

HELP:

DEFINING THE USABILITY REQUIREMENTS OF A BREAST CANCER LONG-
TERM SURVIVORSHIP (LTS) NAVIGATOR

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Submitted to the faculty of the School of
Informatics in partial fulfillment of the
requirements
for the degree of
Master of Science in Health Informatics,
Indiana University

August 2017

Accepted by the Faculty of Indiana University,
in partial fulfillment of the requirements for the degree of
Master of Science in Health Informatics

**Master's Project
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ACKNOWLEDGEMENTS

I am sure this has been said by many a student, but I would still like to thank everyone in the IU School of Informatics and Computing, be it faculty, staff, students, or alumni. I entered this program immediately after obtaining my undergraduate degree with only a very basic knowledge as to what health informatics entailed, in addition to the interplay between technology and the entire healthcare system. Looking back, I now see how much I have grown not only in terms of the information and knowledge gained, but also the soft skills needed to communicate ideas; to work in teams consisting of diverse people; and to truly take your audience/users into consideration when providing them with information, technology, or anything else that would leave with some impact in their lives. All in all, I have, at times, been pushed beyond my comfort level, but it has always been for the best and has, for the most part, resulted in my finest work to date. So, all my thanks to you.

ABSTRACT

Monirah Al-Abdulmunem

HELP: DEFINING THE USABILITY REQUIREMENTS OF A BREAST CANCER LONG- TERM SURVIVORSHIP (LTS) NAVIGATOR

Long-term survivors (LTSs) of breast cancer are defined as patients who have been in remission for a year or longer. Even after being declared breast-cancer-free, many LTSs have questions that were not answered by clinicians. Although online resources provide some content for LTSs, none, or very little, provide immediate answers to specific questions. Thus, the aim involves proposing specifications for a system, the Health Electronic Learning Platform (HELP), that can assist survivors by becoming an all-inclusive resource for LTSs of breast cancer. To achieve this, relevant information from the literature was used to assess the needs of LTSs. Also, data from a study involving the breast cancer survivor's forum project that had been filtered to include posts with mentions of features to be added to the website and usability issues encountered. To complete the actual design of the system, a synthesis of the results obtained from these two sources was performed. HELP is simple in terms of its layout and consists of a main search-bar, where LTSs are able to ask questions using their own terms and language. This navigator should not be taken as definitive solution, but instead, should be used as a starting point toward better patient-centered care.

CHAPTER ONE: INTRODUCTION & SIGNIFICANCE OF PROJECT

Introduction

Breast cancer is caused by an abnormal growth of cells in the breast, forming a tumor that can then invade nearby tissue or metastasize to other areas of the body through the blood stream or the lymph system (The American Cancer Society medical and editorial content team [ACS], 2016d). As about 252,710 new cases will be diagnosed in women in 2017, this type of cancer commonly occurs in this sex; however, incidences in men have also been found (The American Cancer Society medical and editorial content team [ACS], 2017; ACS, 2016d). Although breast cancer is the second leading cause of death in women, there are currently about 3.1 million survivors in the U.S. (ACS, 2017). Additionally, even among those patients who have been diagnosed with stage IV of breast cancer, there is a 22% five-year survival rate (The American Cancer Society [ACS], 2016a). In this paper, long-term survivors (LTSs) are defined as patients who have been in remission for a year or longer. Even after being declared cancer-free, many LTSs continue to be affected by this type of cancer. Many experience the emotional tolls associated with treatment side-effects, their appearance post-treatment, their chances of being able to become pregnant, and the possibility that the cancer might reoccur (The American Cancer Society medical and editorial content team [ACS], 2016b; The American Cancer Society medical and editorial content team [ACS], 2016c).

Several websites have been dedicated to providing an overview of what LTSs are to expect during remission; however, this information is generalized and not tailored specifically to a patient. On the other hand, evidence-based articles may be

difficult to comprehend by LTSs with low literacy rates. Nickell, Burke, Cohen, Caprio and Joseph (2014) note that BreastCancerTrials.org, in addition to other sources of health research information, is in need of improvements regarding the language and literacy levels employed. Furthermore, a review of online literature has found such material to be ambiguous, incomplete or misleading for those with a layman's knowledge of medicine (Austvoll-Dahlgren, Bjørndal, Odgaard-Jensen & Helseth, 2012). Various real-life and online support groups have also been formed where LTSs are able to provide emotional support for one another. They are also able to share experiences and trade information, but concerns regarding misinformation arise. In addition to this, none, or very little, of these resources provide immediate answers to specific questions LTSs may have. In general, Grunfeld and Earle (2010) have found that little research has been done regarding the perspectives of breast cancer LTSs in models of survivorship care (as cited in Haq et al., 2013). Therefore, this project comprises of a prototype of an online-based system designed to help LTSs of breast cancer.

The general concept behind the designed system involves known questions that most breast cancer survivors have a few months after being declared that they have recovered integrated into the system to help these survivors navigate through their daily lives. In addition to this, machine learning would be incorporated in order to dynamically find information on the web and generate answers to new questions based on user data. Folksonomy tags generated and stored by users would involve words or phrases LTSs may use instead of the domain-specific medical terms. The tags would structure the content provided to LTSs, and may, over time, provide a wealthy

knowledge-base for bridging the language between LTSs and clinicians. In order to do so, the folksonomy tags would be connected to the Unified Medical Language System (UMLS) Medical Subject Headings (MeSH) terms. After the patient obtains information that answers their questions, the information can be transformed into Health Level Seven (HL7) so that LTSs have the option of sending the information they have found to their clinician. Once the system has gained some efficacy and reliability, the eventual hope is that it could be integrated with the clinician's side, given the survivor's consent. The current project in this paper focuses on determining usability specifications and requirements pertaining to this system within the context of LTSs of breast cancer, who are mostly women in their 30s to 60s.

Significance

Thus, the aim of this study is to propose specifications for a system, called the Health Electronic Learning Platform (HELP), that can assist survivors in answering questions they may have and become a one-stop shop for LTSs of breast cancer. The overall purpose of this project is to target aspects pertinent to the effects of breast cancer in a patient's daily life. The targeted audience will include potential users of the designed system, so the overall design of the system is centered around the user. This, then, would involve those patients who have had some time after they had been declared breast-cancer free and are now looking for specifically tailored answers to some questions as they go about reconstructing their day-to-day lives. Furthermore, designing such a system and having it be used by LTSs would show that providers need to pay attention to what patients are saying regarding their concerns and how they behave beyond the confines of

the clinic. This is especially so, since healthcare has not been focusing on the “why” or “how” of what patients do, but instead, on whether or not the patient does it, such as adherence to treatment. Overall, the type of questions being targeted with regards to this system are those mostly unknown to healthcare professionals and researchers alike, and are in need of answering for LTSs.

CHAPTER TWO: LITERATURE REVIEW

Several themes were found among the articles presented below, which included the general feasibility of using web-based systems for patients. In addition, a number of the articles discussed the needs of patients in terms of information that a web-based system might provide. Other articles also discussed how information should be presented in web-based systems. Even if information is presented in a way with which most are comfortable, exceptions may occur. So, adaptations to these exceptions should be taken into consideration, such as those with low levels in literacy. Also, even if information was presented in a suitable way, and exceptions were considered in the design of a system, evaluation of the designed system should commence to further its usability and accessibility by the users for whom the system was designed. The following review of the literature is organized along these themes (See Table 1.0.).

Use of Web-Based Systems for Patients

Recent years have shown the increased appearance and use of technology within the field of healthcare. This increased use of technology in healthcare is especially so with patients, who are now able to access a wealth of information on the web, use various technological devices for monitoring their condition or as some form of treatment, and

communicate with health professionals and other patients, usually with similar health conditions. However, it must come to mind the accuracy, usefulness, and efficiency of such systems, particularly when the health of a patient is at stake.

Yu et al. (2012) set to design a self-management system for patients with diabetes by developing the intervention, testing its feasibility, testing for usability, using the results to refine the intervention, and conducting an evaluation of the intervention. They argued that web-based interventions show great potential with regards to self-management (Yu et al., 2012). This is mainly due to this type of intervention being able to target behavior, being easily upgradable when decent monetary values are provided, and being maintainable at a low expense (Yu et al., 2012). However, caution must be taken with regards to this study as the authors have only developed the various phases that would be involved in a future study, their expected results, and conclude in conjunction with several established theories, such as the behavior change theory and the theoretical foundation of self-efficacy (Yu et al., 2012). Therefore, results from testing an actual prototype were not obtained. Having said this, the assumptions are based on previous work, and so a certain generalizability of their arguments and conclusions can be maintained.

Another example of finding use in web-based systems for patients can be seen in a study by Northouse et al. (2014) who sought to transform a nurse-delivered psychoeducational intervention for patients and their caregivers into a tailored, web-based intervention. This newly transformed intervention was to form opportunities for patients to obtain information and interact with their caregivers, and spanned three

sessions over several weeks (Northouse et al., 2014). The results found included patients experiencing a decrease in emotional distress and an increase in their quality of life (QOL) (Northouse et al., 2014). Although one of the web-based program's objectives had been to provide more interaction between patients and their caregivers, no change was found when compared to the original nurse-delivered program (Northouse et al., 2014). Interestingly, while recruitment of patients and their caregivers for the web-based program was found to be difficult, the retention of this program was significantly high in comparison to the nurse-delivered program (Northouse et al., 2014). In general, this study has shown that while some reluctance may be shown to begin such an intervention, once a patient has begun, they will continue with the intervention until completion.

Also, the general transformation of what was usually a nurse-delivered program into a web-based program has been shown to be feasible. Through this new method, and the dialogue that commenced because of enrolling in it, caregivers were able to better understand their patients' needs (Northouse et al., 2014). Therefore, there is potential for the same to occur between patients and their clinicians, so that the latter may better understand the needs of the former, given a tailored, web-based intervention.

It can now be seen that while various web-based systems have the potential of being beneficial to patients, their true potential cannot be realized if they are not able to meet patients' needs from the start. Therefore, a needs assessment should be done during the initial stages of designing the technological intervention.

Patient Needs regarding Web-Based Systems

A study conducted by Wang and Dolezel (2016) regarding personal health records (PHRs), which are similar to an electronic health record (EHR), but are controlled by patients. In this study, they argued that PHRs have the ability to increase patient empowerment in their own care, but that a gap exists in the literature regarding patients' perceptions as to the level of usability of PHRs. In order to study this, two PHRs were compared using the Usefulness, Satisfaction, and Ease of Use (USE) questionnaire (Wang & Dolezel, 2016). After conducting their study, several characteristics regarding a model PHR were found. Generally, PHRs must be effortless to access and use, but more specifically, these characteristics included the availability of "clear-cut choices;" the provision of information regarding health; the existence of a simple interface; the ability to sync the PHR with an existing account for transfer of information; and the ability to track one's overall health and any issues that may arise (Wang & Dolezel, 2016).

One result mentioned by Northouse et al. (2014) involved caregivers gaining more knowledge due to the tailored information provided in the web-based program. For most patients, such tailored information is difficult to find when searching for a topic using common Internet search engines. This difficulty in finding relevant information is especially so since most people tend to use one common search Internet for the majority of their searches (Wang et al., 2012). Wang et al. (2012) sought to compare common search engines in terms of their usability in obtaining health information by searching "breast cancer" in the chosen search engines, saving the top results, and then evaluating the websites based on usefulness in terms of the content provided. The websites found

regarding breast cancer could mainly be categorized into those with basic knowledge, nonprofit organizations, corporations, and those for researchers (Wang et al., 2012). All in all, they found that all search engines provided rich information; however, Google was found to have the least redundancy and the highest validity as it provided users with the most URLs that could be successfully opened (Wang et al., 2012). The authors posited that these results may be indicative of Google's frequency in updating their database of results, thereby highlighting the importance of doing such (Wang et al., 2012). An overview of common user habits when searching was concluded in that users are likely to go through a few of the first pages of the search results and then change some of the keywords used in the search or choose among the ones suggested by the engine (Wang et al., 2012). Overall, the various search engines studied focused on different content; therefore, Wang et al. (2012) suggested the use of multiple search engines, especially during a search for health information. While this may be a sound method for conducting searches on the Internet, repetitively doing so by patients could eventually become tiresome, especially if a patient were to require an answer regarding a certain question immediately. This, then, highlights the need for a comprehensible, yet patient-tailored, search engine that would be able to provide useful and immediate content. However, as was mentioned previously, in order to do so, a patient-needs' assessment must be conducted.

Such an assessment was conducted by Haq et al. (2013) in order to obtain patient needs regarding information. This was then used to design a survivorship care plan (SCP) in two versions; paper- and web-based (Haq et al., 2013). They noted that little research had been done in terms of assessing the needs of breast cancer patients and survivors

(Haq et al., 2013). Although it was found that family physicians needed basic information regarding follow-up monitoring, patients told of needing detailed information focusing on their stage in life, age, and the type of their cancer in a timely manner (Haq et al., 2013). Examples of some of the types of information requested by patients included basic information, such as the date of an appointment; detailed information regarding their type of cancer; information regarding locally available resources; and information pertaining to patients all around the nation, such as health insurance (Haq et al., 2013). The timeliness of such information should involve the entirety of a patient's journey, and should change as a patient shifts from one stage to another (Haq et al., 2013). In order to better represent such shifts, the information should be presented in layers that are tailored to their needs in terms of which stage the patient is currently experiencing (Haq et al., 2013). The information being presented should be within the balance in terms of amount and type (Haq et al., 2013). In addition to this, consideration should be given to those who would not like to be reminded of the illness they had experienced or their current state of survivorship as they would like to be *normal* once more (Haq et al., 2013). Concerning cancer survivors, major concern was found regarding who would be handling their follow-up examinations (Haq et al., 2013). Overall, patients in this study expressed a desire to interact with the complex and changing information needs through methods that are manageable, supportive from trustworthy sources, comfortable in terms of their preference regarding paper- or web-based interventions, and sensitive to the current circumstances (Haq et al., 2013).

Knijnenburg et al. (2013) assessed the perceived usability of a national website with information regarding late effects survivors might experience due to cancer, in addition to contentment with the content itself, among survivors and some parents. This was done, because even those cancer survivors who are knowledgeable about their health risks are still in need of more information from a source that is in-depth and personalized (Knijnenburg et al., 2013). The overall finding was that the survivors and parents involved in the study preferred and requested scientific information (Knijnenburg et al., 2013). Stratified information, where general content could lead to that of more details and complexity, in addition to regular updates of certain types of information were also preferred (Knijnenburg et al., 2013).

However, it has been noted that certain characteristics of patients and other users could influence how Internet resources are used (Knijnenburg et al., 2013). Such characteristics include the way in which information is processed and managed; the effects of their cancer and/or treatment; and the role they play in being a patient, survivor or caregiver (Knijnenburg et al., 2013). According to Pearce, the way an individual processes and manages information is influenced by submitting information, seeking information, consideration and avoidance (as cited in Knijnenburg et al., 2013).

In addition to these factors, effectiveness of web-based interventions is influenced by action-planning that has started at the right time, tailored information to motivation and readiness, and self-efficacy, which is a patient's perceived ability to successfully accomplish a task (Lee, Park, Yun & Chang, 2013). Due to this, Lee et al. (2013) developed a web-based intervention for self-management of diet and exercise targeted

toward cancer survivors. This intervention would have the ability to deliver information for educational purposes, develop the capacity to plan, employ automatic feedback, and evaluate for feasibility (Lee et al., 2013). With regards to diet, the research found that survivors would like to know what they should and should not eat, in addition to becoming motivated in order to change their diet (Lee et al., 2013). In terms of exercise, the research found that survivors were concerned about the possible effects of weight on the recurrence of cancer, how they should exercise during certain stages of treatment or recovery, and the precautions that should be taken when exercising (Lee et al., 2013). The functional requirements that Lee et al. (2013) determined for the web-based intervention included the provision of tailored information, automatic and immediate feedback, comparisons between current status and goal, action planning, and evaluation. For instance, the web-based program required a survivor to input the number of portions from the food groups that had been consumed on a daily basis. The information entered was then used to provide feedback regarding the survivors' progress toward a certain goal (Lee et al., 2013). In addition to functionalities such as these, the web-based program provided daily delivery of reinforcement in the form of positive messages (Lee et al., 2013).

The provision of such feedback on a daily basis relieved survivors in that they believed as if someone were helping them manage their health (Lee et al., 2013). Emotions, therefore, play an important part in how survivors perceive the system and the information it provides at a certain point in time. Lubberding et al. (2015) argued that survivors' needs should be identified in a timely and effective manner. They assessed the

needs of survivors targeted toward accessibility to supportive care via an electronic health application (Lubberding et al., 2015). The use of such applications has been found to be advantageous in providing insights into the course of symptoms, personalized advice, and tailored supportive care (Lubberding et al., 2015). This could be done by providing a sequence of questions that are based on what is already known about the survivor, thereby obtaining adequate results with relatively few questions (Lubberding et al., 2015). The unmet needs of survivors were found to include their being uninformed regarding persisting or new symptoms after their treatment (Lubberding et al., 2015). These survivors also experience a number of barriers, such as emotional barriers that prevent them from informing others of their symptoms; practical barriers by not having an appointment in the nearby future when symptoms arise; and healthcare barriers in that not enough time was spent with their physician to thoroughly discuss symptoms (Lubberding et al., 2015). In addition to these barriers, survivors may experience physicians focusing on the physical symptoms as some topics had not been discussed with their physicians, such as psychosocial symptoms (Lubberding et al., 2015).

