Incorporating Personal Health Records into the Disease Management of Rural Heart Failure Patients

Karen Baron
Nova Southeastern University, kbaronvt@gmail.com

This document is a product of extensive research conducted at the Nova Southeastern University College of Engineering and Computing. For more information on research and degree programs at the NSU College of Engineering and Computing, please click here.

Follow this and additional works at: https://nsuworks.nova.edu/gscis_etd

Part of the Computer Sciences Commons

NSUWorks Citation
https://nsuworks.nova.edu/gscis_etd/85.

This Dissertation is brought to you by the College of Engineering and Computing at NSUWorks. It has been accepted for inclusion in CEC Theses and Dissertations by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.
Incorporating Personal Health Records
into the Disease Management of
Rural Heart Failure Patients

by
Karen Parsley Baron

A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in
Computing Technology in Education
Graduate School of Computer and Information Sciences
Nova Southeastern University
2012
Personal Health Records (PHRs) allow patients to access and in some cases manage their own health records. Their potential benefits include access to health information, enhanced asynchronous communication between patients and clinicians, and convenience of online appointment scheduling and prescription refills. Potential barriers to PHR use include lack of computer and internet access, poor computer or health literacy, security concerns, and provider disengagement. PHRs may help those living in rural areas and those with chronic conditions such as heart failure, monitor and manage their disease, communicate with their health care team and adhere to clinical recommendations. To provide some much needed actual research, a descriptive mixed methods study of the usability, usefulness, and disease management potential of PHRs for rural heart failure patients was conducted. Fifteen participants were enrolled.

Usability issues fell into three categories: screen layout; applying consistent, standard formatting; and providing concise, clear instructions. Participants used PHR features that were more convenient than other methods or that had some additional benefit to them. There was no difference between rural and urban participants. A heart failure nurse promoted recording daily heart failure symptoms in the PHR. Most participants did so at least once, but many found it cumbersome. Reasons for recording included the comfort of having clinical staff monitor the data. Participants who were stable did not find recording as useful as did those who were newly diagnosed or unstable. Participants used asynchronous communication to send messages to the heart failure nurse that they would not otherwise have communicated.

The study expands the knowledge of PHR use by addressing useful functionality and disease management tools among rural patients with heart failure. The patients were able to complete tasks they found useful. The increased communication and disease management tools were useful to some.
Acknowledgments

I want to thank the heart failure patients who so openly shared their thoughts, ideas, experiences, and stories with me. They have expanded our knowledge of PHRs — both what works and how to make them better. Their experience helps take PHR use out of the theoretical realm and place it in actual context.

Cindy Wolkin, the cardiology heart failure nurse, was integral to the research. She provided clinical expertise in developing the disease management functionality incorporated into MyHealth; guided me through the Institutional Review Board process; introduced the study to potential participants; monitored the daily journals of the participants; and shared her insights with me. Much of her work was completed on her own time without compensation. I owe her a tremendous debt of gratitude for sharing my vision and actively working to make it a reality.

In PRISM, my managers, Anne Ireland, Jill Federico, and Deb Dulac provided unwavering support and encouragement. Application coordinators Lisa LaBounty and Vicky Gelber developed and maintained the heart failure features in MyHealth. Charlee McCabe Day transcribed many of the interviews. So many others, on the PRISM team and throughout Fletcher Allen Health Care and the University of Vermont offered help and encouragement. Thank you one and all.

At NSU, many thanks are due to my dissertation committee members Marilyn Olander and Helen St. Aubin for their encouragement, careful reading of the manuscripts, and insightful comments. The words thank you do not begin to convey my gratitude to my advisor Trudy Abramson. Her mentoring and guidance have been constant throughout my coursework, several abandoned idea papers, a leave of absence and return, and finally completing this report.

