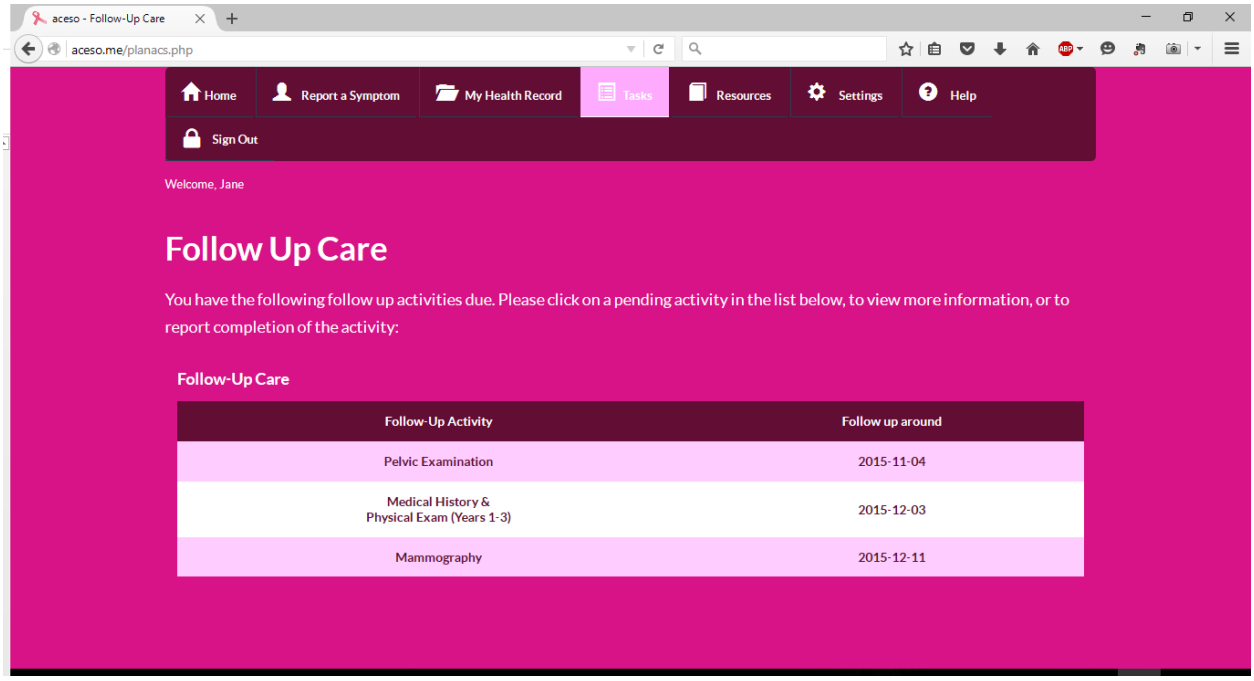
My Health Record page: Survivor symptoms