Regarding the survivors' feelings and acceptance of the electronic health application, a preference was expressed for receiving feedback that would enable them to compare their current status to what is considered normal regarding their symptoms, the ability to avoid having to search for information on the Internet and possibly encountering negative aspects of cancer needlessly, the ability to obtain information in between follow-up consultations, the ability to obtain personalized information on topics not discussed with the physician, the ability to obtain information regarding coping with

various aspects in life that had been influenced by cancer, and the ability to obtain information and tips from expert survivors (Lubberding et al., 2015). Although the survivors were in need of various types of information, they felt that if the electronic health application were to provide too much, then this could cause an increase in their anxiety (Lubberding et al., 2015). Survivors believe that monitoring their quality of life (QOL) would help support them in self-management; however, they also believe that the monitoring of symptoms would only be useful if the symptoms are present (Lubberding et al., 2015). This is indicative that survivors did not want to be confronted with needless information, have some semblance of control over the information they accessed, the ability to avoid upsetting information, and the provision of options within the survivors' own surroundings (Lubberding et al., 2015). Interestingly, survivors indicated that the electronic health application would only act as an addition to the current support they receive, not a substitute (Lubberding et al., 2015).

Presentation of Information in Web-Based Systems

Tseng, Liou and Chiu (2012) designed a computer-based aid for nurses when educating patients. This designed aid was able to generate customized content for educating a patient by integrating several databases regarding disease, medicine and nursing (Tseng, Liou & Chiu, 2012). The system included several modules, such as one for patient data, nursing assessments and diagnoses, clinical lab data, medicine, and health education documents (Tseng, Liou & Chiu, 2012). The health education documents included an introduction to disease, the medical treatments, and information about medication (Tseng, Liou & Chiu, 2012). Suggestions for improving the system

involved integrating it with the existing hospital's information system in order to easily retrieve data and information, such as lab tests (Tseng, Liou & Chiu, 2012). With regards to the patients benefitting from this computer-based educational system, providing narrations, instead of having them read texts, was found to be more effective in having them follow treatment plans (Tseng, Liou & Chiu, 2012).

Following along these lines, Pérez et al. (2014) developed a culturally targeted intervention for cancer-communication that involved African-American breast cancer stories. This was based on the argument that the use of narratives is an effective communication strategy for education, engagement, persuasion, or activation of the public for the promotion of health (Pérez et al., 2014). In addition to this, the developed intervention would target newly diagnosed African-American breast cancer survivors as they might find the content relevant to their current experience and assistive in enhancing their quality of life (QOL), in addition to adhering to follow-up care (Pérez et al., 2014). When shown to breast cancer survivors, participants identified with the storytellers and mentioned that the stories were informative and trustworthy (Pérez et al., 2014). By hearing these stories, survivors were convinced to receive follow-up treatment as had been recommended by their physician (Pérez et al., 2014). Overall, delivery of information in this narrative form has increased health participation in the cohort of the African-American women breast cancer patients, in addition to their engagement, ability to cope with treatment and recovery, and understanding and identification of the information provided (Pérez et al., 2014).

The way in which information is presented is of importance, because it not only helps survivors understand the content but may also provide further engagement. Fu et al. (2016) developed a patient-centered web- and mobile-based system for education and management of lymphedema symptoms among breast cancer survivors, and aimed to test it for feasibility, acceptability, and usability. Once a survivor submits a report of their symptoms to the systems, the report would be evaluated, and recommended self-care strategies would be provided at the point in time (Fu et al., 2016). An educational module would then commence to inform survivors how something occurs in the lymph system by visually showing how this occurs (Fu et al., 2016). In order to minimize technical difficulties that may be faced, the system was designed so that it could be used by simply scrolling up and down, in addition to clicking on clear icons for videos or information regarding intervention (Fu et al., 2016). After conducting an evaluation of this system by utilizing a heuristic evaluation and an end-user study, the results were that the system was easily accessible and user-friendly, increased empowerment, provided information of high quality, and provided simulation videos that were highly interactive (Fu et al., 2016). The ability to access information of high quality is essential for patient-centered care (Fu et al., 2016). In addition, the interactive simulations provided for an engaging training system in order to help build self-care abilities (Fu et al., 2016). The ability to review the self-care strategies previously learned based on their own availability, pace and time also helped enhance survivors' self-care abilities (Fu et al., 2016).

Following along the aim of empowering cancer survivors, Kuijpers et al. (2015) developed an interactive portal that would have access to the electronic medical record

(EMR), be able to report patient outcomes and other feedback, and provide a physical activity support program. In general, the research suggested that interactive portals that are relevant for cancer survivors include education, the ability to self-monitor, provide tailored information, enable self-management, provide a personal exercise program, and enable the communication between survivors and their physicians or other fellow patients and survivors (Kuijpers et al., 2015). When developing the system, it was found that cancer survivors preferred features and functionalities that would assist them in their informational needs; therefore, the system was required to have features related to patient education, an overview of appointments; access to the integrated EMR; feedback in relation to patient-reported outcomes, such as providing tips if a survivor is experiencing fatigue; and provision of a tailored physical activity support program (Kuijpers et al., 2015). After evaluating the developed system, a positive aspect involved accessibility of information while a negative aspect involved lengthy texts and the use of medical jargon (Kuijpers et al., 2015). Regarding the tailored physical activity support program, participants expected to receive information pertaining to which exercises were allowed during treatment (Kuijpers et al., 2015). In terms of the overall design and layout of the system, the content was divided into static chunks with the ability to click when more information was desired; however, several survivors mentioned positioning the most important and relevant information at the top of a page (Kuijpers et al., 2015). Survivors expressed positively regarding the use of images and illustrations (Kuijpers et al., 2015). Overall, Kuijpers et al. (2015) found it important that survivors using this system not only valued its usability but also its aim to increase their empowerment in their own care.

Similarly, Cocker et al. (2015) adapted a computerized pedometer that provides advice for the general population to one that would provide advice specifically for breast cancer survivors, and then tested its usability. The adapted system consisted of the website's name, a welcome page, a list of cancer-related beliefs that had been tailored to the survivor, an approach related to diagnosing breast cancer that had been tailored to the patient, and improving personal control and self-management (Cocker et al., 2015). This system required survivors to login with a username and password, complete baseline information, which involved socio demographics, their perceptions in terms of facilitators, barriers, and beliefs regarding physical activity, and their physical activity for the day in terms of their average daily steps (Cocker et al., 2015). Immediately after a survivor provided this information, feedback that has been tailored to them was provided. After modifying this system, preliminary usability testing commenced, then a process evaluation followed in order to test survivors' performance, satisfaction, acceptability and feasibility of the intervention (Cocker et al., 2015). Results from the preliminary study included some of the survivors misinterpreting questions related to perceptions regarding the facilitators, barriers and beliefs of exercising, in addition to finding the list of symptoms too restraining and recommending that links be provided to national websites containing information related to specific problems that pertain to breast cancer (Cocker et al., 2015). Modifications based on these results were made before conducting the process evaluation, and these involved specifying requirements to answers; defining some terms used in the questionnaire; specifying what is meant by some phrases, such as "usually;" symptoms related to perceived complaints took the place of the question

asking for perceived complaints; survivors were referred to their general practitioner based on the symptoms inputted; and survivors were referred to sites containing evidence-based information (Cocker et al., 2015). Results from the process evaluation included the description of the advice being provided as too lengthy, and that if they were to be referred to using this system, they would prefer it to be done face-to-face by their physician (Cocker et al., 2015). By including barriers related to cancer and strategies for self-management, survivors' self-efficacy and control would be improved (Cocker et al., 2015). Also, as survivors with little to no levels of activity found the information provided relevant, the advice presented could then be concluded to have been acceptable and motivational (Cocker et al., 2015). Overall, it is of importance that the questions, upon which the tailored information would be based, be interpreted correctly and that the information is related to the current situation at that point in time (Cocker et al., 2015). This final conclusion does not only pertain specifically to this study; any system that provides tailored information based on what a user enters would need to maintain utmost transparency in what is being asked of users.

Adaptation of Information Provided in Web-Based Systems

As the population of breast cancer survivors are extremely diverse in terms of literacy, misinterpretation of information or what is being asked by the system may commonly occur. Therefore, this gap in literacy rates should be bridged, especially with regards to information resulting from clinical trials. Nickell, Burke, Cohen, Caprio and Joseph (2014) attempt to do so in their study aimed at providing non-trial-specific information about research in breast cancer using a patient navigator to those of low-

socioeconomic status and limited English proficiency. When developing this navigator, the offline community-based patient navigators were examined, in addition to collaborating with a nonprofit trials-matching service in order to provide the most up-to-date information that has been tailored to a survivor regarding participation opportunities in clinical trials (Nickell et al., 2014). Key factors regarding the intervention associated with this navigator included providing general information about clinical trials, substituting the term “clinical trials” with “health research,” maintaining consistency with the rest of the navigator focusing on women who have established a long-term relationship with their navigator, and addressing barriers pertaining to language and literacy (Nickell et al., 2014). Therefore, the components of the navigator came to include a simple explanation of health research, a list of resources for more information, a questionnaire to identify appropriate clinical trials, a list of clinical trials that has been tailored to the survivor, and a review of the descriptions of these studies (Nickell et al., 2014). In order to bridge the low-literacy gap, visual aids were developed to assist in remembering key components of the script and to increase accessibility (Nickell et al., 2014). These visual aids were also found to be useful in engaging those with low rates in literacy (Nickell et al., 2014).

Austvoll-Dahlgren, Bjørndal, Odgaard-Jensen and Helseth (2012) developed a web portal as an intervention that is tailored and improves the patients’ literacy skills. Patient empowerment and involvement in their own health has been deemed to be of importance, but this can only be effectively done by patients truly understanding research-based information (Austvoll-Dahlgren et al., 2012). The intervention included

facilitators to address the main barriers to obtaining research-based information, which involved, providing access to medical and health-related research databases, providing a checklist to critically assess health information, and providing a checklist that could be used when consulting a healthcare provider (Austvoll-Dahlgren et al., 2012). Overall, using this intervention helped in improving attitudes toward searching for information within health (Austvoll-Dahlgren et al., 2012). However, a compromise was made between the ease of which health information could be accessed (usability) and educational intention, so the portal might require more of a demand in terms of being routed through web pages (Austvoll-Dahlgren et al., 2012). The cause of this was the attempt at improving access to evidence-based information while also attempting to improve users' knowledge and skills (Austvoll-Dahlgren et al., 2012).

Ginossar et al. (2017), in their review, argued that mobile applications have assisted in increasing breast cancer screenings, the spread of information about cancer in rural areas, and as health interventions, such as improving one's eating habits. Also, breast cancer survivors are recommended to incorporate interventions, such as text messages and mobile phone applications in order to supplement the interventions survivors are currently undergoing (Ginossar et al., 2017). However, those survivors with low levels of literacy are less likely to access information via the Internet even when they are in critical need of answers and information (Ginossar et al., 2017). After downloading and evaluating mobile applications pertaining to breast cancer, the most common purpose for such applications was found to be for providing information, followed by for targeting change in behavior, fundraising events, and advocacy of breast cancer (Ginossar et al.,

2017). Among these, applications that targeted behavior change were the highest scored in terms of using plain and easy-to-read language (Ginossar et al., 2017).

Out of the 101 applications found, only 24 cited scientific research to support the information they presented (Ginossar et al., 2017). In addition, none of the applications contained all of the six usability items by the Institute of Medicine (IOM), and most did not allow for customization of information by users (Ginossar et al., 2017). Such findings that indicate the current state of mobile applications geared toward breast cancer present a clear problem, yet one that can be solved. Or, at the very least, improved upon to alleviate some of the problems found. Conducting evaluations with targeted users for each of the applications would be the first step towards redesign.

Highfield, Ottenweller, Pfanz and Hanks (2014) redesigned a web-based healthcare search tool for the navigation of patients in a virtual environment. The purpose of doing so was to bridge the gap between an underserved population and their access to healthcare as it has been described by the Patient Protection and Affordable Care Act (Highfield et al., 2014). The findings in this study included requirements of this system, such as enabling the search for clinics based on several criteria; displaying results of the search and enabling them to be emailed or printed; enabling the sorting of the displayed results; providing distance calculations between one's address and certain clinics; providing a Google map view; enabling the consolidation of search criteria, results, and maintenance forms; and providing the ability to edit clinics by authorization (Highfield et al., 2014). In order to accommodate those with vision problems, labels tied to form fields improved access by a screen reader (Highfield et al., 2014). Overall, this search tool

enables the allocation of local resources (Highfield et al., 2014). However, this requires to be dynamically and automatically updated, which was not achieved in this study (Highfield et al., 2014).

Evaluation of Web-Based Systems

The research studies presented above required some form of adaptation to certain users' needs. This requirement, however, would not have come to be noticed if not for conducting various types of evaluations of the system at hand. One type of evaluation is called the heuristic evaluation, the most common of which is Nielsen's ten heuristics. In this type of evaluation, broad rules regarding the design of a user interface are used to assess systems (Nielsen, 1995). Atashi, Khajouei, Azizi, and Dadashi (2016) employed this set of heuristics in order to evaluate the usability of health information systems in Iran. They found that most of the problems identified in the system were attributed to the heuristic related to consistency and standards, such as in the use of poorly designed icons; followed by the heuristic related to helping users recover from errors; and the heuristic pertaining to recognition rather than recall (Atashi et al., 2016). Solutions to these problems include enabling the disruption of activities in progress, adding undo and redo functionalities, and adding a search feature to menus with long lists (Atashi et al., 2016). In addition, providing guidance would not only help users solve problems they might encounter but would also provide a training role (Atashi et al., 2016). On the other hand, transparency with regards to the system's status would improve users' understanding and ability to navigate (Atashi et al., 2016).

While heuristics are a common method of evaluation as they are relatively uncostly and require experts who are likely to be readily available, the results from this type of evaluation should not be taken as the only problems that might be found with the system. Dias, de Fortes, and Masiero (2014) argued that although one study by Rosa and Veras (2013) employing Nielsen's heuristics for evaluation may have found problems in usability, it did not detect problems related to accessibility, such as the size of the font used or the lack of providing navigation via the keyboard. Furthermore, although the use of automatically generated accessibility metrics by Freire, Goularte and Fortes (2007) was found to be powerful a tool, usability was not considered (as cited in Dias et al., 2014). Therefore, the authors proposed HEUA, a questionnaire to assess the usability and the accessibility of web systems (Dias et al., 2014). This tool involves 93 requirements classified under 10 questions, each of which must be answered by the specialist (Dias et al., 2014). After this, a set of measures would be used to calculate a result that is indicative of the degree to which accessibility and usability are fulfilled (Dias et al., 2014). Dias et al. (2014) tested their tool by comparing two web systems, which resulted in M_{HEUA} ; the sum of how much the system meets the usability and accessibility requirements that ranges from -100, low usability and accessibility, to +100, high usability and accessibility. In addition, two percentages indicating the number of questions fulfilled can be used in the form of satisfied (S) and not satisfied (NS) (Dias et al., 2014). Systems with a higher percentage of S and a lower percentage of NS require less effort to become usable and accessible, and vice versa (Dias et al., 2014).

Even if a tool that is able to assess for both usability and accessibility is used, and a redesign commenced incorporating the solutions to the problems found, this does not indicate that the newly redesigned system is free of errors. The evaluation and then subsequent redesign of systems is an iterative process that is best when different methods of evaluation are used during each iteration. So, one would design a system, evaluate it, analyze the results, then refine the system based on the results from this evaluation, and then reevaluate the system. Lyles, Sarkar and Osborn (2014) mention several methods of evaluating a system, such as:

- qualitative methods in which users are able to generate new components to add to a system, such as an online tutorial;
- system usage data, which involve the average length of time it took for a user to respond to the system as one outcome of usability;
- think-aloud usability tests, which involve users voicing their thoughts as they go through the system;
- cognitive walkthroughs involving experts evaluating the system for its first-time use, and heuristic evaluations involving pre-established rules (Lyles et al., 2014).

Although most studies employ some form of survey in order to determine usability, when determining a users' behavior is of utmost importance, system usage data and think-aloud usability tests might provide more insight (Lyles et al., 2014). In addition to this, system usage data provide for a more objective feedback regarding a system's usability; however, thresholds as to what can be determined as being desired would still

need to be determined (Lyles et al., 2014). Overall, as each of the evaluation methods listed above have certain benefits and are more suitable to be used for certain purposes over others, determining what is needed in the current design iteration would help in the selection of an evaluation tool (Lyles et al., 2014). This would, then, provide for better results in an iterative design process that is user-centered (Lyles et al., 2014).

Table 1.0.