Final thanks go to my family: my husband, Dana, my children Erica and Joanne, and my mother, Jeanne. You have been my anchor. You gave me space when I needed to work, and reprise I needed when the work was done. You picked me up when I stumbled and cheered when things went well. You understood and supported my dream, and helped make it a reality. I love you all.
Table of Contents

Abstract iii
List of Tables vii
List of Figures ix

Chapters

1. Introduction 1
   Context 1
   Problem Statement 4
   Dissertation Goal 5
   Research Questions 6
   Relevance and Significance 6
   Definitions and Acronyms 8
   Organization of the Study 9

2. Review of the Literature 11
   Personal Health Record Description 12
   Personal Health Record Potential Benefits and Barriers 17
   Acceptance of Technology 32
   Usability 41
   Heart Failure 46
   Rural Health 50
   Conclusion 53

3. Methodology 54
   Research Design 54
   Procedure 56
   Instrumentation 60
   Data Collection and Analysis 64
   Summary 65

4. Results 66
   Demographics and Descriptive Statistics 67
   Comparison with other PHR Data 68
   Usability 70
      Screen Layout 74
      Site Conventions 75
      Instruction Clarity 77
      Learning to Use the Site 82
      Summary 84
   Usefulness 85
      Fletcher Allen and Non-Fletcher Allen PCPs 86
Results 88
Appointments and Prescription Refills 90
The Message Center 92
Other Useful Features 93
Health Team Communication 94
Disease Management 95
Subject Management of their Heart Failure 96
MyHealth and Disease Management 102
Provider Engagement 106
Conclusion 108

5. Conclusion 109
Research Question 1: How usable is the PHR for heart failure patients? 110
Research Question 2: What PHR features do heart failure patients find useful? 114
Research Question 3: Can a PHR be useful in the disease management of heart failure
patients? 120
Limitations 122
Implications and Recommendations 123
Summary 125

Appendixes
A. University of Vermont Institutional Review Board Approval 130
B. Nova Southeastern University Institutional Review Board Approval 131
C. Recruitment Brochure 132
D. Informed Consent Form 135
E. HIPAA Consent Form 140
F. Detailed Usability Results 146
G. Rural – Urban Mix of Participants 170
H. Computer Expertise Questions and Results 171
I. Usability Patient Details 173
J. System Usability Scale Questions and Results 176
K. MyHealth Usage Data 178
L. Daily Journal 180

Reference List 181
List of Tables

Tables

Table 1. Usefulness of PHR Features - National Data and Participants 70
Table 2. Usability Task Efficiency and Effectiveness Statistics 72
Table 3. Medical Information Task Summary Statistics 150
Table 4. Medical Information Task Satisfaction Question Means 150
Table 5. Results Task Summary Statistics 153
Table 6. Results Task Satisfaction Question Means 153
Table 7. Daily Journal Task Summary Statistics 156
Table 8. Daily Journal Task Satisfaction Question Means 156
Table 9. Massage Task Summary Statistics 158
Table 10. Task Satisfaction Question Means 158
Table 11. Questionnaire Task Summary Statistics 162
Table 12. Questionnaire Task Satisfaction Question Means 163
Table 13. Appointment Task Summary Statistics 165
Table 14. Task Satisfaction Question Means 166
Table 15. Heart Failure Prevention Resources Task Summary Statistics 167
Table 16. Heart Failure Prevention Resources Task Satisfaction Question Means 167
Table 17. Prescription Refill Task Summary Statistics 168
Table 18. Prescription Refill Task Satisfaction Question Means 168
Table 19. Urban-Rural Mix of Participants and Cardiology Patients 170
Table 20. Computer Expertise Scales 171
Table 21. Expert and Intermediate Ratings on Four Computer Scales by Subject 172

Table 22. Usability Patient Details 173

Table 23. MyHealth System Usability Scale Survey 176

Table 24. Initial and Final System Usability Score Summary Statistics 177

Table 25. MyHealth Activity Usage Data 178
List of Figures

Figures

Figure 1. Geisinger and MyHealth PHR Attitudes. 69
Figure 2. MyHealth Home Screen on Usability Test Computer 75
Figure 3. Inconsistent Links on MyHealth Home Page 76
Figure 4. MyHealth Test Result Detail with Provider Comments 80
Figure 5. MyHealth Request an Appointment Initial Screen Text 82
Figure 6. Mean Satisfaction Scores for MyHealth Usability Tasks 84
Figure 7. Three ways to access Medical Information in MyHealth 151
Figure 8. Accessing Health Summary Information 152
Figure 9. Location of Test Results in MyHealth 154
Figure 10. MyHealth Results Screen with Comments from the Provider 155
Figure 11. New Message Announcement 159
Figure 12. Access a message in the Medical Center Inbox by Clicking its Subject 160
Figure 13. Contact Doctor’s Office Screen 161
Figure 14. Initial and Final System Usability Scores by Participant 177
Figure 15. Fletcher Allen Heart Failure Journal Sample Page 180
Chapter 1