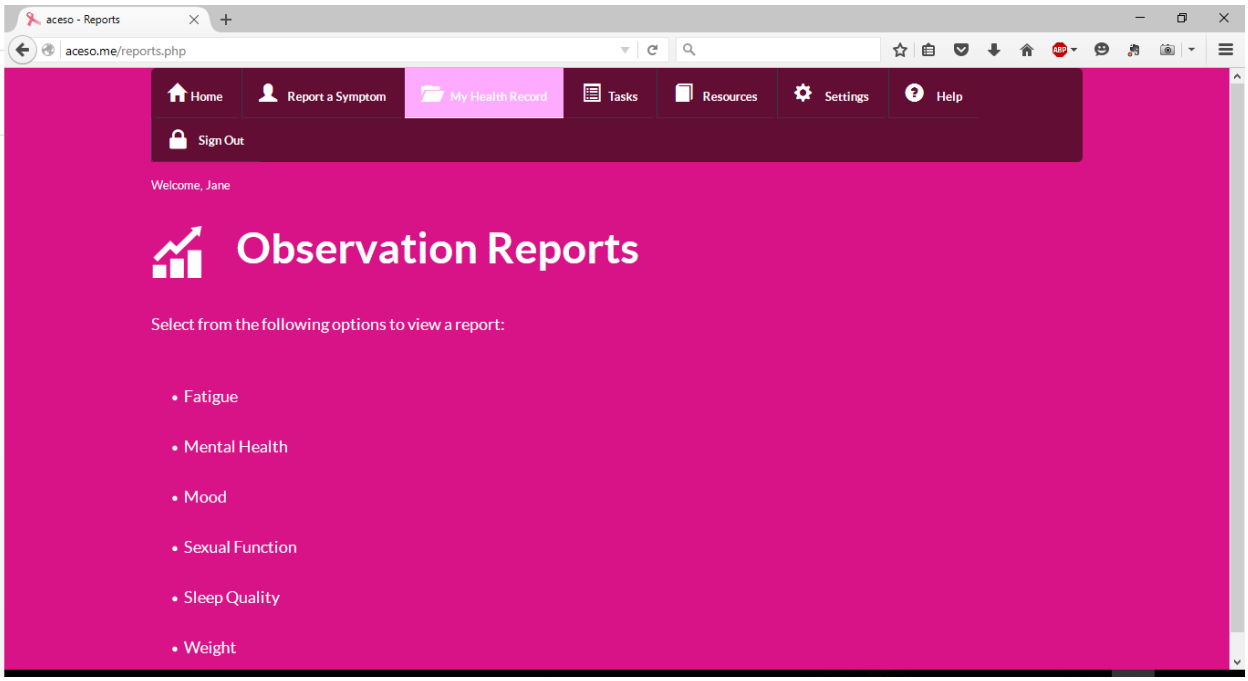
My Health Record page: Alerts History



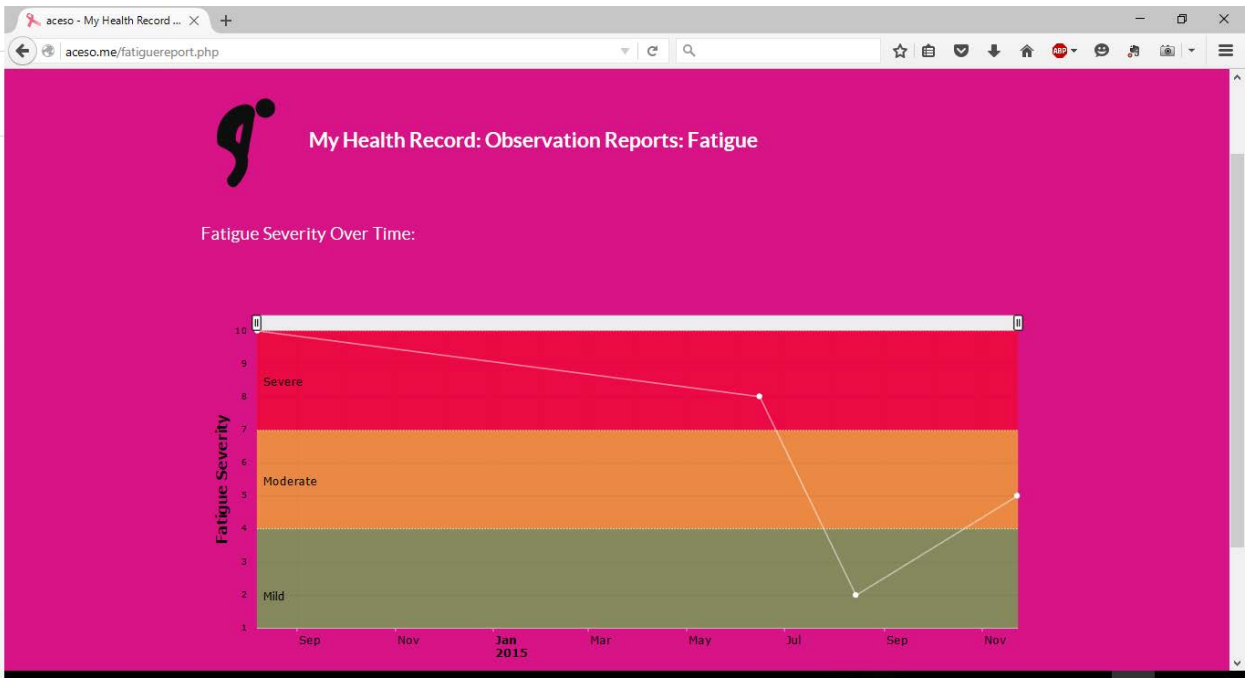
Record Observations (ODLs) page – Observations Due