A Summary of the Articles Found in the Literature Review

Author	Year	Topic/theme within paper	Objective(s)	Methods	Conclusion(s)
Yu et al.	2012	Use of Web-Based Systems for Patients	To develop a web-based patient self-management system for type 2 diabetes and determine its feasibility.	Developed the system, tested for feasibility and usability, and evaluated the system using mixed methods.	Web-based interventions show great potential with regards to self-management due to targeting behavior, being easily upgradable, and being maintainable at low expenses.
Northouse et al.	2014	Use of Web-Based Systems for Patients	To determine the feasibility of translating a nurse-delivered psychoeducational intervention into a web-based format.	Web-based questionnaires given to cancer patients and their caregivers before and after the intervention were assessed.	Patients experienced a decrease in emotional distress and an increase in their quality of life (QOL). Although recruitment of patients and their caregivers for the web-based program was found to be difficult, the

					retention of this program was significantly high in comparison to the nurse-delivered program.
Wang & Dolezel	2016	Patient Needs regarding Web-Based Systems	To bridge the knowledge gap regarding patients' perceptions as to the level of usability of PHRs.	Mixed methods by using the Usefulness, Satisfaction, and Ease of Use questionnaire to assess consumers' perceptions of two commercial PHRs.	<p>PHRs must:</p> <ul style="list-style-type: none"> • Be effortless to access and use • Contain "clear-cut choices" • Provide information regarding health • Contain a simple interface • Be able to sync with an existing account for transfer of information • Be able to track one's overall health and any issues that may arise
Wang et al.	2012	Patient Needs	To compare common	Searching "breast	The websites found regarding

		regarding Web-Based Systems	search engines in terms of their usability in obtaining health information.	cancer” in the chosen search engines, saving the top results, and then evaluating the websites based on usefulness in terms of the content provided.	breast cancer could mainly be categorized into those with basic knowledge, nonprofit organizations, corporations, and those for researchers. Since search engines focused on different results, multiple search engines should be used, especially during a search for health information.
Haq et al.	2013	Patient Needs regarding Web-Based Systems	To obtain breast cancer patient needs regarding information.	Designed and evaluated a survivorship care plan for breast cancer patients.	<p>Information requested by patients:</p> <ul style="list-style-type: none"> • the date of an appointment • their type of cancer • locally available • health insurance. <p>The information should be presented in layers that are tailored to patient needs in terms of which stage they are currently experiencing.</p>

Knijnenburg et al.	2013	Patient Needs regarding Web-Based Systems	To assess the perceived usability of a national website with information regarding late effects survivors might experience due to cancer.	Questionnaires and a qualitative analysis were used to evaluate the usability and content of the website for childhood cancer survivors and their parents.	Survivors and parents involved in the study preferred and requested scientific information. Also, stratified information, where general content could lead to that of more details and complexity were preferred.
Lee, Park, Yun & Chang	2013	Patient Needs regarding Web-Based Systems	To develop and evaluate a web-based self-management system for the diet and exercise of cancer survivors.	Identified user requirements and then developed and evaluated the web-based system.	Functional requirements of the intervention included: <ul style="list-style-type: none"> • provision of tailored information • automatic and immediate feedback • comparisons between current status and goal • action planning • provision of daily feedback
Lubberding et al.	2015	Patient Needs regarding	To assess the needs of survivors targeted	Conducted interviews with cancer survivors.	The unmet needs of survivors were found to include:

		Web-Based Systems	toward accessibility to supportive care via an electronic health application.		<ul style="list-style-type: none"> • information regarding persisting or new symptoms after their treatment • feedback that would enable them to compare their current status to what is considered normal regarding their symptoms • the ability to obtain information in between follow-up consultations • the ability to obtain personalized information on topics not discussed with the physician
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Tseng, Liou & Chiu	2012	Presentation of Information in Web-Based Systems	To develop a web-based system for the education of psychiatric patients.	Integrated databases pertaining to disease, medicine and nurses' knowledge, then the system was evaluated.	Providing narrations, instead of having patients read texts, was found to be more effective in having them follow treatment plans.
Pérez et al.	2014	Presentation of Information in Web-Based Systems	To understand the impact of breast cancer survivors' stories on newly diagnosed patients.	Developed a cancer-communication intervention, categorized the videos based on theme, and then piloted with breast cancer survivors.	Delivery of information in this narrative form has increased health participation in the cohort of the African-American women breast cancer patients, in addition to their engagement, ability to cope with treatment and recovery, and understanding and identification of the information provided.
Fu et al.	2016	Presentation of Information in Web-Based Systems	To evaluate a self-care web-and-mobile-based intervention for breast cancer survivors.	Conducted a heuristic evaluation and user testing.	The interactive simulations provided for an engaging training system in order to help build self-care abilities. The ability to review the self-care strategies previously learned based on their own availability, pace

					and time also helped enhance survivors' self-care abilities.
Kuijpers et al.	2015	Presentation of Information in Web-Based Systems	To present an interactive portal that would empower cancer survivors.	Conducted an evaluation of the portal by health professionals breast and lung cancer survivors.	A positive aspect of the system involved accessibility of information while a negative aspect involved lengthy texts and the use of medical jargon.
Cocker et al.	2015	Presentation of Information in Web-Based Systems	To adapt pedometer-based step advice that was used for the general public to the breast cancer survivor population.	Adapted the device and then conducted evaluations using usability tests and a process evaluation.	The description of the advice being provided was found to be too lengthy. Also, the information provided was stressed to be related to the current situation at that point in time.
Nickell, Burke, Cohen, Caprio & Joseph	2014	Adaptation of Information Provided in Web-Based Systems	To reduce information and access disparities for breast cancer research opportunities among people with a limited proficiency in the English language and a low socioeconomic	Developed the intervention to educate patients about research studies, and then conducted a pilot test with breast cancer survivors.	Visual aids were found to assist survivors in remembering key components of the script and in increasing accessibility. These visual aids were also found to be useful in engaging those with low rates in literacy

			ic background.		
Austvoll-Dahlgren, Bjørndal, Odgaard-Jensen & Helseth	2012	Adaptation of Information Provided in Web-Based Systems	To evaluate the effects of a web portal used to access health information.	Evaluated the web portal by having participants complete certain tasks.	Using this intervention was found to have helped in improving attitudes toward searching for information within health.
Ginossar et al.	2017	Adaptation of Information Provided in Web-Based Systems	To analyze the content, usability and utilization of literate design standards of all applications related to breast cancer.	Used a content analysis scheme on all breast cancer-related mobile phone applications.	Out of the 101 applications found, only 24 cited scientific research to support the information they presented. In addition, none of the applications contained all of the six usability items by the Institute of Medicine (IOM), and most did not allow for customization of information by users.
Highfield, Ottenweller, Pfanz & Hanks	2014	Adaptation of Information Provided in Web-Based Systems	To bridge the gap between an underserved population and their access to healthcare as it has been described by the Patient Protection	Obtained user feedback regarding patient navigators.	Requirements of the system were found to include: <ul style="list-style-type: none"> enabling the search for clinics based on several criteria displaying results of

			and Affordable Care Act.		<p>the search and enabling them to be emailed or printed</p> <ul style="list-style-type: none"> • enabling the sorting of the displayed results • providing distance calculations between one's address and certain clinics • providing a Google map view
Atashi, Khajouei, Azizi, & Dadashi	2016	Evaluation of Web-Based Systems	To evaluate the usability of health information systems used in Iran.	Heuristic evaluations were conducted by experts and non-experts in health information systems. The number of problems and the given severity ratings were then compared.	Most of the problems identified in the system were attributed to the heuristic related to consistency and standards, such as in the use of poorly designed icons; followed by the heuristic related to helping users recover from errors; and the heuristic pertaining to

					recognition rather than recall.
Dias, de Fortes, & Masiero	2014	Evaluation of Web-Based Systems	To propose a method for simultaneously evaluating usability and accessibility.	Developed a questionnaire , and then used it to test two web-based systems.	The tool was able to calculate the usability and accessibility of a system, in addition to the amount of effort needed to improve it.
Lyles, Sarkar & Osborn	2014	Evaluation of Web-Based Systems	To describe methods for usability testing that have been adopted by healthcare researchers and facilities.	Conducted a narrative review of studies testing for the usability of a mobile- or web-based system.	Each of the evaluation methods have certain benefits and are more suitable to be used for certain purposes over others, determining what is needed in the current design iteration would help in the selection of an evaluation tool.

Table 1.0. Literature review summary

Problem Statement

Even with the number of studies seen above, more needs to be done regarding the design and creation of electronic systems that meet patients' needs, and more specifically that of LTSs of breast cancer. LTSs' needs should first be assessed regarding the information they seek to acquire; ways in which this information can be appropriately presented to LTSs should then be determined; LTSs with special needs should be

accounted for when determining the presentation of information; and the appropriate tools for conducting an evaluation should be decided upon.

CHAPTER THREE: APPROACH TO SOLUTION

Suggested Approaches to Solve the Problem

In order to account for the problem regarding LTSs' needs in terms of immediately accessing information and finding answers to several questions, relevant information from the literature was used to further assess these needs. In addition to this, data from a previous study involving breast cancer survivors' forum project that had been filtered to include forum posts with mentions of features to be added or changed in the forum site and the usability issues encountered by breast cancer patients and survivors were examined. The information gathered from both of these two main sources would then be consolidated and synthesized. Results from a previous project involving folksonomy tagging would also be taken into consideration. This would be used to guide the design and functionality of the web-based navigator.

The rationale behind selecting these sources of data and information lies in the mostly qualitative nature of the information gathered. As LTSs thoughts, feelings, and capabilities are being taken into consideration when designing the navigator, a mostly qualitative approach is appropriate. Also, by employing such diverse sources of information, a more comprehensive navigator could be designed as the LTSs accessed

through these sources would be varied in terms of demographics, education, location, among other variables.

Procedures to Solve Problem

In order to complete the design of this system, several resources would need to be utilized. This would mainly involve extracting relevant information from the literature review. In order to complete the literature review presented in a previous section of this paper, several of the University Library's databases were utilized to gather relevant articles within the existing literature. To begin, databases pertaining to the field of informatics and computing, in addition to healthcare and rehabilitation sciences, were chosen. The databases in which searches were conducted included ACM Digital Library, ProQuest, PubMed, and Web of Science. Within each of these databases, the search filters used included full-text, peer-reviewed, from the year 2012 to 2017, and the English language. The search terms used comprised of "system usability," "health system usability," "health patient portal usability," "breast cancer usability system," and "breast cancer survivor usability." When determining which articles to use for this project, several inclusion criteria were determined, such as the subject of the article involving a health system; the targeted users being patients or were in some way involved; usability, development of a system, and/or needs requirements was/were discussed.

To further gather information regarding needs and usability issues encountered in other electronic systems, data regarding breast cancer forums from the comments, suggestions, and help forum of Breastcancer.org had been obtained. The file contained 443 posts that had been filtered from this forum using Java due to being 150 words of

length or greater. Each of these posts was read and then the information contained within was assessed as to whether it contained requests for any features of the website or any usability issues. Those posts that did not contain any relevant information were disregarded; however, those that did were included in a table. In this table, the post number and a formal interpretation of what was said in the relevant were included.

In order to complete the actual design of the system, a consolidation and synthesis of the results obtained from the literature review and the Breastcancer.org forum posts were performed. During this consolidation, a list of requirements for the navigator in terms of the functionalities, the layout, and other features pertaining to usability was defined. Based on these requirements, sketches were drawn in order to determine the positioning of each of the necessary components of the navigator, in addition to the flow from one page to another caused by interacting with certain objects in each page. Once the determination of this was finalized, a working prototype was created.

CHAPTER FOUR: FINAL PROJECT DEVELOPMENT

Developed Project (Outcomes)

The developed navigator was based on the review of 20 articles. This is in addition to going through the text obtained from the Breastcancer.org forum (see Table 2.0.). Some commonalities were seen between some of the requests and usability issues.

The proposed system in this project, the Health Electronic Learning Platform (HELP), is simple in terms of its layout and consists of a main search bar in which LTSs are able to ask a question using their own terms and language. The following design choices are based on findings from the comments found on breastcancer.org that have been supported by the literature. At the top of the navigator, simple icons can be clicked in order to lead to more pages:

- the items listed in the frequently asked questions page include detailed information regarding effects based on cumulative dosage and treatment a LTS may have had. In addition, information regarding how to utilize the navigator, how tagging works, among other topics are listed. All of this information is expandable to gain more complex information as was recommended by Haq et al. (2013), Lubberding et al. (2015), and Knijnenburg et al. (2013);
- a page for how to navigate, recover from errors and general help with the system as was recommended by Atashi, Khajouei, Azizi, and Dadashi (2016);

- a page for viewing one's profile and to enable tailored information as was mentioned by Haq et al. (2013), Lubberding et al. (2015), Ginossar et al. (2017), and Lee, Park, Yun and Chang (2013).

Under the main search bar, a menu with filters pertaining to an expected search can be expanded. This customization of information received was recommended by Lubberding et al. (2015). When a user asks a question using the main search bar, depending on what content is most suitable in answering the question, the resulting page has several layouts:

- if the question pertains to how to do something, images, simulations and videos that utilize the art of storytelling to provide information, along with some text, may be the result of the search. Storytelling in the form of videos may go a little beyond forums in terms of connecting to LTSs. This format in presenting information was mentioned by Pérez et al. (2014), Fu et al. (2016), and Tseng, Liou and Chiu (2012).
- if the question pertains to symptoms or what is to be expected for the future, relevant articles from databases would be the result. Once an article has been selected, stratification can be used to transform and translate the article into one containing the same information, but told in layman terms, instead of using medical jargon. This would assist those with low rates in literacy. Such adaptation of the information presented to patients was mentioned by Kuijpers et al. (2015) and Cocker et al. (2015).

- if the question pertains to allocating resources within the LTSs area, then the results would be a list of available resources. By further selecting one of the resources, more pertinent information regarding the resource can be viewed, in addition to a map with distances relative to a location set by the LTS. Filters would be most useful in this search, since the resulting resources requires such specificity. Such a format of presenting this type of information was recommended by Highfield, Ottenweller, Pfanz and Hanks (2014).
- if the question pertains to searching through forums, especially ones that are long and ongoing, then forums and any pertinent posts under each would be the result. This would eliminate the need to go through many posts before arriving at the one needed as was mentioned by Austvoll-Dahlgren, Bjørndal, Odgaard-Jensen and Helseth (2012).

Table 2.0.

A Sample of the Common Feature Requests and Usability Issues

Forum#/Post#	Formal Interpretation
F93/P1	threads, sort through enormous amounts of information, navigate through long ongoing posts, remain containing posts for future
F93/P29	Search engine, search engine does not offer the common features for specifying the search
F93/P23	Monitoring, misinformation being accepted as facts
F93/P30	Search engine, add feature for finding direct matches only

Table 2.0. Breastcancer.org site features and usability issues

Suggested Evaluation Method

Once the navigator has been designed, evaluation of its usability should commence. Therefore, the evaluation of this designed system is a future research goal. Since the system is still at a relatively early stage, utilizing the cognitive walkthrough method would be informative as to any problems that might occur when using the system for the first time. This was also mentioned by Lyles, Sarkar and Osborn (2014).

Employing a set of heuristics to evaluate the system would also be of benefit as it would ensure that the system is, at the very least, error-free from a professional's point of view as was performed by Atashi, Khajouei, Azizi, and Dadashi (2016). The resulting problems found from the cognitive walkthrough and the heuristics could then be compared, and those most urgent should be incorporated into a simple redesign of the navigator. Afterwards, think-aloud protocols would be beneficial in this instance, because it would provide information regarding the thoughts, confusion, and perception of LTSs when using this system. When going through the articles discussed in the literature review, it was discovered that some users preferred a system that required a log-in while others preferred an open system. It would be worthwhile to conduct an evaluative user study that would compare the currently designed navigator and a prototype of a redesigned navigator that requires LTSs using the system to login.

CHAPTER FIVE: DISCUSSION

Explanation of Outcomes

The presented HELP navigator is designed to be an open system that somewhat resembles an Internet search engine or that of a library database. In this instance, LTSs can interact with any information found by downloading, emailing, or printing the content. At the same time, however, personalization occurs in being able to add tags to content found, in addition to the search functionality itself, which with more LTSs tagging various content in their own terms, would improve the results provided. The format in which the content is presented varies, because the information can be better told

in a certain format rather than another. However, as the navigator merely links LTSs with the information they need, presented in a format they find suitable, the content and information are not a part of the navigator's design. This implies that in addition to being able to link folksonomy tagging with UMLS MeSH terms, thereby providing evidence-based information using the patient's own terms during a search, it would also need to be able to prioritize the content found based on the most appropriate format in which it is to be presented. For instance, if a LTS wants to find information regarding how to perform certain exercises, and the navigator was able to find the answer in the form of a video and in the form of a written article, the video would be given high priority. However, LTSs have different preferences. This inherent prioritization could be overridden by having LTSs decide their preference, which could be done by setting a search filter that only provides textual information.

Implications of Results

The results found in this project present one step toward studying patient perceptions regarding their informational needs, especially LTSs of breast cancer; a severely underserved population. In addition to this, providing a patient-centered approach inherently necessitates constant change and iteration of design and usability. Therefore, the results presented should not be taken as a definite, but instead, should be used as a starting point toward a better approach for engaging LTSs in their own care and better equipping them for this engagement.

CHAPTER SIX: CONCLUSION

Limitations & Future Research

Although this project is based on others' work, in addition to being a part of a larger project and framework, the work presented was completed by one person. In many instances, this would not have posed any problems; however, the nature of this work, in particular, would have greatly benefited from a multi-disciplinary team. Also, the data and information gathered to specify the usability recommendations were indirectly gathered from potential users. Although this provides some benefit in that potential users are free from any bias that might have been caused had they been directly asked for the purpose of this project, combining both direct and indirect sources might have provided for more comprehensive and all-inclusive results.

In order to move on to the next step involved in creating this navigator, user studies in preferably uncontrolled environments should commence. After the prototype of the designed system is complete, the rate of its success will first be assessed by a clinician or hospital staff member from the hospital associated with this project. Once the results from that assessment have been obtained, several redesigns of the prototype will commence. An evaluation would then be conducted of the newly redesigned prototype. In this user study, some evaluation methods, such as heuristics, would be utilized to evaluate the initial prototype. Several recommendations would then be made for future redesigns of the prototype based on the results obtained.