Introduction

Context

In 2004 President Bush challenged the American health care industry to provide most Americans with access to Electronic Health Records (EHRs) by 2014 (White House, 2004). The Obama administration's Health Information Technology for Economic and Clinical Health Act, commonly known by its initials HITECH, is helping meet the challenge by providing $27 billion over 10 years in financial incentives through Medicaid and Medicare for hospitals and health care providers to adopt and use EHRs in meaningful ways (Blumenthal & Tavenner, 2010). EHRs replace paper charts and bring information technology into the clinical realm to improve safety, quality, and efficiency of care. Their functionality spans inpatient hospitalization, outpatient and ambulatory care, and access to personal health data via personal health records (PHRs).

Three main components of EHR systems are (a) clinical decision support, (b) computerized physician order entry, and (c) electronic charting. Clinical decision support systems match individual patient characteristics with a computerized knowledge base and software algorithms to create patient-specific care recommendations, alerts of critical values, reminders for preventative health screenings, advice for drug prescriptions, and critiques of existing orders (Garg, Adhikari, McDonald, Devereaux,
Beyene, Sam, & Hayes, 2005). Computerized provider order entry allows physicians and other health care providers to enter orders, medication, tests, and procedures electronically, ensuring that orders are legible and complete (Maviglia, Kuperman, & Middleton, 2005). Medication dosage guidelines and alerts for drug allergies, cross-sensitivities, interactions, and dosage guidelines are common features. Standardized order scenarios can simplify the order process and provide standard levels of care. Some systems monitor lab results, notifying the provider by email or pager of critical values. Computerized order entry requires providers to enter orders in a standard manner, rather than freely written text. The standardization is used to build the clinical knowledge base. Electronic charting moves data availability from one physical chart to any computer on the network, providing immediate access to the information and reducing time spent waiting to use or searching for the chart (Geibert, 2006). Aggregated data are used for research, management, quality assurance, and safety improvement efforts (Maviglia, et al., 2005).

PHRs are a component of EHRs that provide a patient-centered view of the record, allowing individuals access to their own health information. Functionality falls into three basic categories, (a) access to information such as test results, medications, doctor's instructions and educational material; (b) convenience through the use of features such as online medication refill requests, appointment scheduling and reminders, and (c) secure electronic communication (California HealthCare Foundation, 2010). Their potential to improve communication between patients and providers, enhance patient safety, and reduce health care costs has led to their inclusion in health care reform's meaningful use incentives (Blumenthal & Tavenner, 2010).
PHRs may help individuals with chronic conditions monitor and manage their disease. Heart failure is a chronic condition affecting over 5 million Americans. It is the most common cause of hospitalization for those over the age of 65, and Medicare spends more on heart failure than any other condition. Although heart failure is a life-long condition, its progress can be slowed or stopped with treatment that includes medication, life-style changes, and careful monitoring of disease symptoms (American College of Cardiology Foundation & American Heart Association Task Force on Practice Guidelines, 2009). Patients' self-management and provider-patient communication are essential components of effective heart failure care (Cleland & Ekman, 2010). The communication and monitoring features of a PHR may be of benefit in the process.

Those living in rural areas have poorer overall health than their urban counterparts. Outcomes are poorer for rural heart failure patients than patients living in more urban settings (Clark, Freyberg, Heath, Savard, McDonald, & Strain, 2008; Zahnd, Scaife, & Francis, 2009). Whether or not PHRs use might benefit this population has not been studied.

Fletcher Allen Health Care, in partnership with the University of Vermont's Colleges of Medicine, Nursing, and Health Sciences, is Vermont’s academic medical center. Its vision is to improve the health of the people in the communities it serves by integrating patient care, education, and research in a caring environment. Fletcher Allen is a teaching hospital providing clinical experience for students in medical school and health care programs at the University of Vermont and other post-secondary programs in Vermont and northern New York. It serves as a community hospital for approximately 150,000 residents in Vermont's Chittenden and Grand Isle counties, and as a regional
referral center, providing tertiary care to approximately one million people in Vermont and northern New York. As part of its strategic plan, in 2010 Fletcher Allen completed a three-year, $57 million project to implement its EHR known as Patient Record Information System Management (PRISM) across the organization. PRISM is based on software supplied by Epic, a leading EHR software firm in the US. The implementation placed Fletcher Allen among the 3% of hospitals nationwide with a fully-functioning EHR (Fletcher Allen Health Care, 2011).