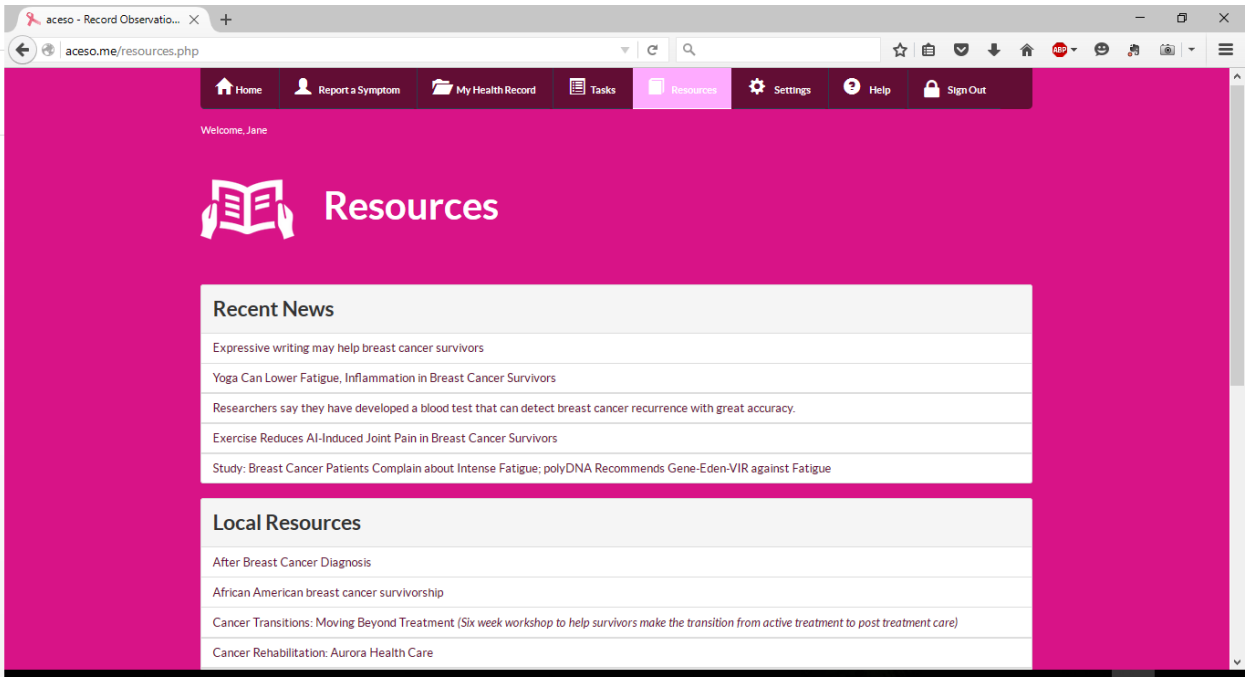
Follow Up Care page: Follow Up Activities Due