Summary

By completing this project, and designing the system described, a new direction was added to how the effects of cancer in general can be alleviated. As most research regarding cancer focuses on the cure or treatment, this would add a new aspect in the form of how society views the effects of cancer. That is, how these effects can continue even after the cancer has been removed. Also, by using this system, new information would be gained to further understand the lives of those patients declared free of cancer.

REFERENCES

- Atashi, A., Khajouei, R., Azizi, A., & Dadashi, A. (2016). User Interface Problems of a Nationwide Inpatient Information System: A Heuristic Evaluation. *Applied Clinical Informatics*, 7, 89–100. Retrieved from <http://dx.doi.org/10.4338/ACI-2015-07-RA-0086>
- Austvoll-Dahlgren, A., Bjørndal, A., Odgaard-Jensen, J., & Helseth, S. (2012). Evaluation of a Web Portal for Improving Public Access to Evidence-Based Health Information and Health Literacy Skills: A Pragmatic Trial. *PloS one*, 7(5), e37715. Retrieved from <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0037715>
- De Cocker, K., Charlier, C., Van Hoof, E., Pauwels, E., Lechner, L., Bourgois, J., ... & De Bourdeaudhuij, I. (2015). Development and usability of a computer-tailored pedometer-based physical activity advice for breast cancer survivors. *European Journal of Cancer Care*, 24(5), 673-682. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12225/abstract>
- Dias, A. L., de Mattos Fortes, R. P., & Masiero, P. C. (2014, April). HEUA: A Heuristic Evaluation with Usability and Accessibility requirements to assess Web systems. In *Proceedings of the 11th Web for All Conference* (p. 18). ACM. Retrieved from <http://dl.acm.org/citation.cfm?id=2596706>
- Fu, M. R., Axelrod, D., Guth, A. A., Wang, Y., Scagliola, J., Hiotis, K., ... & El-Shammaa, N. (2016). Usability and feasibility of health IT interventions to enhance Self-Care for Lymphedema Symptom Management in breast cancer

- survivors. *Internet Interventions*, 5, 56-64. doi:10.1016/j.invent.2016.08.001
- Ginossar, T., Shah, S. F. A., West, A. J., Bentley, J. M., Caburnay, C. A., Kreuter, M. W., & Kinney, A. Y. (2017). Content, Usability, and Utilization of Plain Language in Breast Cancer Mobile Phone Apps: A Systematic Analysis. *JMIR mHealth and uHealth*, 5(3). doi:10.2196/mhealth.7073
- Haq, R., Heus, L., Baker, N. A., Dastur, D., Leung, F. H., Leung, E., ... & Parsons, J. A. (2013). Designing a multifaceted survivorship care plan to meet the information and communication needs of breast cancer patients and their family physicians: results of a qualitative pilot study. *BMC Medical Informatics and Decision Making*, 13(1), 76. doi:10.1186/1472-6947-13-76
- Highfield, L., Ottenweller, C., Pfanz, A., & Hanks, J. (2014). Interactive web-based portals to improve patient navigation and connect patients with primary care and specialty services in underserved communities. *Perspectives in health information management*, 11(Spring). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3995492/>
- Knijnenburg, S. L., Kremer, L. C., Versluys, A. B., Braam, K. I., Mud, M. S., van der Pal, H. J., ... & Jaspers, M. W. (2013). Evaluation of a patient information website for childhood cancer survivors. *Supportive Care in Cancer*, 21(4), 919-926. doi:10.1007/s00520-012-1604-7
- Kuijpers, W., Groen, W. G., Oldenburg, H. S., Wouters, M. W., Aaronson, N. K., & van Harten, W. H. (2015). Development of MijnAVL, an interactive portal to empower breast and lung cancer survivors: an iterative, multi-stakeholder

approach. *JMIR Research Protocols*, 4(1). doi:10.2196/resprot.3796

Lee, M. K., Park, H. A., Yun, Y. H., & Chang, Y. J. (2013). Development and formative evaluation of a web-based self-management exercise and diet intervention program with tailored motivation and action planning for cancer survivors. *JMIR Research Protocols*, 2(1). doi:10.2196/resprot.2331

Lubberding, S., 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.
doi:10.1111/jocn.12753

Lyles, C. R., Sarkar, U., & Osborn, C. Y. (2014). Getting a technology-based diabetes intervention ready for prime time: a review of usability testing studies. *Current Diabetes Reports*, 14(10), 534. Retrieved from
<https://link.springer.com/article/10.1007/s11892-014-0534-9>

Nickell, A., Burke, N. J., Cohen, E., Caprio, M., & Joseph, G. (2014). Educating low-SES and LEP survivors about breast cancer research: pilot test of the health research engagement intervention. *Journal of Cancer Education*, 29(4), 746-752.
Retrieved from <https://link.springer.com/article/10.1007/s13187-014-0650-x>

Nielsen, J. (1995, January 1). 10 Usability Heuristics for User Interface Design.

Retrieved from <https://www.nngroup.com/articles/ten-usability-heuristics/>

Northouse, L., Schafenacker, A., Barr, K. L., Katapodi, M., Yoon, H., Brittain, K., ... & An, L. (2014). A tailored web-based psycho-educational intervention for cancer

patients and their family caregivers. *Cancer Nursing*, 37(5), 321.

doi:10.1097/NCC.000000000000159

Pérez, M., Sefko, J. A., Ksiazek, D., Golla, B., Casey, C., Margenthaler, J. A., ... & Jeffe, D. B. (2014). A novel intervention using interactive technology and personal narratives to reduce cancer disparities: African American breast cancer survivor stories. *Journal of Cancer Survivorship*, 8(1), 21-30. Retrieved from <https://link.springer.com/article/10.1007/s11764-013-0308-4>

The American Cancer Society medical and editorial content team [ACS]. (2016a, June 1). Breast Cancer Survival Rates. Retrieved from <https://www.cancer.org/cancer/breast-cancer/understanding-a-breast-cancer-diagnosis/breast-cancer-survival-rates.html>

The American Cancer Society medical and editorial content team [ACS]. (2016b, August 18). Emotions and Breast Cancer. Retrieved from <https://www.cancer.org/cancer/breast-cancer/living-as-a-breast-cancer-survivor/emotions-and-breast-cancer.html>

The American Cancer Society medical and editorial content team [ACS]. (2016c, August 18). Pregnancy After Breast Cancer. Retrieved from <https://www.cancer.org/cancer/breast-cancer/living-as-a-breast-cancer-survivor/pregnancy-after-breast-cancer.html>

The American Cancer Society medical and editorial content team [ACS]. (2016d, August 18). What Is Breast Cancer? Retrieved from <https://www.cancer.org/cancer/breast-cancer/about/what-is-breast-cancer.html>

- The American Cancer Society medical and editorial content team [ACS]. (2017, January 5). How Common Is Breast Cancer? Retrieved from <https://www.cancer.org/cancer/breast-cancer/about/how-common-is-breast-cancer.html>
- Tseng, K. J., Liou, T. H., & Chiu, H. W. (2012). Development of a computer-aided clinical patient education system to provide appropriate individual nursing care for psychiatric patients. *Journal of Medical Systems*, 36(3), 1373-1379. Retrieved from <https://link.springer.com/article/10.1007/s10916-010-9599-4>
- Wang, T., & Dolezel, D. (2016). Usability of Web-based Personal Health Records: An Analysis of Consumers' Perspectives. *Perspectives in health information management*, 13(Spring). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4832130/>
- Wang, L., Wang, J., Wang, M., Li, Y., Liang, Y., & Xu, D. (2012). Using Internet search engines to obtain medical information: a comparative study. *Journal of Medical Internet Research*, 14(3). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3799567/>
- Yu, C. H., Parsons, J., Mamdani, M., Lebovic, G., Shah, B. R., Bhattacharyya, O., ... & Straus, S. E. (2012). Designing and evaluating a web-based self-management site for patients with type 2 diabetes-systematic website development and study protocol. *BMC Medical Informatics and Decision Making*, 12(1), 57. doi:10.1186/1472-6947-12-57

APPENDICES

Appendix A: Most Common Site Feature Requests and Usability Issues

Note: the actual text from user's comments on breastcancer.org were not included due to the size of this paper.

Forum #/Post	Formal interpretation
F93/P1	threads, sort through enormous amounts of information, navigate through long ongoing posts, remain containing posts for future
F93/P4	threads, long pages contributed by users having long profiles, redundancy of profile information every time a user posts, length of user's diagnosis signature
F93/P5	successful threads, topics stray from titular topic, new readers
F93/P8	length of a user's diagnosis signature, suggested viewing it by clicking on a user's name

F93/P11	replies, Request for a quote feature, include person's name in replies,
F93/P12	replies, Requests for a quote feature
F93/P21	posts, no way to directly link to a specific post in an mail or another post, posts not sequentially numbered
F93/P23	monitoring, misinformation being accepted as facts
F93/P29	search engine, search engine does not offer the common features for specifying the search
F93/P30	search engine, add feature for finding direct matches only
F93/P35	posts, how many of the same post can be made across different threads without it being considered spam, rules, freedom of thought
F93/P37	posts, including link to where the original post can be found when deleting posts considered spam
F93/P44	threads, separate based on level of breast cancer, stage 4 cancer
F93/P46	recommendation, posts, offer private posting, stage 4 cancer

F93/P54	inclusivity, even those not diagnosed with stage 4 can still see information about it and seek others who are at that stage in order to be prepared
F93/P59	privacy of forums, others should only post on forums dedicated to stage 4 for condolences, but the forums should still be public for viewing
F93/P66	posts, forum dedicated to a specific type of breast cancer, but others not diagnosed with it are posting, graphic pictures posting
F93/P67	forum titles more descriptive, differentiate between chat group about a scare and a support group
F93/P68	posters; differentiating between those who don't have breast cancer, those who do, and those who have survived; help survivors move on from posting on BC-specific forums; moderate new posters to reduce spam;
F93/P70	forums, indicate the type of members who can post in a specific forum (e.g. stage 4 only)
F93/P71	authentication, provide some form of authenticating that a poster is diagnosed with BC w/o giving away PHI, such as a simple form from a physician

F93/P72	posters, those not dx with BC should ask their question and then move on, instead of continuing to post
F93/P73	posters, only those diagnosed can answer questions related to that diagnosis
F93/P76	forum signature line, add different options for how patients prefer to call their dx. E.g. IDC could be called IDC with DCIS associations
F93/P78	forum signature line; clarify those having more than one type of BC; clarify those listing a timeline of dx, surgeries and treatments; pick stage of cancer then from drop-down pick type, tumor size and nodal status; ensure type, size and nodal status are consistent with stage
F93/P79	log-in, provide an option to keep user logged-in on one device even when the account is being used on another device, enable switching between platforms
F93/P84	forums, clarify forums dedicated to those not diagnosed with cancer, separate forums about surgery for BC and non-BC
F93/P85	forums, reorganize misplaced posts into appropriate forums

F93/P87	posters, include date of last activity alongside date joined
F93/P88	posters, consider caregivers acting on behalf of patient
F93/P94	forums, be able to block entire subheadings under a forum topic to avoid posting there
F93/P95	posts, be able to report posts that could potentially be spam
F93/P101	posters, indicate age of poster to help when ascertaining the advice they provide
F93/P103	forum signature line, add oncotype scores and whether cold cap user (or other treatment/preventative measures using/having used)
F93/P105	recommendation, recommended articles, needs improvement, should be filtered based on personal information found in profile
F93/P110	forums; indicate target of forum in big, bold letters; use visual cues to guide new users; accommodate those with visual cognition problems
F93/P115	recommended articles, increase relevancy, include opt-out feature, public or private diagnosis

F93/P116	forums, excessive number, consolidate forums rarely used into one
F93/P117	links should change color if they have been clicked, enable resizing of text, add forum description at the top, reconsider utilization of vertical space, signatures too long in listing all dx
F93/P118	forums, constant scrolling, place menu of topics horizontally, enable full-screen view of topics, enable navigation from one topic to another, links clicked should change color
F93/P119	forums, give precedence to topics with new content over who posted content, warm layout,
F93/P120	forums, gentle colors, css overrides html
F93/P121	list rare and common types of BC separately
F93/P122	customization to ignore forums of threads, size of posts, replace “dashboard” with “my home,”
F93/P124	show members’ posts entirely when searching rather than first few words
F93/P126	provide the option of choosing between different layouts based on preference
F93/P144	include a place for newest BC research articles

F93/P145	posts, include function to like posts, would also act as a bookmark
F93/P146	posts, include function to like posts, would save needless posting
F93/P152	forums, lock inactive personal threads, flag profiles of deceased members
F93/P172	forums, move caregiver forums higher, make more noticeable
F93/P174	forums, decrease number, redundant
F93/P176	forums, create detailed forums under surgery, unsure where to post, better masterlist of all forums
F93/P178	banner, warning about giving medical advice
F93/P183	forums, include forum for patients experiencing recurrence and significant other walking out on them
F93/P189	forums, include forum for positive thoughts or messages
F93/P200	posts, fact check button, include number of people concerned with the accuracy of information in a post
F93/P204	forums, navigate through pages by moving every 10 pages, remove members who have never logged in or posted
F93/P212	posts, provide context for information and links

F93/P228	posts, restrict number of posts for new users
F93/P234	posts, when clicking on a forum, last post made by user would be highlighted, last mention of user's username would be highlighted, get message when a response was made to someone's post, email updates
F93/P237	posts, after adding a post, should show the post that has just been added, allow for edits
F93/P240	posters, delete account for those who have only logged in once and never posted after a certain point in time has passed, send warning email that account will be deactivated
F93/P241	posters, would like to know true size of community
F93/P243	add general facts about BC to allay misconceptions
F93/P255	motivation, track weight
F93/P256	moderate language used, inappropriate medical advice given
F93/P257	posts, deleted posts should be replaced with reason for deletion and what rule(s) were violated
F93/P258	health tracker, statistics about those experiencing certain symptoms after undergoing certain treatments

F93/P269	forums, Provide a section for rare forms of cancer, such as mucinous breast carcinoma
F93/P271	forums, provide a consolidated section for posts about bone health
F93/P272	forums, relate breast cancer to other comorbidities, how this affects decisions about treatment
F93/P273	forums, topics, include toxins to avoid, commercialization of BC
F93/P287	add feature to create groups that meet face-to-face, perform group activities, retreat, swap personal stories
F93/P289	forums, create a separate forum for resources available in one's country
F93/P305	posters, include age at dx and current, optional, better for decision-making
F93/P307	posters, prefer private site for posting reconstruction images
F93/P309	posters, remove 5 posts per day limit, new patients have many questions, unlimited private messaging
F93/P315	forums, monitor old topics resurfacing
F93/P316	forums, list of active topics should have the most active topic at the top for each page based on the current forum

F93/P323	advertisements, commercial, appear educational, mark misleading ads as those for advertisement
F93/P325	replies, quotes, formatting quotes, differentiating quotes from the rest
F93/P327	forum, include forum for middle-aged women
F93/P331	forum, include forum for those with no family support
F93/P349	recommendation, provide equal information on all stages of BC, not just early stages, early monitoring
F93/P351	information, labyrinth, specific information for specific conditions
F93/P353	posters, post contradicting information for the sake of posting
F93/P356	compatibility with viewing on different browsers, different devices
F93/P361	posts, limit on number of posts for new members, frustrating, rationing posts
F93/P362	posts, limit on number of posts, leads others to go elsewhere
F93/P363	posts, limit on number of posts, uplifting restriction could have helped newly diagnosed patients

F93/P364	posts, limit on number of posts, frustrated, could not respond to those trying to help
F93/P366	reply window larger, size of posts should fill page,
F93/P367	consider how things look on other computers (mac), wrap text when posting a long link, have recommended links on the right to follow user as they scroll down forum, instead of blank space
F93/P368	reporting, accountability for reporting others, show username of reporter, limit number of reports per day, show history of reports to mods
F93/P369	misuse of report button, give warning, ban from site
F93/P374	disable private message option, prevent bullying,
F93/P381	utility of site, social networking aspect taking over, should be for making sense of complex information and informed decision-making
F93/P382	too many forums, too many choices, unsure where to post
F93/P385	post whom should be contacted for projects using data from site
F93/P386	disable reporting feature in certain forums, social forums

F93/P394	problems posting links to posts from BC.org
F93/P405	add DCIS MI to diagnosis options, mismatch between tumor size and nodal status,
F93/P408	send reassuring message that comment or issue encountered would be looked at, feedback
F93/P409	use contrasting colors for tables
F93/P410	every post made to a forum automatically includes that forum to list of favorite topics, have to delete unwanted ones
F93/P412	forums, logical ordering of form topics is unclear
F93/P413	place forum about lymphedema at top, most common topic related to all
F93/P414	place username above avatar, standardize font size for legibility, include "last edited" date to posts, organize forum topics by those most commonly dealt with by each specific user
F93/P415	label search boxes, indicate which search box should be used to obtain which results
F93/P422	forums, order topics by direction of recovery
F93/P423	forums, too many sections and groups, include long-term side effects section

F93/P424	posts, help remembering where posts were made
F93/P425	include separate section for long term survivor concerns
F93/P427	private messages, allow deleting sent and received messages
F93/P442	pictures, requires the use of third-party to host pictures on site, encountered problems doing so

Appendix B: The Designed Prototype



HELP

Health Electronic Learning Platform

USERNAME

PASSWORD

[Forgot username or password?](#)

Not a member?