With the full implementation of its EHR, Fletcher Allen was able to allow patients access to their medical record through an Internet-based PHR. MyHealth, the name Fletcher Allen has given to its version of Epic's PHR, was made available to patients in June, 2011.

**Problem Statement**

PHRs are an emergent component of the EHR industry. Nationally only 7% of adults use a PHR (California HealthCare Foundation, 2010). Consensus about what constitutes a PHR – its purpose, useful functionality, access, and ownership, security, and industry standards for data sharing – has yet to emerge. Research is needed to develop the knowledge base from which decisions on these topics can be made. Calls for PHR research include several major areas of focus: the evaluation of various potential PHR functions, adoption and attitudes among various stakeholders, privacy and security issues, architecture development, and studies documenting the outcome of PHR use (California HealthCare Foundation, 2010; Detmer, Bloomrosen, Raymond, & Tang, 2008; Kaelber, Ashish, Johnston, Middleton, & Bates, 2008; National Committee on Vital and Health Statistics, 2006; Tang, Ash, Bates, Overhage, & Sands, 2006).
When describing the need for research in adoption and attitudes among various stakeholders, Detmer et al. (2008) call for sound, objective, credible information about consumers' views on the value and desired functions of a PHR. Kaelber et al. (2008) echo the sentiment, calling for studies of both patients and providers, as each brings different needs, expectations and perspectives to the PHR discussion. They cite the need for data on special populations including those with chronic conditions such as diabetes and heart failure, and those living in rural areas. The National Committee on Vital and Health Statistics (2006) recommends consumer research to identify who is adopting PHRs, how individuals use the systems, and barriers to adoption. They also suggest research on the ability of PHRs to change the way individuals relate to the healthcare system or modify their health behaviors.

**Dissertation Goal**

The goal was to examine the potential benefits of a PHR in the disease management of heart failure patients living in a rural setting. The study embedded a PHR into the disease management protocols for a group of Fletcher Allen heart failure patients living in northern Vermont and upstate New York.

The standard features available in the PHR were augmented by heart failure educational resources, a daily journal for recording heart failure symptoms that was viewable by both the patient and the disease management team, and secure, asynchronous communication directly to the heart failure nurse. The usability and usefulness both the standard and heart failure features and the overall disease management capabilities of the PHR were studied.
Research Questions

To examine the potential benefits of a PHR in the disease management of heart failure patients living in a rural setting, three research questions were posed:

1. How usable is the PHR for heart failure patients?
2. What PHR features do heart failure patients find useful?
3. Can a PHR be useful in the disease management of heart failure patients?

Relevance and Significance

Patients with heart failure need to actively manage their condition on a daily basis, checking their weight and blood pressure, monitoring their energy levels, swelling, and ease of breathing, watching their diet, and taking their medications. It requires concentrated effort, diligence, perseverance, and self-motivation (American College of Cardiology Foundation & American Heart Association Task Force on Practice Guidelines, 2009). By providing monitoring tools, access to test results, educational resources, and convenient, secure communication with clinicians, PHRs may be a useful tool for some heart failure patients. People living in rural areas have poorer overall health and health outcomes than those living in urban areas (Clark, et al., 2008; McCarthy, 2007; Zahnd, et al., 2009). PHR's functions may also help those living in rural areas access clinical resources to improve their health.

PHRs are a new technology whose theoretical usefulness has yet to be validated. Their usability among heart failure patients has not been documented. The medical records of heart failure patients can be lengthy and complex. Whether patients can access their health information, make sense of it, or use it in their disease management routines is an open question. Rural heart failure patients have unique issues. Travel distance to
clinics, lack of public transportation, lower education, poorer health, and lower incomes all play a factor. Can the educational resources and communication functions in a PHR help mitigate some of these issues, or will the barriers caused by lack of high speed Internet access, and lower literacy skills prove too big an obstacle? As PHRs are refined, developers need answers to usability questions. They need to know what functionality patients find useful, and where changes need to be made. As PHR usage spreads, clinicians need to know what health information is useful to patients, and what initial training and ongoing support are needed for their patients to understand the information and use the system.