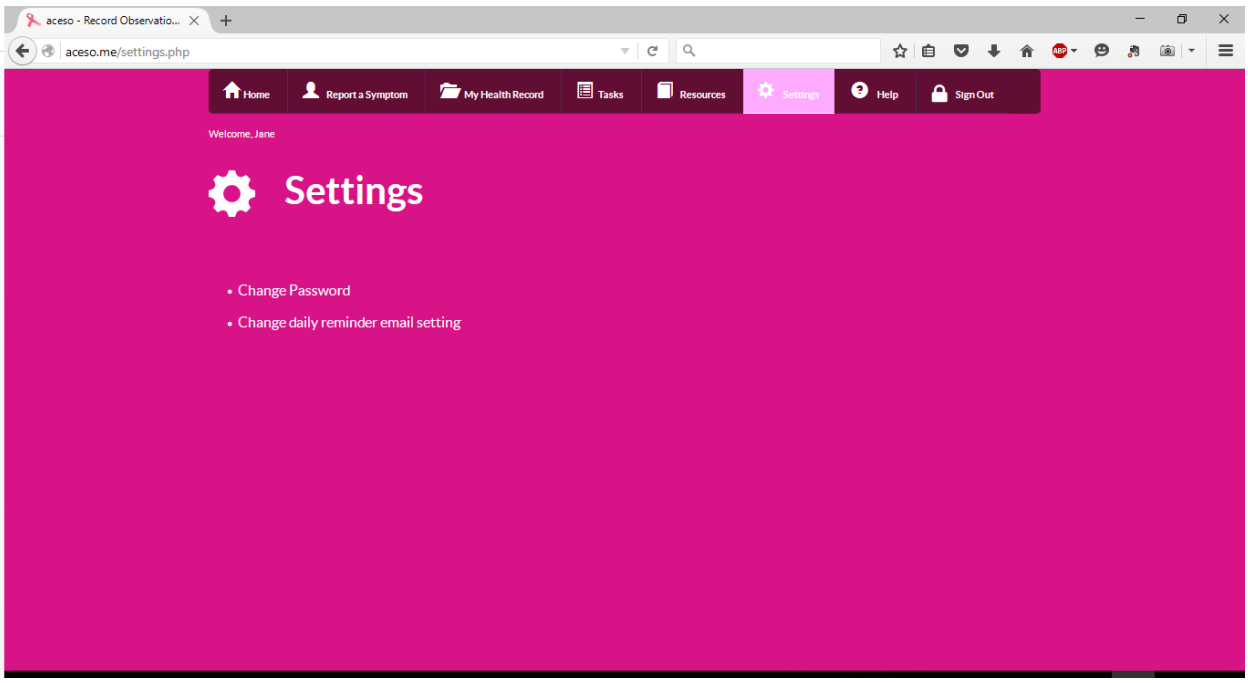
Observation Reports page



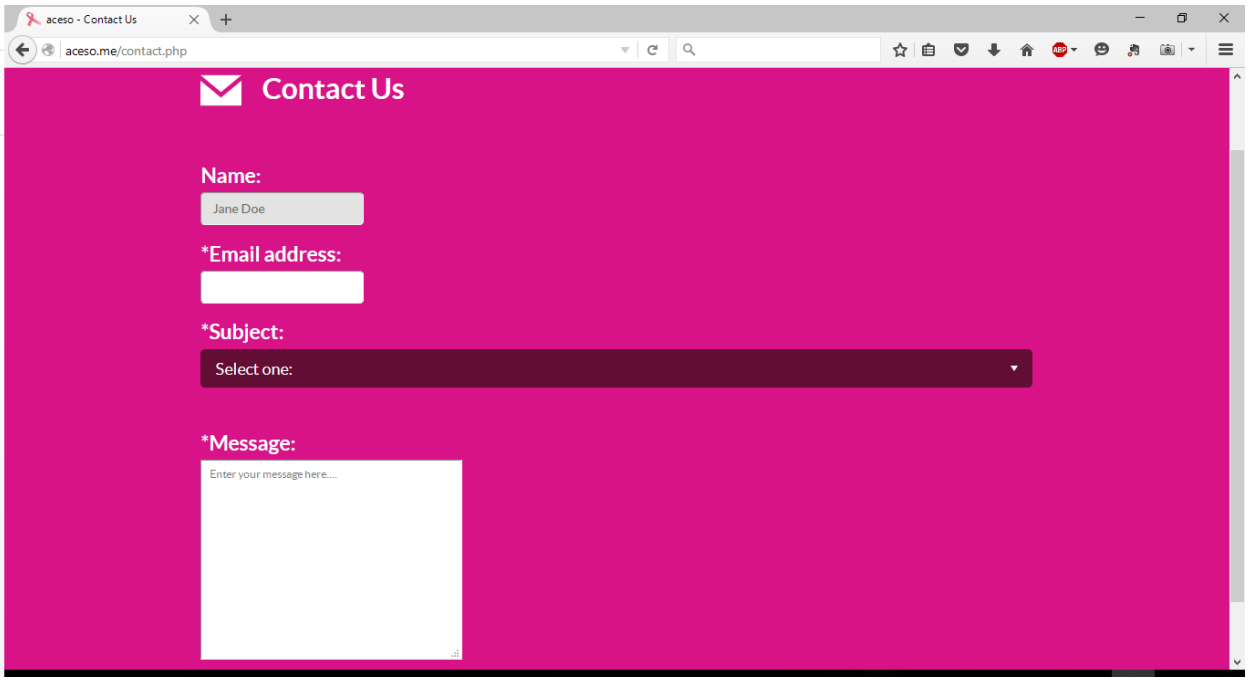
Observation Reports page: Fatigue severity over time



Resources page



Settings page



Contact Us page

Appendix E:

ACESO Database Physical Model

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
RuleId	int	11	0	Yes	No
RuleName	varchar	50	0	No	No
RuleResource	varchar	200	0	No	No
RuleMessage	varchar	500	0	No	No
RuleInfoLink	varchar	500	0	No	Yes
RuleIsActive	tinyint	1	0	No	No
RuleType	varchar	4	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
WeightValue	decimal	4	1	No	Yes
DateTimeRecorded	timestamp	0	0	No	Yes
WeightId	int	11	0	Yes	No
ScheduleID	int	11	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PTestId	int	11	0	Yes	No
SNOMEDId	varchar	18	0	No	No
SNOMEDDescrId	varchar	18	0	No	No
DateTimeRecorded	timestamp	0	0	No	Yes
PTestValue	varchar	8	0	No	Yes
PId	int	11	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PSymptomId	int	11	0	Yes	No
SNOMEDId	varchar	18	0	No	Yes
SNOMEDDescrId	varchar	18	0	No	Yes
SymptomStartDate	date	0	0	No	Yes
SymptomEndDate	date	0	0	No	Yes
DateTimeRecorded	timestamp	0	0	No	No
Comments	varchar	100	0	No	Yes
PId	int	11	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PSQIDURAT	tinyint	4	0	No	Yes
PSQIDISTB	tinyint	4	0	No	Yes
PSQILATEN	tinyint	4	0	No	Yes
PSQIDAYDYS	tinyint	4	0	No	Yes
PSQIHSE	tinyint	4	0	No	Yes
PSQISLPQUAL	tinyint	4	0	No	Yes
PSQIMEDS	tinyint	4	0	No	Yes
PSQI	tinyint	4	0	No	Yes
DateTimeRecorded	timestamp	0	0	No	Yes
SleepId	int	11	0	Yes	No
ScheduleId	int	11	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
FSF1	int	1	0	No	Yes
FSF2	int	1	0	No	Yes
FSF3	int	1	0	No	Yes
FSF4	int	1	0	No	Yes
FSF5	int	1	0	No	Yes
FSF6	int	1	0	No	No
FSF7	int	1	0	No	Yes
FSF8	int	1	0	No	Yes
FSF9	int	1	0	No	Yes
FSF10	int	1	0	No	Yes
FSF11	int	1	0	No	Yes
FSF12	int	1	0	No	No
FSF13	int	1	0	No	No
FSF14	int	1	0	No	No
FSF15	int	1	0	No	No
FSF16	int	1	0	No	No
FSF17	int	1	0	No	No
FSF18	int	1	0	No	No
FSF19	int	1	0	No	No
Desire	decimal	3	1	No	No
Arousal	decimal	3	1	No	No
Lubrication	decimal	3	1	No	No
Orgasm	decimal	3	1	No	No
Satisfaction	decimal	3	1	No	No
Pain	decimal	3	1	No	No
SFSIFinalScore	decimal	3	1	No	Yes
DateTimeRecorded	timestamp	0	0	No	Yes
SexualityId	int	11	0	Yes	No
ScheduleId	int	11	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PRulesID	int	11	0	Yes	No

RuleId	int	11	0	No	No
PRulesDate	timestamp	0	0	No	No
PId	int	11	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PProviderId	int	11	0	Yes	No
ProviderName	varchar	45	0	No	Yes
ProviderStreetAddress	varchar	60	0	No	Yes
ProviderCity	varchar	45	0	No	Yes
ProviderState	char	2	0	No	Yes
ProviderZip	int	5	0	No	Yes
ProviderPhone	int	10	0	No	Yes
ProviderEmail	varchar	45	0	No	Yes
ProviderWebsite	varchar	60	0	No	Yes
PId	int	11	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PProcedureId	int	11	0	Yes	No
SNOMEDId	varchar	18	0	No	No
SNOMEDDescrId	varchar	18	0	No	No
Notes	varchar	500	0	No	Yes
ProcedureStartDate	date	0	0	No	Yes
ProcedureEndDate	date	0	0	No	Yes
PId	int	11	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
DateActivityCompleted	date	0	0	No	Yes
PPlanActivityId	int	11	0	Yes	No
PPlanActivityScheduleId	int	11	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PAM1	tinyint	4	0	No	Yes
PAM2	tinyint	4	0	No	Yes
PAM3	tinyint	4	0	No	Yes
PAM4	tinyint	4	0	No	Yes
PAM5	tinyint	4	0	No	Yes
PAM6	tinyint	4	0	No	Yes
PAM7	tinyint	4	0	No	Yes
PAM8	tinyint	4	0	No	Yes
PAM9	tinyint	4	0	No	Yes
PAM10	tinyint	4	0	No	Yes
PAM11	tinyint	4	0	No	Yes