Figure 1.1. The sign-in page of the designed prototype.



HELP

Health Electronic Learning Platform

USERNAME

janedoe

PASSWORD

Log-in

[Forgot username or password?](#)

Not a member?

Register

Figure 1.2. The sign-in page after a user has entered their username and password.

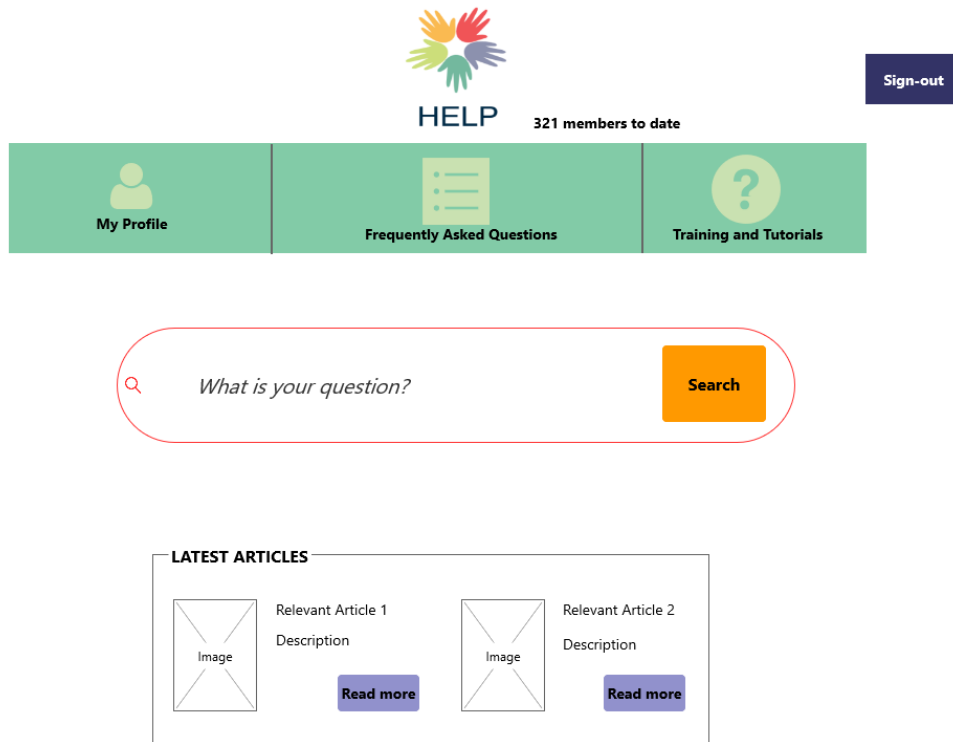


Figure 1.3. The homepage of the prototype where a user can view recent articles that are relevant to them based on information provided in their profile and ask a question by typing it into the search bar.

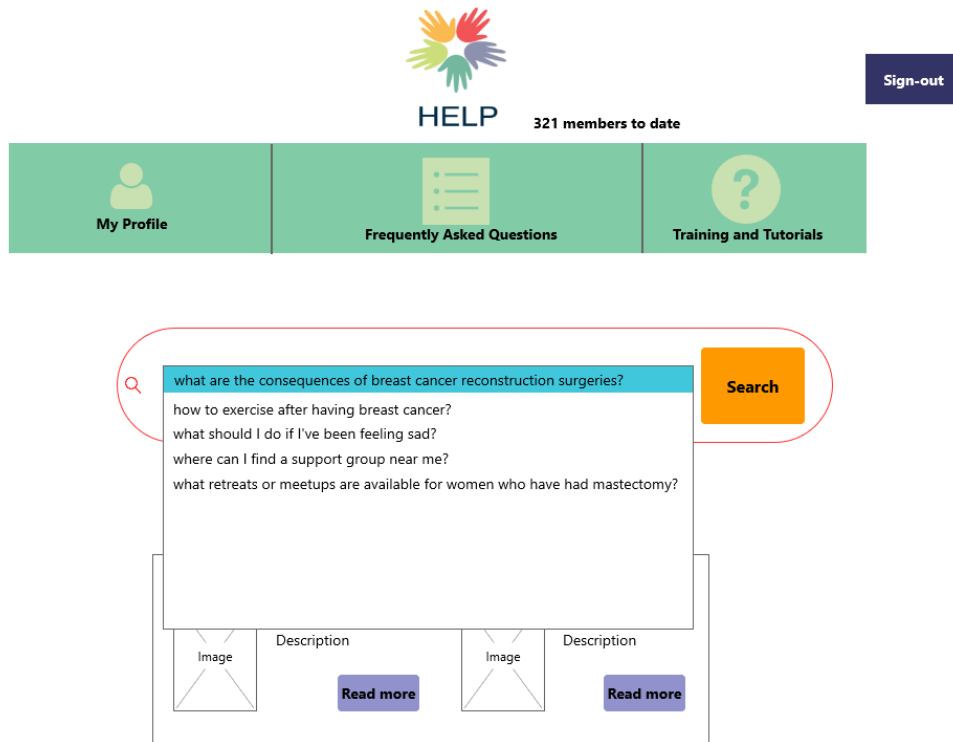
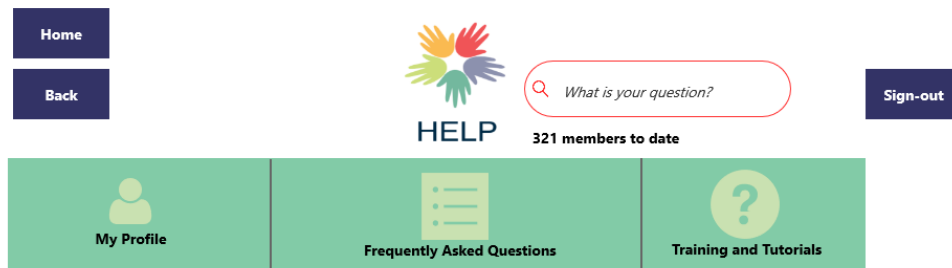


Figure 1.4. A user can type in any question they may have at the time. Above is a list of example questions users might ask. Answers to each of these questions may be suited to be presented in different formats.



"what are the consequences of breast cancer reconstruction surgeries?"

Sort by

Possible Answers

Article

<short description>

TAGS: [tag1](#) [tag2](#) [tag3](#)

[Read](#)

[Personalized reading version](#)

Article

<short description>

TAGS: [tag3](#) [tag4](#) [tag5](#)

[Read](#)

[Personalized reading version](#)

Figure 1.5. Possible answers to this question may be found in the form of articles. A user can read the article as it was originally written or at a reading level more suitable for them. The system would use the tags a patient has been using and substitute any medical jargon found in an article with the corresponding tags.

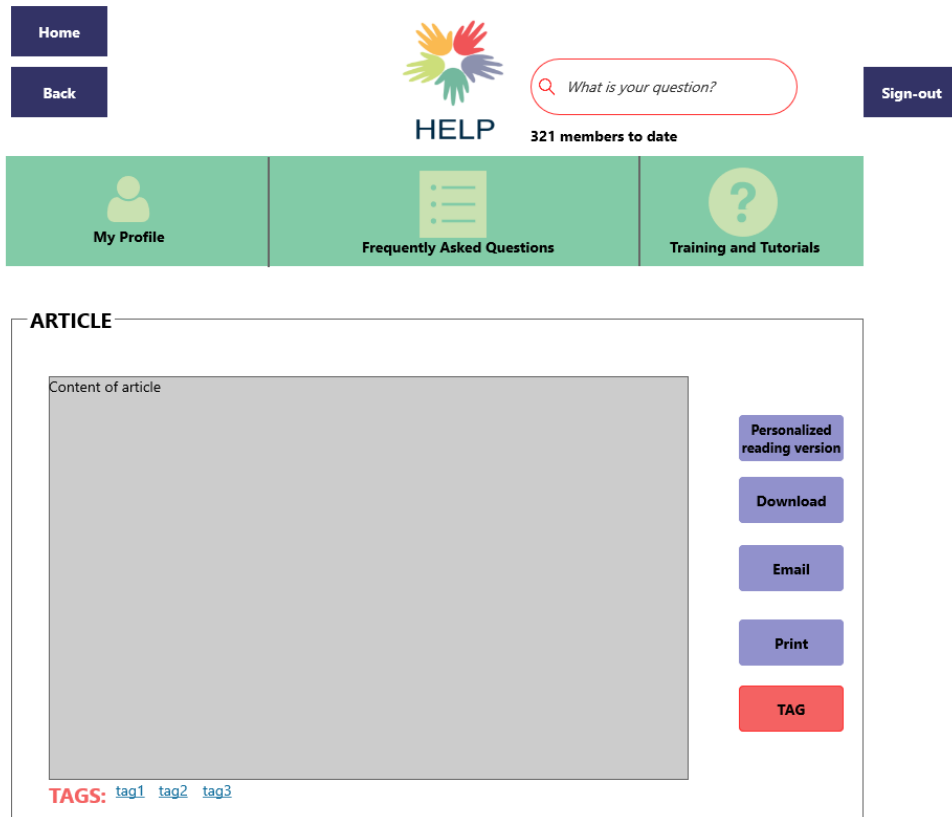


Figure 1.6. An example of how an article is viewed and the options available for interacting with the chosen article.

Home

Back

HELP 321 members to date

What is your question?

Sign-out

My Profile

Frequently Asked Questions

Training and Tutorials

ARTICLE

Content of article

TAGS

Current tags: breast reconstruction, infection

Your tags:

Add tag Cancel

Personalized reading version

Download

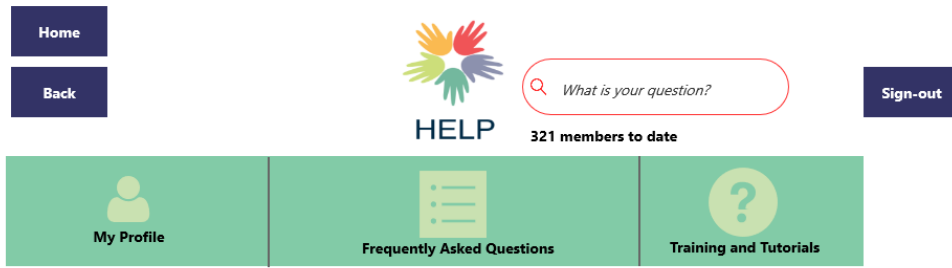
Email

Print

TAG

TAGS: [tag1](#) [tag2](#) [tag3](#)

Figure 1.7. An example of the pop-up box used for tagging. This box is the same across all of the formats in which information can be presented.



"how to exercise after having breast cancer?"

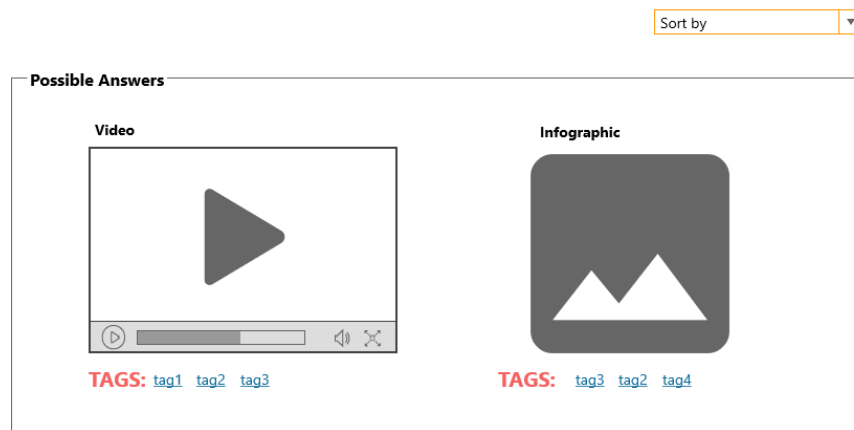


Figure 1.8. Possible answers to this question may be found in the form of videos, simulations, images and infographics.

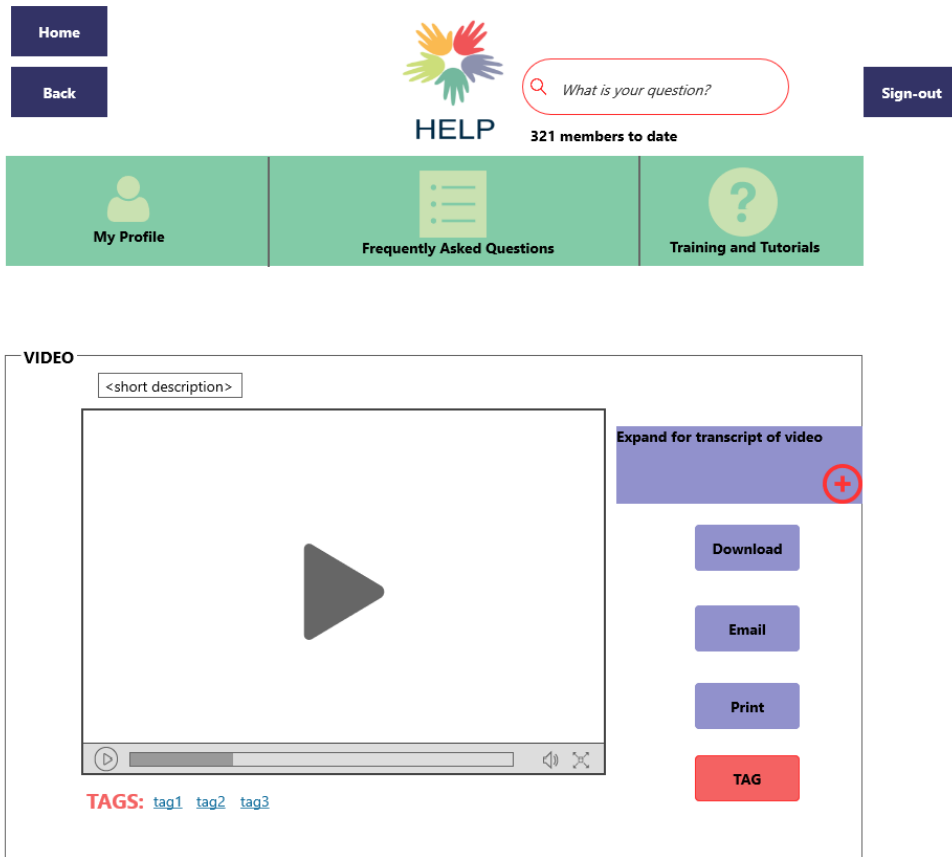
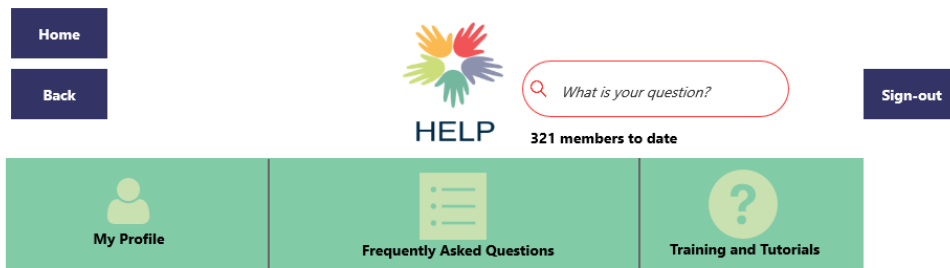


Figure 1.9. An example of how a video is viewed. For users who are not comfortable with videos, an option to view the transcript is available.



"what should I do if I've been feeling sad?"

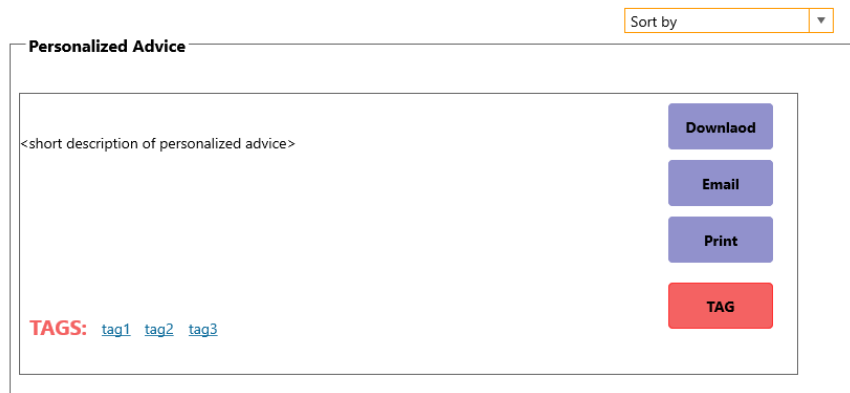
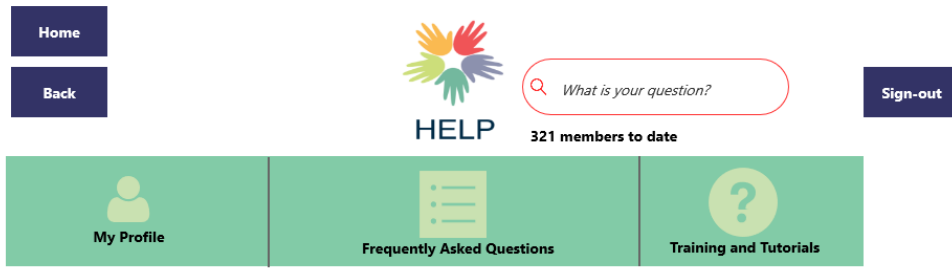


Figure 1.10. Possible answers to this question may be found in the form of personalized advice. The system would be able to integrate the personal information a user has entered into their profile and evidence-based information in order to form the advice. At times, information to contact a health professional would be given.