With the implementation of its PHR, Fletcher Allen had the opportunity to participate in the ongoing research of PHR adoption. The study, the first research project using Fletcher Allen's PHR, provides insight into the use of the PHR in heart failure patient care. Its research questions fit into the national PHR research agenda by looking at the usability, training requirements, and potential usefulness of a PHR for heart failure patients and their disease management team, a group with specialized health needs. Because of its location in northern Vermont, results also address the potential of the PHR for heart failure patients in a rural setting.

The descriptive mixed methods design of the study combined the collection of descriptive statistics with semi-structured interview data. Results of the usability study and usage reports from the PHR provide objective data on the usability of the product, subject interaction with the software, and how often various functions were used. The interviews allowed the investigator to explore participants' reactions to the PHR, and the thoughts and motivations accompanying its use. Together, the result are useful not only
for Fletcher Allen's clinicians and information technology (IT) staff, but also for others implementing PHRs and providing care to patients with heart failure and other chronic conditions, and to patients living in rural areas.

Definitions and Acronyms

BUN: Blood Urea Nitrogen, a blood test that measures renal function

EHR: Electronic Health Record

Fletcher Allen: Fletcher Allen Health Care

Fletcher Allen Health Care: Vermont's medical center whose vision is to be a national model for the delivery of high-quality academic health care for a rural region and to improve the health of the people in the communities it serves by integrating patient care, education, and research in a caring environment.

IT: Information Technology

MyHealth Online: Fletcher Allen Health Care's Internet-based PHR, a PHR tethered to PRISM. The PHR is referred to as MyHealth throughout the document.

PCP: Primary Care Physician

PHR: Personal Health Record. There is no consistently applied PHR definition currently in use. The study used an Internet-based PHR, MyHealth, which is tethered to Fletcher Allen Health Care's institutional EHR, PRISM.

PRISM: Patient Record Information System Management – Fletcher Allen Health Care's Electronic Medical Record
Provider: A health care professional overseeing a patient’s care – a physician, nurse practitioner, or physician’s assistant

TAM: Technology Acceptance Model

Organization of the Study

The introductory chapter lays the study's foundation and framework. The context, goals, research questions, relevance, and significance have been outlined.

In Chapter 2 related literature and applicable theories are discussed providing the background for the research. A description of PHRs and their theoretical implications begins the chapter. Where it exists, relevant clinical data is presented. Technology acceptance follows, looking at several theoretical models including the diffusion of innovation and the Technology Acceptance Models. Both models address both usefulness and usability as key components to acceptance. Thus a closer look at usability theory is warranted and presented. The chapter ends with a general overview of heart failure and the unique health challenges faced by those living in rural areas.

Chapter 3 describes the research methodology. A descriptive mixed methods design that combined quantitative and qualitative approaches was used. Fifteen heart failure patients living in northern Vermont and New York were recruited. They participated in two interviews, one of which included a usability study. They were given access to their PHR with disease management features and their PHR usage was monitored. The design, procedure, instrumentation, data collection, and analysis methodologies used are presented.

Chapter 4 presents the results. Demographic and descriptive statistics are followed by a comparison of the data with existing data. Usability issues, falling into
three broad categories, screen layout, site conventions, and instruction clarity are presented. The usefulness of the various PHR features as well as barriers to their usefulness are discussed. The disease management potential and challenges of the daily journal and communication features are described.

Finally, in Chapter 5 each of the research questions is posed, and conclusions from the research presented. Study limitations are discussed. Implications and recommendations of the research are placed in a broader context. The chapter concludes with a summary of the entire research project.
Chapter 2