PAM12	tinyint	4	0	No	Yes
PAM13	tinyint	4	0	No	Yes
PAMRAW	tinyint	4	0	No	Yes
PAM_Activation_Score	decimal	4	1	No	Yes
IsPre	tinyint	1	0	No	Yes
pamlevel	tinyint	1	0	No	Yes
DateTimeRecorded	timestamp	0	0	No	Yes
PAMId	int	11	0	Yes	No
ScheduleID	int	11	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
MoodValue	tinyint	1	0	No	No
DateTimeRecorded	timestamp	0	0	No	Yes
MoodId	int	11	0	Yes	No
ScheduleId	int	11	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PMedicationID	int	11	0	Yes	No
SNOMEDId	varchar	18	0	No	No
SNOMEDDescrId	varchar	18	0	No	No
Notes	varchar	500	0	No	Yes
Dosage	varchar	45	0	No	Yes
Frequency	varchar	45	0	No	Yes
StartDate	date	0	0	No	Yes
EndDate	date	0	0	No	Yes
PId	int	11	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PPlanActivityScheduleId	int	11	0	Yes	No
ActivityId	int	11	0	No	Yes
PId	int	11	0	No	Yes
ActivityPlannedStartDate	date	0	0	No	No
Frequency	varchar	45	0	No	Yes
NextDueDate	date	0	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
ActivityId	int	11	0	Yes	No
ActivityName	varchar	45	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable

BFI1	tinyint	1	0	No	No
BFI2	tinyint	1	0	No	No
BFI3	tinyint	1	0	No	No
BFI4	tinyint	1	0	No	No
BFI5	tinyint	1	0	No	No
BFI6	tinyint	1	0	No	No
BFI7	tinyint	1	0	No	No
BFI8	tinyint	1	0	No	No
BFI9	tinyint	1	0	No	No
BFIFinalScore	int	1	0	No	No
DateTimeRecorded	timestamp	0	0	No	No
FatigueId	int	11	0	Yes	No
ScheduleId	int	11	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PDiagnosisID	int	11	0	Yes	No
SNOMEDId	varchar	18	0	No	No
SNOMEDDescrId	varchar	18	0	No	No
Notes	varchar	500	0	No	Yes
DateDiagnosed	date	0	0	No	Yes
PId	int	11	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
CESD1	tinyint	4	0	No	Yes
CESD2	tinyint	4	0	No	Yes
CESD3	tinyint	4	0	No	Yes
CESD4	tinyint	4	0	No	Yes
CESD5	tinyint	4	0	No	Yes
CESD6	tinyint	4	0	No	Yes
CESD7	tinyint	4	0	No	Yes
CESD8	tinyint	4	0	No	Yes
CESD9	tinyint	4	0	No	Yes
CESD10	tinyint	4	0	No	Yes
CESDFinalScore	int	11	0	No	Yes
DateTimeRecorded	timestamp	0	0	No	Yes
DepressionId	int	11	0	Yes	No
ScheduleId	int	11	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
IsLumpKnot	tinyint	1	0	No	Yes
IsSwellingWarmth	tinyint	1	0	No	Yes
IsChangeSizeShape	tinyint	1	0	No	Yes
IsDimplingPuckering	tinyint	1	0	No	Yes
IsRedSoreRash	tinyint	1	0	No	Yes

IsInverted	tinyint	1	0	No	Yes
IsFluidDischarge	tinyint	1	0	No	Yes
IsPainSpot	tinyint	1	0	No	Yes
DateRecorded	date	0	0	No	Yes
BreastExamId	int	11	0	Yes	No
ScheduleId	int	11	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
ScheduleId	int	11	0	Yes	No
ODLId	int	11	0	No	Yes
PId	int	11	0	No	Yes
POdlPlannedStartDate	date	0	0	No	Yes
Frequency	varchar	45	0	No	Yes
NextDueDate	date	0	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
PId	int	11	0	Yes	No
PLName	varchar	45	0	No	No
PMname	varchar	45	0	No	Yes
PFName	varchar	45	0	No	No
PStartDate	date	0	0	No	Yes
PEmail	varchar	45	0	No	Yes
PPhone	varchar	10	0	No	Yes
PDoB	date	0	0	No	Yes
PStreetAddress	varchar	60	0	No	Yes
PCity	varchar	45	0	No	Yes
PState	char	2	0	No	Yes
PZip	int	5	0	No	Yes
PUsername	varchar	100	0	No	Yes
PPassword	varchar	100	0	No	Yes
PVisits	mediumint	8	0	No	No
PPLanScan	varchar	20	0	No	Yes
GetEmailReminders	varchar	1	0	No	No
Ethnicity	varchar	30	0	No	Yes
EducationLvl	varchar	30	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
ODLId	int	11	0	Yes	No
ODLName	varchar	45	0	No	Yes