"where can I find a support group near me?"

Sort by

Possible Answers

Name of support group 1

3 miles away

<short description>

TAGS: [tag1](#) [tag2](#) [tag3](#)

[Find out more](#)

Name of support group 2

16.1 miles away

<short description>

TAGS: [tag4](#) [tag2](#) [tag5](#)

[Find out more](#)

Figure 1.11. Possible answers to this question may be found based on a certain location.

All results are able to be sorted by those most recent, most viewed, or most relevant.

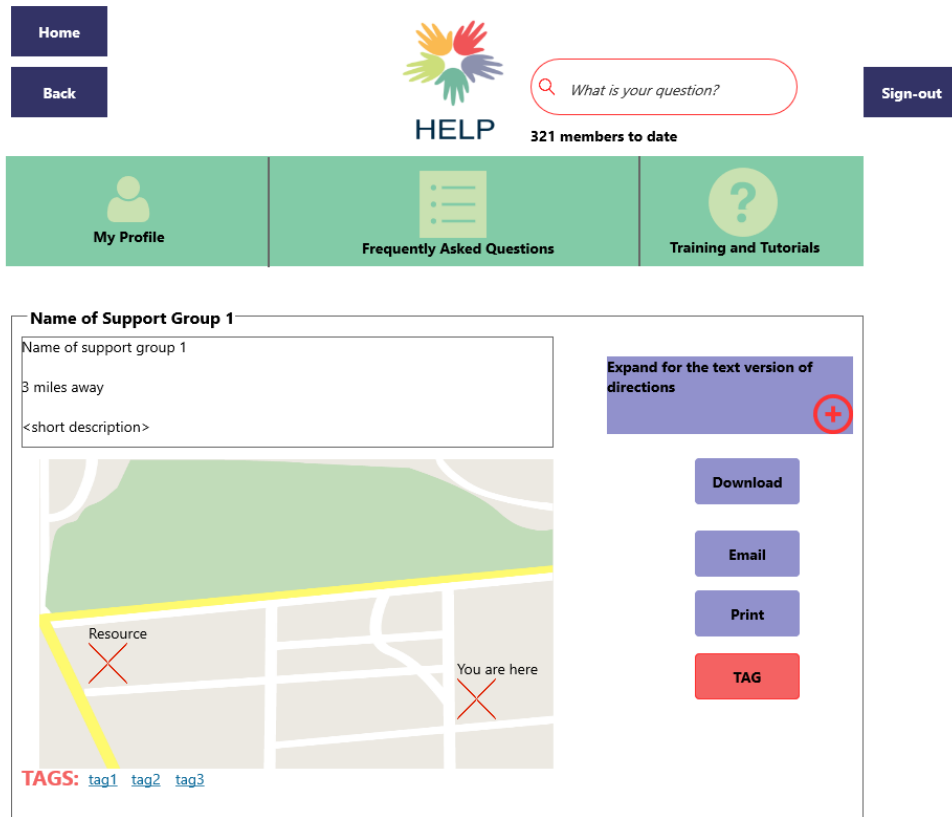
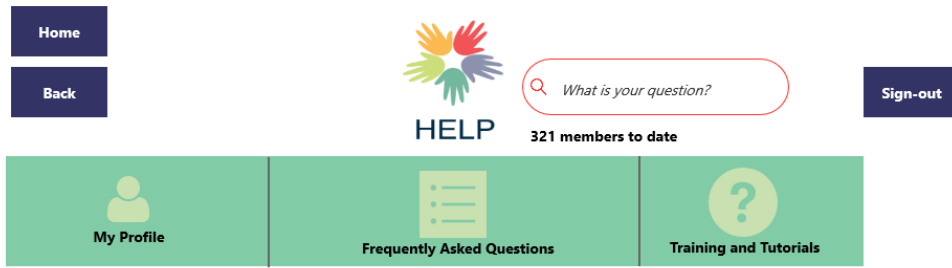


Figure 1.12. An example of how a resource is viewed. For users who are uncomfortable viewing maps, text-based directions are available.



"what retreats or meetups are available for women who have had mastectomy?"



Figure 1.13. Possible answers to this question may be found in forum posts. Similar to other formats, the results may be sorted based on those with most recent posts, most viewed posts, or most relevant posts to the question and the information found in a user's profile.

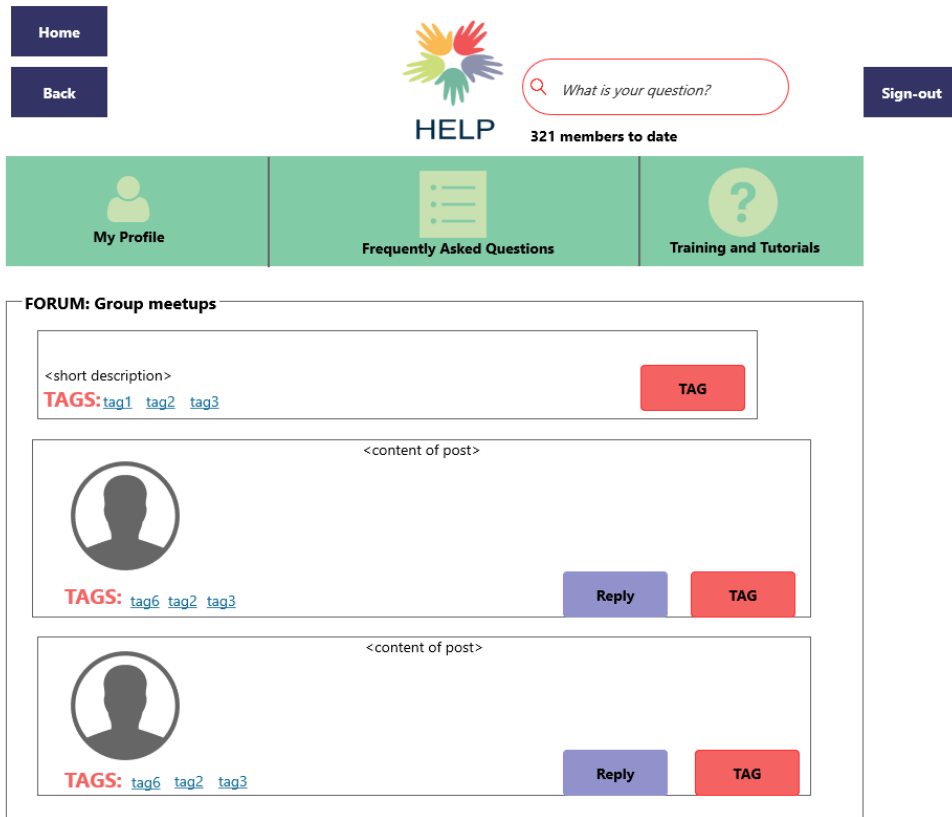


Figure 1.14. An example of how a forum would appear. Users may tag the entire forum or a single post.

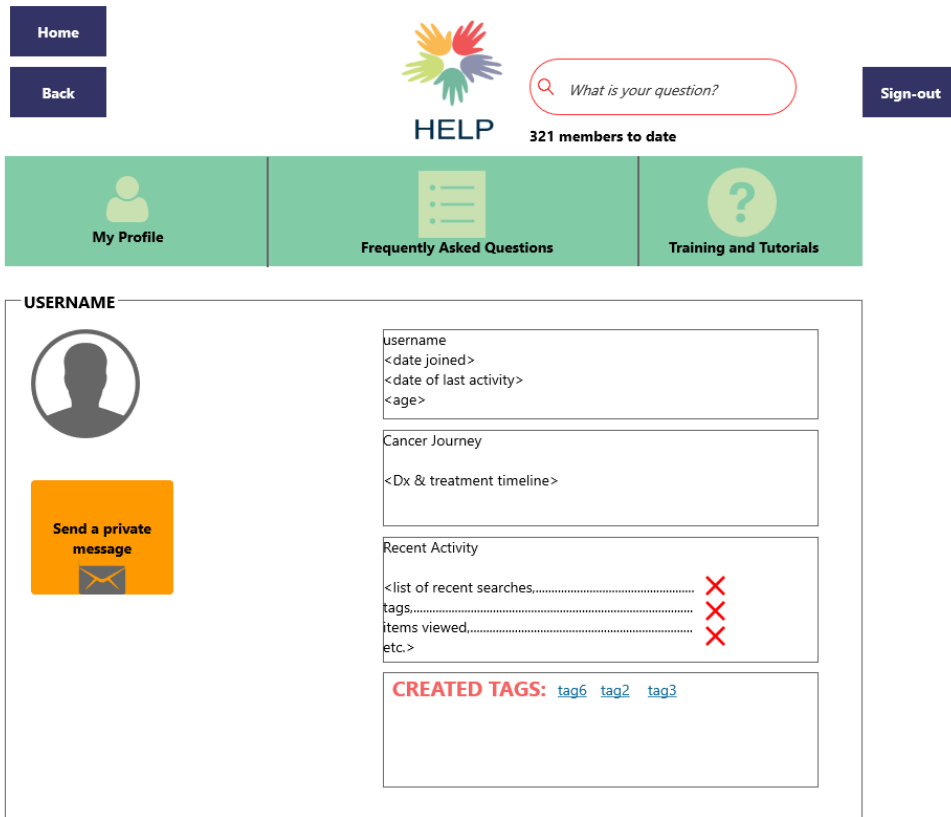


Figure 1.15. An example of how another user’s profile would appear. Their recent activity and tags created or used can be viewed.

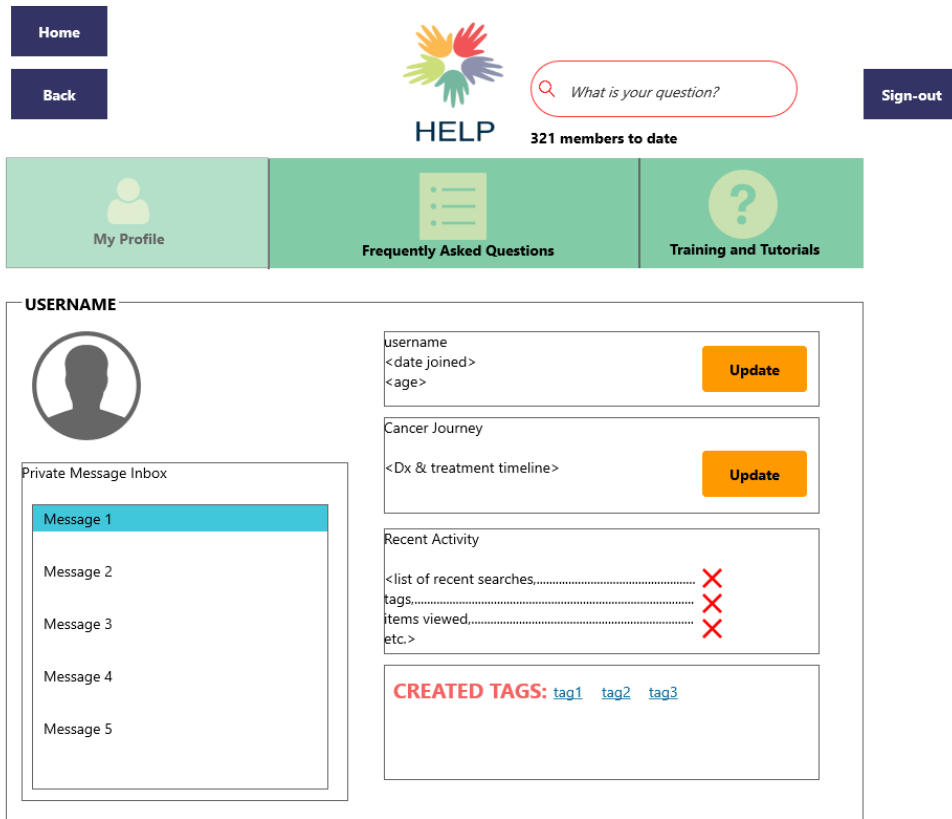


Figure 1.1.6. An example of how a user’s profile would appear to them. A user may fill out information, such as their diagnoses and timeline of their cancer journey to provide for more personalized information. They may also remove certain recent activity so that others cannot view them.

Home

Back

HELP 321 members to date

What is your question?

Sign-out

My Profile

Frequently Asked Questions

Training and Tutorials

FAQ

Effects based on cumulative dose and treatment	+
Checklist to assess health information	+
How tags work	+
About this navigator	+
Website rules	+
Disclaimer	+

Figure 1.17. The frequently asked questions page. This page includes general information pertinent to all breast cancer survivors and may help as a starting point for asking questions.

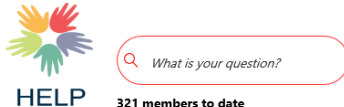
The screenshot shows a user interface for a 'HELP' section. At the top, there are navigation buttons for 'Home', 'Back', and 'Sign-out'. The central logo features a colorful hand icon above the word 'HELP' and the text '321 members to date'. A search bar contains the placeholder text 'What is your question?'. Below this is a green navigation bar with three main categories: 'My Profile', 'Frequently Asked Questions', and 'Training and Tutorials'. The 'Frequently Asked Questions' section is expanded to show a list of FAQ items, each with a red '+' icon for expansion and a red '-' icon for collapse.

FAQ	
Effects based on cumulative dose and treatment	+
Checklist to assess health information	+
How tags work	+
About this navigator	+
Website rules	-
Forum etiquette	+
Cyberbullying	+
Disclaimer	+

Figure 1.18. The information in this page is stratified in that if users would like to know even more about this topic, they can expand to view more complex information.

Home

Back



What is your question?

My Profile

Frequently Asked Questions

Training and Tutorials

"tag 1"

Sort by

Content tagged with tag 1

Article


<short description>

TAGS: tag1 tag2 tag3

Read

Personalized reading version

Video



TAGS: tag1 tag2 tag3

Personalized Advice

<short description>

Download

Email

Print

TAG

TAGS: tag1 tag2 tag3

Name of support group 1

3 miles away

<short description>

TAGS: tag1 tag2 tag3

Find out more

FORUM: Group meetups

<short description>

<date of last post>

TAGS: tag1 tag2 tag3

Find out more

Figure 1.19. When clicking on any tag in any page, a list of all information tagged with that tag appears.

Appendix C: CV

Monirah
AI-ABDUMUNEM

Indianapolis, Indiana, USA

EXPERIENCE

while in college

August 2015 / May 2017

GRADUATE ASSISTANT at IU SOIC Health
Information Management Department

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WHY ME?

I am interested in working at the intersection of healthcare, data, and user-experience design and evaluation. I strive to design methods by which information can be made to be user-centered, actionable, and transformable into knowledge.

EDUCATION

August 2017 (expected)

M.S.: Health Informatics

Indiana University, Indianapolis, IN

May 2015

B.S.: Biology, Pre-Med

University of Indianapolis, Indianapolis, IN
Cum Laude

PROFESSIONAL SKILLS

Computer Science Experience: Intro to C++, Object-Oriented Programming, MySQL Workbench, Python, and Weka, HTML/CSS and JavaScript

User Experience/Interaction Skills:

Contextual inquiry, Low- and High-Fidelity prototyping, Cognitive walkthrough, Heuristic evaluation, Think-aloud protocols, Data analysis, Communicating results and findings

selected PROJECTS

December 2016

INFO-H 543 INTERACTION DESIGN METHODS for Dr. Aqueasha Martin-Hammond

Usability Testing and Evaluation of an Application for Relieving Stress in the Teenage Population

October 2016

INFO-H 541 INTERACTION DESIGN PRACTICE for Dr. Lynn Dombrowski

User Experience Research and Design of a Kiosk Connecting People Experiencing Food Insecurity to Matching Non-profit Organizations

May 2016

INFO-B 513 DESIGN, IMPLEMENTATION, AND EVALUATION OF ELECTRONIC HEALTH RECORD SYSTEMS for Dr. Saptarshi Purkayastha

OpenMRS Dementia Care Form for Data Management and Analysis

HELP:
DEFINING THE USABILITY REQUIREMENTS
OF A BREAST CANCER LONG-TERM
SURVIVORSHIP (LTS) NAVIGATOR

Monirah Al-Abdulmunem

Josette Jones, R.N., Ph.D.
INFO-B 691 Project in Health Informatics
SOIC Indiana University-Purdue University
Indianapolis

GETTING FIRST-RATE HEALTH CARE WILL ALWAYS BE QUITE DIFFERENT FROM ORDERING SOMETHING FROM AMAZON. WE'RE TALKING ABOUT THE MOST PRECIOUS PART OF LIFE—ONE'S HEALTH—NOT BUYING A BOOK. BUT THE COMMON THREAD IS **THE POWER OF INFORMATION AND INDIVIDUALIZATION.**

-Eric Topol, *The Patient Will See You Now*

BACKGROUND

- **Breast cancer (BC)**
 - abnormal growth of cells in the breast, forming a tumor, that can then
 - invade nearby tissue or
 - metastasize to other areas of the body through
 - the blood stream or
 - the lymph system (ACS, 2016c).
 - About 252,710 new cases (ACS, 2017).
- **Survivorship**
 - About 3.1 million survivors in the U.S. (ACS, 2017).



WHY A NAVIGATOR?