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
id	varchar	18	0	Yes	No

effectivetime	char	8	0	No	No
active	char	1	0	No	No
moduleid	varchar	18	0	No	No
sourceid	varchar	18	0	No	No
destinationid	varchar	18	0	No	No
relationshipgroup	varchar	18	0	No	No
typeid	varchar	18	0	No	No
characteristictypeid	varchar	18	0	No	No
modifierid	varchar	18	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
id	varchar	18	0	Yes	No
effectivetime	char	8	0	No	No
active	char	1	0	No	No
moduleid	varchar	18	0	No	No
conceptid	varchar	18	0	No	No
languagecode	varchar	2	0	No	No
typeid	varchar	18	0	No	No
term	varchar	255	0	No	No
casesignificanceid	varchar	18	0	No	No

Discriminator	Version	Schema	DDL Clauses

Name	Type	Length	Scale	PrimaryKey	Nullable
id	varchar	18	0	Yes	No
effectivetime	char	8	0	No	No
active	char	1	0	No	No
moduleid	varchar	18	0	No	No
definitionstatusid	varchar	18	0	No	No

Appendix F:

ASCO Breast Cancer Survivorship Care Plan

General Information	
Patient Name:	Patient DOB:
Patient phone:	Email:
Health Care Providers (Including Names, Institution)	
Primary Care Provider:	
Surgeon:	
Radiation Oncologist:	
Medical Oncologist:	
Other Providers:	

Treatment Summary		
Diagnosis		
Cancer Type/Location/Histology Subtype:		Diagnosis Date (year):
Stage: ☐I ☐II ☐III ☐Not applicable		
Treatment		
Surgery ☐ Yes ☐No	Surgery Date(s) (year):	
Surgical procedure/location/findings:		
Radiation ☐ Yes ☐No	Body area treated:	End Date (year):
Systemic Therapy (chemotherapy, hormonal therapy, other) ☐ Yes ☐No		
Names of Agents Used		End Dates (year)
Persistent symptoms or side effects at completion of treatment: □ No □ Yes (enter type(s)) :		
Familial Cancer Risk Assessment		
Genetic/hereditary risk factor(s) or predisposing conditions:		
Genetic counseling: □ Yes □ No	Genetic testing results:	

Follow-up Care Plan		
Need for ongoing (adjuvant) treatment for cancer ☐ Yes ☐ No		
Additional treatment name	Planned duration	Possible Side effects

Schedule of clinical visits	
Coordinating Provider	When/How often

Cancer surveillance or other recommended related tests	
Coordinating Provider	What/When/How Often

Please continue to see your primary care provider for all general health care recommended for a (man) (woman) your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:

1. Anything that represents a brand new symptom;
2. Anything that represents a persistent symptom;
3. Anything you are worried about that might be related to the cancer coming back.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:

Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

☐ Emotional and mental health ☐ Fatigue ☐ Weight changes ☐Stopping smoking

☐ Physical Functioning ☐ Insurance ☐ School/Work ☐Financial advice or assistance

☐ Memory or concentration loss ☐ Parenting ☐ Fertility ☐ Sexual functioning

☐ Other

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

☐Tobacco use/cessation ☐ Diet

☐Alcohol use ☐Sun screen use

☐Weight management (loss/gain) ☐Physical activity

Resources you may be interested in:

Other comments:

Prepared by:	Delivered on:

CURRICULUM VITAE

AKSHAT KAPOOR
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Biomedical and Health Informatics
College of Engineering and Applied Science

EDUCATION

Graduate Certificate (Public Health) May, 2012
University of Wisconsin – Milwaukee

M.S. (Bioinformatics) August, 2008
Marquette University, Milwaukee, WI
Medical College of Wisconsin, Milwaukee, WI

B.IS. (Information Systems) August, 2004
Guru Gobind Singh Indraprastha University, New Delhi, India

PROFESSIONAL EXPERIENCE

2014 – present **Graduate Research Assistant**
Department of Health Administration & Policy
College of Health & Human Services
University of Wisconsin - Milwaukee

2010-2015 **Graduate Project Assistant**
Graduate School – IT & Analysis
University of Wisconsin – Milwaukee

2008-2009 **Database Administrator & IT Support**
The Delafield Hotel
Delafield, WI

RESEARCH

Research Interests

- Consumer/Public Health Informatics
- Social Media and Public Health
- Intelligent Decision Support Systems
- Health Information Privacy and Security

Publications and presentations (peer-reviewed)

- **Kapoor, A.** & Nambisan, P. (2016). Implementing Clinical Guidelines: An Online Breast Cancer Survivorship Tool for Education and Knowledge Representation. *IEEE International Conference on Biomedical and Health Informatics 2016*, Las Vegas, NV.

- **Kapoor, A.** & Nambisan, P. (2015). ACESO (After Cancer Education and Support Operations): a clinical decision support system approach for engaging breast cancer survivors. *American Medical Informatics Association (AMIA) Annual Symposium 2015*, San Francisco, CA.

- Nambisan, P., Luo, X., **Kapoor, A.**, Patrick, T., & Cisler, R. (2015). Social Media, Big Data and Public Health informatics: Ruminating behavior of depression revealed through Twitter. Proceedings of the *HICSS -48 (Hawaii International Conference on System Sciences) conference*, Kauai, Hawaii.

- Nambisan, P., Luo, X., **Kapoor, A.** (2014). Social Media and Big Data: Can tweet moods predict illness and hospital visits in a region? *APHA conference 141st Annual Meeting*, New Orleans, LA..

- **Kapoor, A.** & Nazareth, L. (2013). Medical Data Breaches: What the Reported Data Illustrates, and Implications for Transitioning to Electronic Medical Records. *Journal of Applied Security Research*, 8(1), 61-79.

- Bushee, G., **Kapoor, A.**, Cruz, N. D., Peterson, F., Volkman, B. & Twigger, S. N.. "Annotation workflows for structural genomics"; *Genome Informatics*, Cambridge, UK, October 2006.

Manuscripts under preparation

Kapoor, A., Nambisan, P. Patient acceptance and usability of an online breast cancer survivorship tool – To be submitted to *JAMIA*.

Kapoor A., Nambisan, P. Preparing future survivors: Role of an online breast cancer survivorship plan in patient education and empowerment. To be submitted to *Journal of Cancer Education.*

Kapoor, A., Nambisan, P. Looking Beyond Patient Portals: Patient Engagement via an Online Breast Cancer Survivorship Tool. To be submitted to AcademyHealth.

Manuscripts under review

Kapoor, A., Nambisan, P. Staying up late and gaining weight: Challenges and considerations for weight management among breast cancer survivors, portrayed on Twitter – under review at American Public Health Association (APHA) Annual Meeting 2016.

Kapoor, A., Nambisan, P. Self-management apps for breast cancer survivors: Applying clinical terminology standards for personal decision support – under review at American Medical Informatics Association (AMIA) Annual Meeting 2016.

TEACHING

Teaching areas

- Health Informatics
- Healthcare Administration & Policy

Teaching Experience

- Lead Instructor, HS 102 – Health Care Delivery in the United States – Spring 2014, Dept. of Health Informatics & Administration, College of Health Sciences, UWM.

- Lead Instructor, HS 224 (Core course) - Introduction to Microcomputers for Allied Health Professions – Spring 2014, Fall 2015; Dept. of Health Informatics & Administration, College of Health Sciences, UWM.

AWARDS & HONORS

- Chancellor's Graduate Student Award, **College of Engineering and Applied Science, University of Wisconsin-Milwaukee,** 2016.

- Chancellor's Graduate Student Award, **College of Health Sciences, University of Wisconsin-Milwaukee,** 2014.

- Graduate Student Research Award, **Biomedical and Health Informatics Research Institut**e, University of Wisconsin-Milwaukee, 2014.

- Dean's Scholarship, **College of Engineering and Applied Science**, **University of Wisconsin-Milwaukee,** 2014.

- Folk-Patrick Medical Informatics Award, **Biomedical and Health Informatics Research Institute**, University of Wisconsin-Milwaukee, 2013.

- Chancellor's Graduate Student Award, **College of Engineering and Applied Science, University of Wisconsin-Milwaukee,** 2011.

- Graduate Project Assistantship, **Graduate School, University of Wisconsin-Milwaukee** (Fall 2010 - Spring 2015).

Professional Service

Reviewer for the following journals:

- Journal of the American Medical Informatics Association (JAMIA)

Reviewer for the following academic conferences:

- American Medical Informatics Association (AMIA)
- American Public Health Association (APHA)
- Hawaii International Conference on System Sciences (HICSS)

Professional Affiliations

- American Medical Informatics Association (AMIA)
- American Public Health Association (APHA)
- Institute of Electrical and Electronics Engineers (IEEE)