- Many experience emotional toll, have questions that need immediate answers, navigate daily life after BC
- Most support groups are not open 24/7
- Currently

Evidence-based articles	Navigators	In the literature
Difficult to comprehend by those LTSs with low literacy rates (Nickell et al., 2014).	<ul style="list-style-type: none">• Led by professionals in a physical setting• Survivorship: main focus on adherence to post-treatment surveillance• Patient navigation effective in increasing screening tests• More studies needed for patient navigation in survivorship (Baik et al., 2016)	Little research has been done regarding the perspectives of breast cancer survivors in models of survivorship care (as cited in Haq et al., 2013).

- Some survivors continue using past online resources (forums) to help others, but those still with BC want them to move on

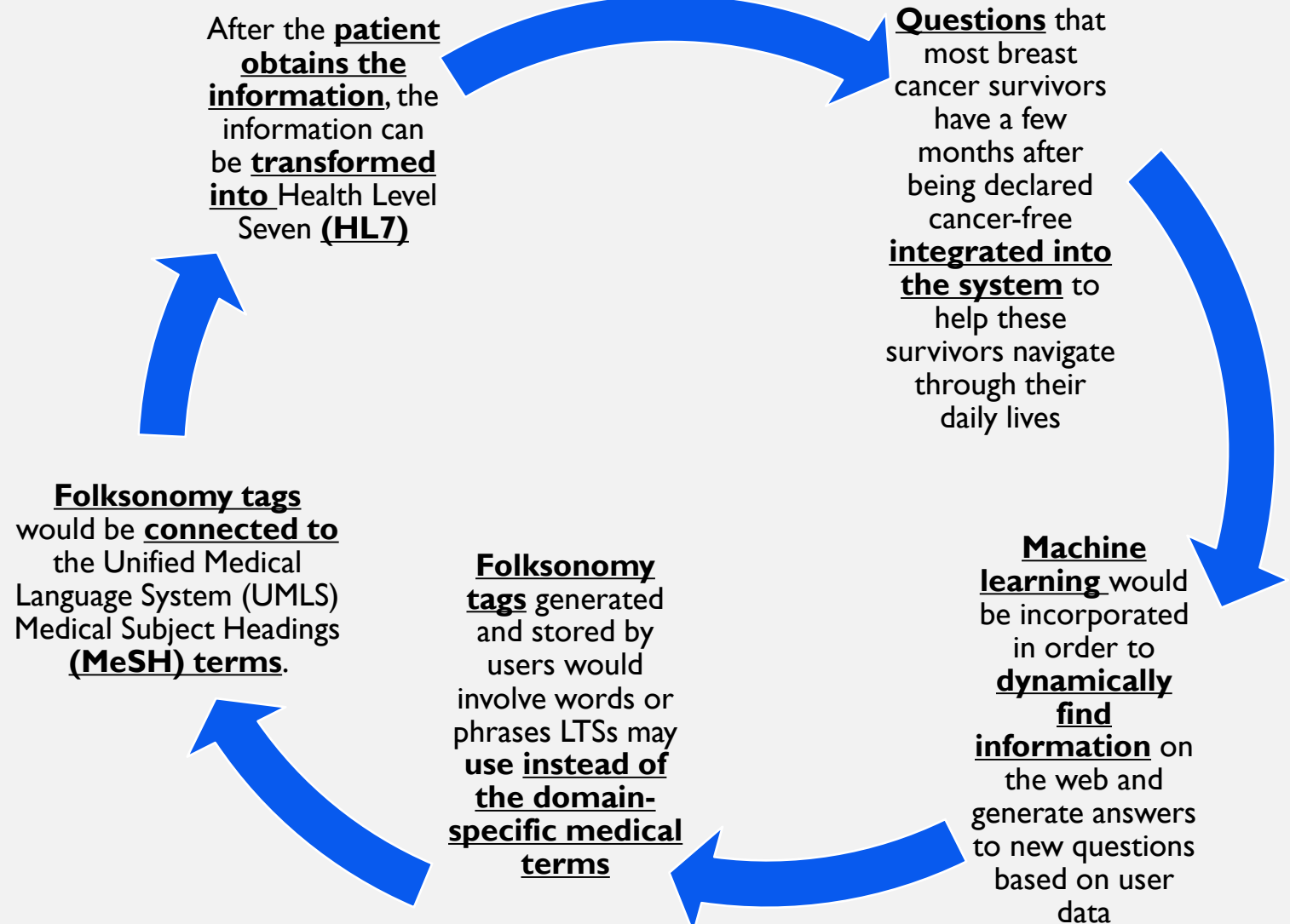
WHO WOULD USE IT?

- Characteristics of **survivors**
 - Mainly women
 - Aged 30-60
- **Long-term survivors (LTSs)**
 - patients who have been in remission for a year or longer.
- In **need of**
 - questions to be answered at any time
 - specific to their current circumstances
 - in a format that promotes accessibility



PATIENT-CENTERED INFORMATICS LAB (PATIENT CONTEXTUAL INFORMATION)

- Overview of the thought-process behind the navigator prior to working on it
- Health Electronic Learning Platform (HELP)



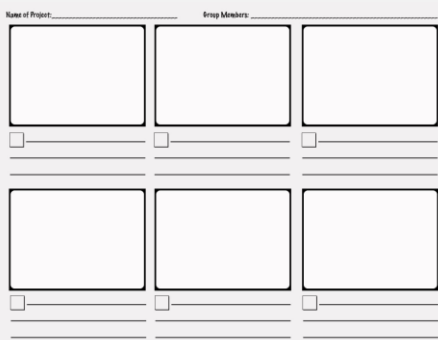
PREVIOUS PROJECTS

- Navigator for Long-term Survivors of Breast Cancer (Kshirsagar, Hinkley, & Ovbiebo, 2016)
 - The solution to the increasing number of survivors was to create an online navigator that would provide comprehensive resource for personalized recommendations regarding underlying issues involving finances, mental health etc.
- Navigator for Long-Term Breast Cancer Survivors: Using Forums with Social Tagging Folksonomy (McGann, 2017)
 - Survivors can organize and structure content in their own terms via folksonomy social tagging. Common questions and issues were identified into three topic areas of concern for LTSs:
 - Well-Being and Actions to Take to Feel Better;
 - Physical Health and Side Effects;
 - Emotional and Social Support.
- Mallet Results from Breast Cancer Survivors Forums
 - MALLET data involving breast cancer survivors' forum project that had been filtered to include forum posts with mentions of features to be added or changed in the forum site and the usability issues encountered regarding breastcancer.org

OBJECTIVE

- Propose specifications in terms of usability for a system, called the Health Electronic Learning Platform (HELP), that can assist survivors in answering questions they may have and become a one-stop shop for LTSs of breast cancer.
- Usability: qualitative, can be used to determine the ease of use of interfaces (Nielsen, 2012)
 - Helps in preventing users from leaving if they encounter any difficulties
- Utility: qualitative, can be used to determine whether a system provides features that are needed (Nielsen, 2012)

OVERVIEW OF METHODS



LITERATURE REVIEW

- **Use of Web-Based Systems for Patients**

- Yu et al. (2012) argued that web-based interventions show great potential with regards to self-management.
 - This intervention able to target behavior,
 - easily be upgraded given when decent monetary values are provided,
 - and be maintained at a low expense.
- Northouse et al. (2014) sought to transform a nurse-delivered psychoeducational intervention for patients and their caregivers into a tailored, web-based intervention.
 - while some reluctance may be shown to begin such an intervention, once a patient has begun, they will continue with the intervention until completion.
 - Also, the general transformation of what was usually a nurse-delivered program into a web-based program has been shown to be feasible.

LITERATURE REVIEW (CONT.)

- **Patient Needs regarding Web-Based Systems**

- Wang and Dolezel (2016),
 - argued that personal health records (PHRs) have the ability to increase patient empowerment in their own care
 - a gap exists in the literature regarding patients' perceptions as to the level of usability of PHRs.
- Wang et al. (2012) sought to compare common search engines in terms of their usability in obtaining health information by searching “breast cancer” in the chosen search engines.
 - The various search engines studied focused on different content; therefore, the use of multiple search engines, especially during a search for health information.
- Haq et al. (2013) sought to obtain patient needs regarding information.
 - designed a survivorship care plan (SCP) in two versions; paper- and web-based.
 - Patients in this study expressed a desire to interact with the complex and changing information needs through methods that are comfortable in terms of their preference regarding paper- or web-based interventions, manageable, supportive from trustworthy sources, and sensitive to the current circumstances.
- Knijnenburg et al. (2013) assessed the perceived usability of a national website with information regarding late effects of cancer.
 - Patients wanted scientific and stratified information, where general content could lead to that of more details and complexity, in addition to regular updates of certain types of information were also preferred

LITERATURE REVIEW (CONT.)

- Lee et al. (2013) developed a web-based intervention for self-management of diet and exercise targeted toward cancer survivors.
 - Diet: survivors would like to know what they should and should not eat, in addition to becoming motivated in order to change their diet.
 - Exercise: survivors were concerned about the possible effects of weight on the recurrence of cancer, how they should exercise during certain stages of treatment or recovery, and the precautions that should be taken when exercising
- Lubberding et al. (2015) argued that survivors' needs should be identified in a timely and effective manner.
 - Survivors did not want to be confronted with needless information,
 - have some semblance of control over the information they accessed,
 - the ability to avoid upsetting information,
 - and the provision of options within the survivors' own surroundings
- Interestingly, survivors indicated that the electronic health application would only act as an addition to the current support they receive, not a substitute.

LITERATURE REVIEW (CONT.)

- **Presentation of Information in Web-Based Systems**

- Tseng, Liou and Chiu (2012) designed a computer-based aid for nurses when educating patients.
 - This was able to generate customized content for educating a patient by integrating several databases regarding disease, medicine and nursing.
 - For the benefit of patients, providing narrations, instead of having them read texts, was found to be more effective in having them follow treatment plans.
- Pérez et al. (2014) developed a culturally targeted intervention for cancer-communication that involved African-American breast cancer stories.
 - Based on the argument that the use of narratives is an effective communication strategy for education, engagement, persuasion, or activation of the public for the promotion of health.
 - When shown to breast cancer survivors, participants identified with the storytellers and mentioned that the stories were informative and trustworthy.
- Fu et al. (2016) developed a patient-centered web- and mobile-based system for education and management of lymphedema symptoms among breast cancer survivors, and aimed to test it for feasibility, acceptability, and usability.
 - A training system would then commence to inform survivors how something occurs in the lymph system by visually showing how this occurs.
 - The interactive simulations provided for an engaging training system in order to help build self-care abilities.

LITERATURE REVIEW (CONT.)

- Kuijpers et al. (2015) developed an interactive portal that would
 - have access to the electronic medical record (EMR),
 - be able to report patient outcomes and other feedback,
 - and provide a physical activity support program.
- After evaluating the developed system, a positive aspect involved accessibility of information while a negative aspect involved lengthy texts and the use of medical jargon.
- Cocker et al. (2015) adapted a computer-tailored pedometer that provides advice for the general population to one that would provide advice specifically for breast cancer survivors, and then tested its usability.
 - By including barriers related to cancer and strategies for self-management, survivors' self-efficacy and control would be improved.

LITERATURE REVIEW (CONT.)

- **Adaptation of Information Provided in Web-Based Systems**

- Nickell, Burke, Cohen, Caprio and Joseph (2014) attempt to bridge gaps in literacy rates by providing non-trial-specific information about research in breast cancer using a patient navigator to those of low-socioeconomic status and limited English proficiency.
 - visual aids were developed to assist in remembering key components of the script and to increase accessibility.
- Austvoll-Dahlgren et al. (2012) developed an intervention that included facilitators to address the main barriers to obtaining research-based information, which involved,
 - providing access to medical and health-related research databases,
 - providing a checklist to critically assess health information,
 - and providing a checklist that could be used when consulting a healthcare provider.
- Overall, using this intervention helped in improve attitudes toward searching for information within health

LITERATURE REVIEW (CONT.)

- Ginossar et al. (2017) argued that mobile applications have assisted in
 - increasing breast cancer screenings,
 - the spread of information about cancer in rural areas,
 - and as health interventions, such as improving one's eating habits.
- Only 24 cited scientific research to support the information they presented.
- Most did not allow for customization of information by users.
- Highfield, Ottenweller, Pfanz and Hanks (2014) redesigned a web-based healthcare search tool for the navigation of patients in a virtual environment. The purpose of doing so was to bridge the gap between underserved population and their access to healthcare.
 - This search tool enables the allocation of local resources.
 - However, this requires to be dynamically and automatically updated, which was not achieved in this study.

LITERATURE REVIEW (CONT.)

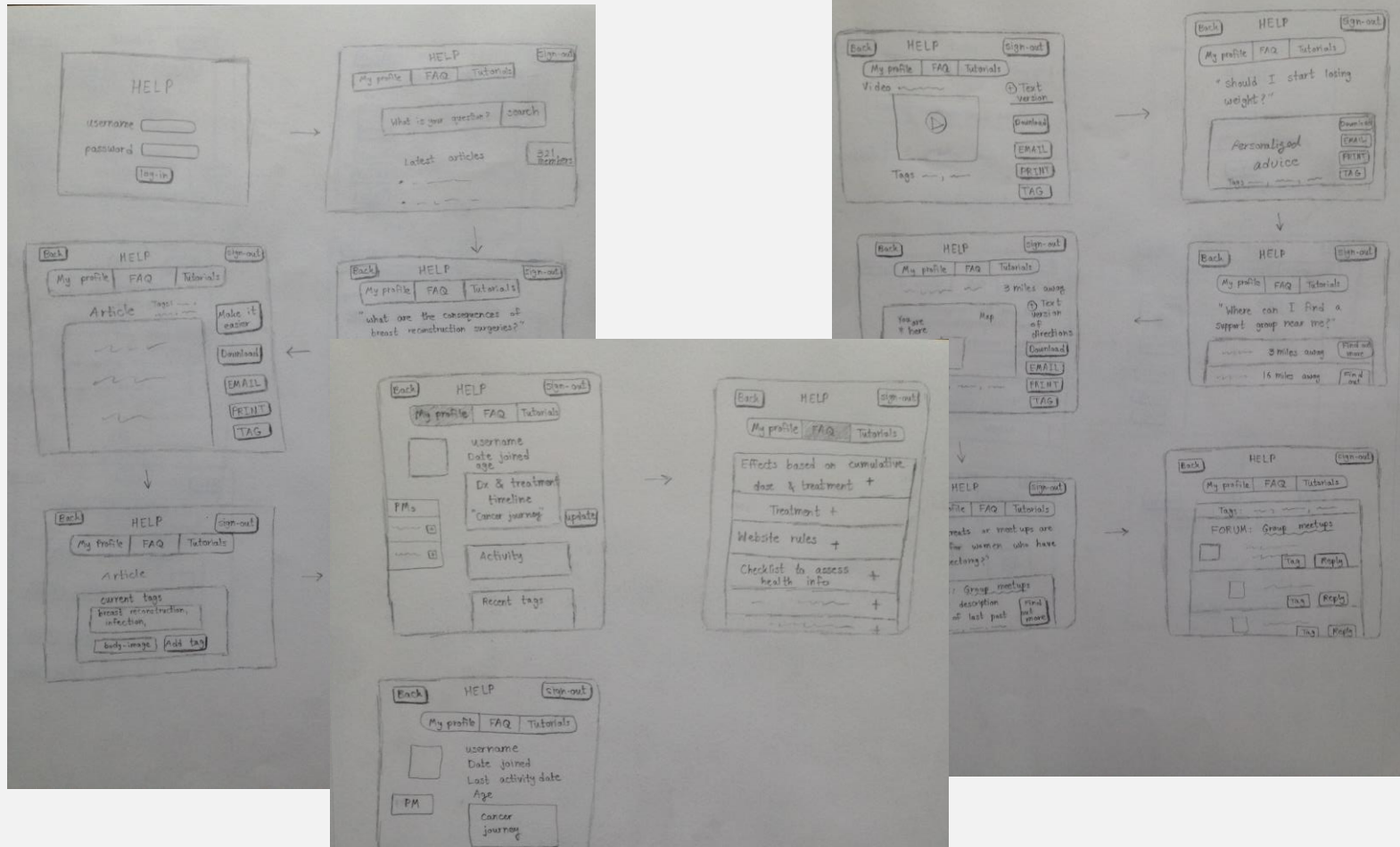
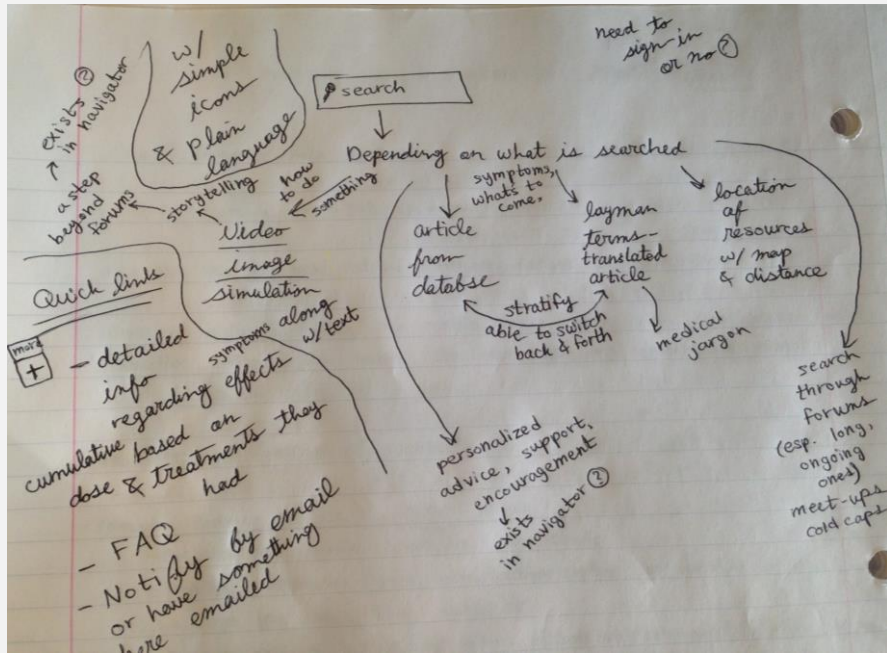
- **Evaluation of Web-Based Systems**

- Atashi, Khajouei, Azizi, and Dadashi (2016) employed Nielsen's ten heuristics in order to evaluate the usability of health information systems in Iran.
 - They found that most of the problems identified in the system were attributed to the heuristic related to consistency and standards, such as in the use of poorly designed icons;
 - followed by the heuristic related to helping users recover from errors;
 - and the heuristic pertaining to recognition rather than recall.
- Dias et al. (2014) proposed HEUA, a questionnaire to assess the usability and the accessibility of web systems
- Lyles, Sarkar and Osborn (2014) mention several methods of evaluating a system, such as:
 - qualitative methods in which users are able to generate new components to add to a system, such as an online tutorial;
 - system usage data, which involve the average length of time it took for a user to respond to the system as one outcome of usability;
 - think-aloud usability tests, which involve users voicing their thoughts as they go through the system;
 - cognitive walkthroughs involving experts evaluating the system for its first-time use, and heuristic evaluations involving pre-established rules

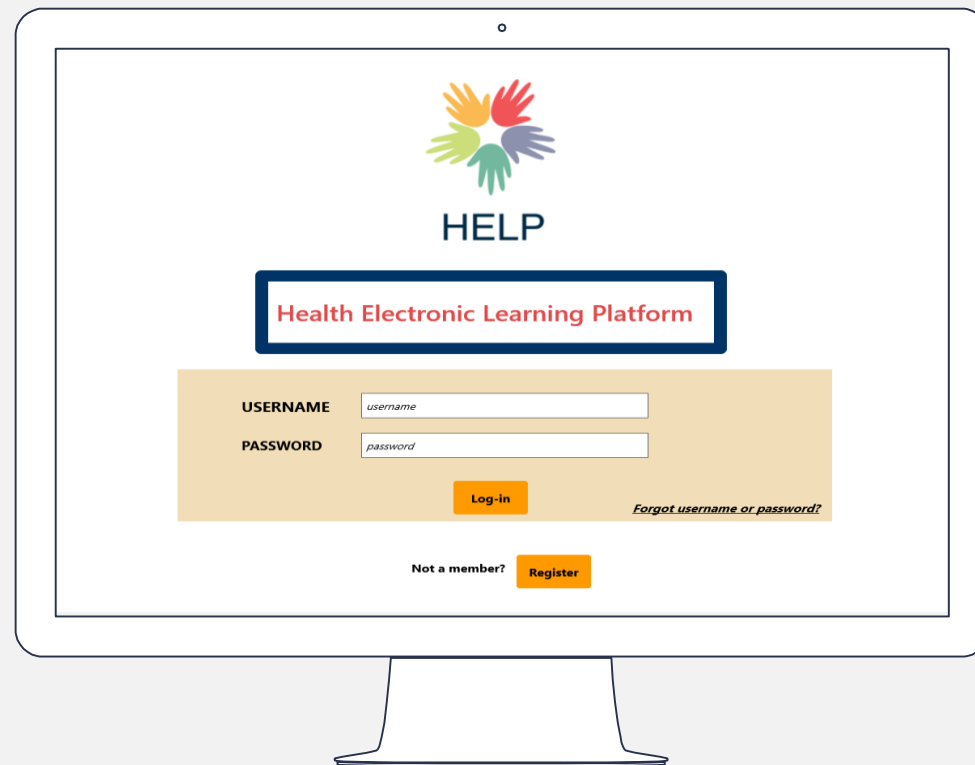
RESULTS

- **Consolidated usability requirements:**
 - the provision of information regarding health (appointments, type of cancer, health insurance, etc.);
 - providing a checklist to critically assess health information in FAQ
 - add general facts about BC and survivorship in FAQ to allay misconceptions
 - the provision of tailored information, automatic and immediate feedback, and comparisons between current status and goal
 - scientific, stratified information, where general content could lead to that of more details and complexity, in addition to regular updates of certain types of information
 - daily delivery of reinforcement in the form of positive messages
 - use of narratives and visual aids to convey information
 - scrolling up and down, in addition to clicking on clear icons for videos or information
 - labels tied to form fields improved access by a screen reader to accommodate those with vision problems,
 - include age, type(s) of cancer, date joined and date of last activity in a user's profile
 - recommended articles are relevant to information found in a user's profile
 - a simple interface with an adequate amount of information provided

SKETCHING AND STORYBOARDING



PROTOTYPE



CONCLUSION

- A new direction was added to how the effects of cancer in general can be alleviated.
- As most research regarding cancer focuses on the cure or treatment, this would add a new aspect in the form of how we view the effects of cancer. That is, how these effects can continue even after the cancer has been removed.
- New information would be gained to further understand the lives of those patients declared free of cancer.
- HELP is simple in terms of its layout and consists of a main search bar, where LTSs are able to ask questions using their own terms and language. This navigator is a supplement to current resources available to LTSs. Also, this navigator should not be taken as definite, but instead, should be used as a starting point toward better patient-centered care.

LIMITATIONS

- Current work in this specific project was completed by one person
- Data and information gathered to specify the usability recommendations were indirectly gathered from potential users.
 - Provides some benefit in that potential users are free from any bias that might have been caused had they been directly asked for the purpose of this project,
 - Combining both direct and indirect sources might have provided for more comprehensive and all-inclusive results.

MOVING FORWARD

- After the prototype of the designed system is complete, the rate of its success will first be assessed by a clinician or hospital staff member from the hospital associated with this project.
- Once the results from that assessment have been obtained, several redesigns of the prototype will commence.
- An evaluation would then be conducted of the newly redesigned prototype.
 - In this user study, some evaluation methods, such as heuristics, would be utilized to evaluate the initial prototype.
 - Several recommendations would then be made for future redesigns of the prototype based on the results obtained.

REFERENCES

- Atashi, A., Khajouei, R., Azizi, A., & Dadashi, A. (2016). User Interface Problems of a Nationwide Inpatient Information System: A Heuristic Evaluation. *Applied Clinical Informatics*, 7, 89–100. Retrieved from <http://dx.doi.org/10.4338/ACI-2015-07-RA-0086>
- Austvoll-Dahlgren, A., Bjørndal, A., Odgaard-Jensen, J., & Helseth, S. (2012). Evaluation of a Web Portal for Improving Public Access to Evidence-Based Health Information and Health Literacy Skills: A Pragmatic Trial. *PloS one*, 7(5), e37715. Retrieved from <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0037715>
- Baik, S.H., Gallo, L.C., & Wells, K.J. (2016). Patient Navigation in Breast Cancer Treatment and Survivorship: A Systematic Review. *Journal of Clinical Oncology* 34(30), 3686-3696. Retrieved from <http://ascopubs.org/doi/full/10.1200/jco.2016.67.5454>
- De Cocker, K., Charlier, C., Van Hoof, E., Pauwels, E., Lechner, L., Bourgois, J., ... & De Bourdeaudhuij, I. (2015). Development and usability of a computer-tailored pedometer-based physical activity advice for breast cancer survivors. *European Journal of Cancer Care*, 24(5), 673-682. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12225/abstract>
- Dias, A. L., de Mattos Fortes, R. P., & Masiero, P. C. (2014, April). HEUA: A Heuristic Evaluation with Usability and Accessibility requirements to assess Web systems. In *Proceedings of the 11th Web for All Conference* (p. 18). ACM. Retrieved from <http://dl.acm.org/citation.cfm?id=2596706>
- Fu, M. R., Axelrod, D., Guth, A. A., Wang, Y., Scagliola, J., Hiotis, K., ... & El-Shammaa, N. (2016). Usability and feasibility of health IT interventions to enhance Self-Care for Lymphedema Symptom Management in breast cancer survivors. *Internet Interventions*, 5, 56-64. doi:10.1016/j.invent.2016.08.001
- Ginossar, T., Shah, S. F. A., West, A. J., Bentley, J. M., Caburnay, C. A., Kreuter, M. W., & Kinney, A. Y. (2017). Content, Usability, and Utilization of Plain Language in Breast Cancer Mobile Phone Apps: A Systematic Analysis. *JMIR mHealth and uHealth*, 5(3). doi:10.2196/mhealth.7073
- Haq, R., Heus, L., Baker, N. A., Dastur, D., Leung, F. H., Leung, E., ... & Parsons, J. A. (2013). Designing a multifaceted survivorship care plan to meet the information and communication needs of breast cancer patients and their family physicians: results of a qualitative pilot study. *BMC Medical Informatics and Decision Making*, 13(1), 76. doi:10.1186/1472-6947-13-76
- Highfield, L., Ottenweller, C., Pfanz, A., & Hanks, J. (2014). Interactive web-based portals to improve patient navigation and connect patients with primary care and specialty services in underserved communities. *Perspectives in health information management*, 11(Spring). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3995492/>
- Knijnenburg, S. L., Kremer, L. C., Versluys, A. B., Braam, K. I., Mud, M. S., van der Pal, H. J., ... & Jaspers, M. W. (2013). Evaluation of a patient information website for childhood cancer survivors. *Supportive Care in Cancer*, 21(4), 919-926. doi:10.1007/s00520-012-1604-7
- Kshirsagar, M., Hinkley, N., & Ovbiebo, O. (2016). Navigator for Long-term Survivors of Breast Cancer [unpublished].
- Kuijpers, W., Groen, W. G., Oldenburg, H. S., Wouters, M. W., Aaronson, N. K., & van Harten, W. H. (2015). Development of MijnAVL, an interactive portal to empower breast and lung cancer survivors: an iterative, multi-stakeholder approach. *JMIR Research Protocols*, 4(1). doi:10.2196/resprot.3796
- Lee, M. K., Park, H. A., Yun, Y. H., & Chang, Y. J. (2013). Development and formative evaluation of a web-based self-management exercise and diet intervention program with tailored motivation and action planning for cancer survivors. *JMIR Research Protocols*, 2(1). doi:10.2196/resprot.2331
- Lubberding, S., 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. doi:10.1111/jocn.12753
- Lyles, C. R., Sarkar, U., & Osborn, C. Y. (2014). Getting a technology-based diabetes intervention ready for prime time: a review of usability testing studies. *Current Diabetes Reports*, 14(10), 534. Retrieved from <https://link.springer.com/article/10.1007/s11892-014-0534-9>
- McCallum, A. K. (2002). MALLETT: A Machine Learning for Language Toolkit. Retrieved from <http://mallet.cs.umass.edu>
- McGann, S. (2017). Navigator for Long-Term Breast Cancer Survivors: Using Forums with Social Tagging Folksonomy [unpublished].
- Nickell, A., Burke, N. J., Cohen, E., Caprio, M., & Joseph, G. (2014). Educating low-SES and LEP survivors about breast cancer research: pilot test of the health research engagement intervention. *Journal of Cancer Education*, 29(4), 746-752. Retrieved from <https://link.springer.com/article/10.1007/s13187-014-0650-x>
- Nielsen, J. (2012, January 4). Usability 101: Introduction to Usability. Nielsen Norman Group. Retrieved from <https://www.nngroup.com/articles/usability-101-introduction-to-usability/>

REFERENCES (CONT.)

- Northouse, L., Schafenacker, A., Barr, K. L., Katapodi, M., Yoon, H., Brittain, K., ... & An, L. (2014). A tailored web-based psycho-educational intervention for cancer patients and their family caregivers. *Cancer Nursing*, 37(5), 321. doi:10.1097/NCC.000000000000159
- Pérez, M., Sefko, J. A., Ksiazek, D., Golla, B., Casey, C., Margenthaler, J. A., ... & Jeffe, D. B. (2014). A novel intervention using interactive technology and personal narratives to reduce cancer disparities: African American breast cancer survivor stories. *Journal of Cancer Survivorship*, 8(1), 21-30. Retrieved from <https://link.springer.com/article/10.1007/s11764-013-0308-4>
- The American Cancer Society medical and editorial content team [ACS]. (2016a, August 18). Emotions and Breast Cancer. Retrieved from <https://www.cancer.org/cancer/breast-cancer/living-as-a-breast-cancer-survivor/emotions-and-breast-cancer.html>
- The American Cancer Society medical and editorial content team [ACS]. (2016b, August 18). Pregnancy After Breast Cancer. Retrieved from <https://www.cancer.org/cancer/breast-cancer/living-as-a-breast-cancer-survivor/pregnancy-after-breast-cancer.html>
- The American Cancer Society medical and editorial content team [ACS]. (2016c, August 18). What Is Breast Cancer? Retrieved from <https://www.cancer.org/cancer/breast-cancer/about/what-is-breast-cancer.html>
- The American Cancer Society medical and editorial content team [ACS]. (2017, January 5). How Common Is Breast Cancer? Retrieved from <https://www.cancer.org/cancer/breast-cancer/about/how-common-is-breast-cancer.html>
- Tseng, K. J., Liou, T. H., & Chiu, H. W. (2012). Development of a computer-aided clinical patient education system to provide appropriate individual nursing care for psychiatric patients. *Journal of Medical Systems*, 36(3), 1373-1379. Retrieved from <https://link.springer.com/article/10.1007/s10916-010-9599-4>
- Wang, T., & Dolezel, D. (2016). Usability of Web-based Personal Health Records: An Analysis of Consumers' Perspectives. *Perspectives in health information management*, 13(Spring). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4832130/>
- Wang, L., Wang, J., Wang, M., Li, Y., Liang, Y., & Xu, D. (2012). Using Internet search engines to obtain medical information: a comparative study. *Journal of Medical Internet Research*, 14(3). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3799567/>
- Yu, C. H., Parsons, J., Mamdani, M., Lebovic, G., Shah, B. R., Bhattacharyya, O., ... & Straus, S. E. (2012). Designing and evaluating a web-based self-management site for patients with type 2 diabetes-systematic website development and study protocol. *BMC Medical Informatics and Decision Making*, 12(1), 57. doi:10.1186/1472-6947-12-57

THANK YOU!

Any questions?

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WHY ME?

I am interested in working at the intersection of healthcare, data, and user-experience design and evaluation. I strive to design methods by which information can be made to be user-centered, actionable, and transformable into knowledge.

EDUCATION

August 2017 (expected)

M.S.: Health Informatics

Indiana University, Indianapolis, IN

May 2015

B.S.: Biology, Pre-Med

University of Indianapolis, Indianapolis, IN
Cum Laude

PROFESSIONAL SKILLS

Statistics/Computer Science Experience:

Undergraduate Courses:

Elementary Statistics
Intro to C++
Object-Oriented Programming

Graduate Courses:

Intro to MySQL Workbench, statistics using Python, and Weka
Creating forms in OpenMRS (an open-source electronic health record system) using HTML/CSS and JavaScript

User Experience/Interaction Skills:

Design:

Contextual inquiry
Affinity diagramming,
Empathy mapping
Sketching
Storyboarding
Low- and High-Fidelity
prototyping

Evaluation:

Personas
User profiles and scenarios
Cognitive walkthrough
Heuristic evaluations
Developing test plans
Think-aloud protocols
Data analysis
Communicating results and
findings

EXPERIENCE while in college

February 2017 / Present

SUBJECT MATTER EXPERT (SME) FOR HEALTH AND WELLNESS COURSE DEVELOPMENT at the American College of Education (ACE)

August 2015 / May 2017

GRADUATE ASSISTANT at IU SOIC Health Information Management Department
Assisted with several courses, in addition to adding rigor to M420 Healthcare Planning and Information Systems and M470 Healthcare Reimbursement System.

selected PROJECTS

December 2016

INFO-H 543 INTERACTION DESIGN METHODS for Dr. Aqueasha Martin-Hammond

Usability Testing and Evaluation of an Application for Relieving Stress in the Teenage Population

Participated in a group of 5 students to redesign an application for a new user group by analyzing qualitative and quantitative data gathered from user studies and surveys, leading to 3 key redesign recommendations.

October 2016

INFO-H 541 INTERACTION DESIGN PRACTICE for Dr. Lynn Dombrowski

User Experience Research and Design of a Kiosk Connecting People Experiencing Food Insecurity to Matching Non-profit Organizations

Participated in a group of 2 students to design a technological solution to a social problem by analyzing qualitative data gathered from ethnographic studies, leading to the creation of a prototype.

May 2016

INFO-B 513 DESIGN, IMPLEMENTATION, AND EVALUATION OF ELECTRONIC HEALTH RECORD SYSTEMS for Dr. Saptarshi Purkayastha

OpenMRS Dementia Care Form for Data Management and Analysis

Participated in a group of 3 students to create an electronic form in an open-source system that would also be connected to a simple data analysis functionality within the system to analyze trends of inputted data and information over time.

December 2015

INFO-I 501 INTRO TO INFORMATICS for Dr. Saptarshi Purkayastha

Drug-related Trends of Severity and Toxicity in Emergency Department Visits due to Adverse Drug Reactions

Participated in a group of 5 students to answer several research questions by analyzing a dataset using MySQL Workbench to manage the data and a Python package for statistics and data representation.