Review of the Literature

PHR implementation research draws from several fields that will be examined here. There is no standard definition of the core functionality of PHRs. The literature review starts with an examination of the various definitions of PHRs and three major types of PHR implementations found in the marketplace and literature: stand-alone, tethered, and integrated. Next, the potential benefits of and barriers to PHR adoption are examined. Because PHRs have not been widely adopted, there is little research to back the claims of proponents or opponents of the software. Where there are substantive studies, they are included. Although there is little research on PHR adoption, technology adoption in other areas has been extensively studied and can be of use. Two theoretical models are examined, the diffusion of innovation and the technology acceptance models. A major influence in technological adoption is usability. PHRs' usability is challenged by the complexity of the language and content of health information, the number and variety of health conditions a patient may have, and the wide variation of computer skills found in the patient population. PHR usability studies and their findings are explored. A brief discussion of heart failure, its description, and treatment is provided. Finally, a discussion of rural health and its impact on heart failure is addressed.
**Personal Health Record Description**

One of the challenges to PHR research is the lack of a consistently applied PHR definition (Kaelber, et al., 2008; U.S. Department of Health and Human Services, 2006a). The Markle Foundation, a private organization providing targeted funding for PHR research, provides a comprehensive definition of a PHR in its 2003 report:

> The Personal Health Record (PHR) is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. PHRs offer an integrated and comprehensive view of health information, including information people generate themselves such as symptoms and medication use, information from doctors such as diagnoses and test results, and information from their pharmacies and insurance companies. Individuals access their PHRs via the Internet, using state-of-the-art security and privacy controls, at any time and from any location. Family members, doctors or school nurses can see portions of a PHR when necessary and emergency room staff can retrieve vital information from it in a crisis. People can use their PHR as a communications hub: to send email to doctors, transfer information to specialists, receive test results and access online self-help tools. PHR connects each of us to the incredible potential of modern health care and gives us control over our own information. (Connecting For Health, 2003).

Many researchers use the first sentence of this definition, or a portion of it as their definition (Kaelber, et al., 2008; Lober, Zierer, Herbaugh, Shinstrom, Stolyar, Kim, & Kim, 2006). Yet, the entire paragraph is needed to convey Markle's vision clearly.

The Markle definition places the PHR on the Internet. A national survey of PHR use in 2010 followed suit asking participants:

> Some hospitals, doctors’ offices, health plans, and different companies are offering Web sites where you could get, keep, and update your health information online. This information could be lab test results, medicines, doctors’ visits, or other information. You would get a user name and password so that only you could see your information on this Web site. Have you ever used one of these Web sites where you can get, keep, or update your health information? (California HealthCare Foundation, 2010, p. 5)

Kaelber et al. (2008) not only reduce Markle's definition to its first sentence, but also change Internet-based tools to computer-based tools, removing the anytime,
anywhere aspect of Internet access to the information. The National Committee on Vital and Health Statistics differentiates between a PHR, which refers to "the collection of information about an individual's health and health care, stored in electronic format" (National Committee on Vital and Health Statistics, 2006, p. 15) and a PHR system which more closely resembles the Markle definition and includes "the addition of computerized tools that help an individual understand and manage the information contained in a PHR" (National Committee on Vital and Health Statistics, 2006, p. 15).

A joint American Health Information Management Association and American Medical Informatics Association position paper encouraging PHR use provides the definition: "The PHR is a tool for collecting, tracking, and sharing important, up-to-date information about an individual’s health or the health of someone in their care" (American Health Information Management Association & American Medical Informatics Association, 2007). While they recommend using electronic media, the format is not essential to their PHR vision. Rather, users are encouraged to choose the format that works best for them, even if it is paper. Developers of My Health Companion, a PHR created to support rural women with chronic conditions, did just this, creating a paper-based model owned, controlled, and managed by the patients (Weinert, Cudney, & Kinion, 2010). The definition used by the joint task force of the Medical Library Association and the National Library of Medicine recognizes the lack of clarity by stating that a PHR may or may not include data from various sources, and may or may not be linked to an EHR, and may be sponsored by vendors who may or may not charge a fee (Jones, Shipman, Plaut, & Shelden, 2010). In this discussion, an electronic, Internet-based format will be assumed unless it is otherwise noted.
Nearly all attributes of a PHR vary by study or researcher including the scope and source of information, the features and functions offered, the owner of the records, the storage location, the technical approach, and who can authorize record access (U.S. Department of Health and Human Services, 2006a). Different researchers stress different aspects as key components to a PHR, leading the National Committee on Vital and Health Statistics to recommend the development of a framework for characterizing PHR systems. Further calls for standardization come from those striving to make PHRs interoperable, transportable, and secure (Jones, et al., 2010).

PHR differences are apparent in the three basic types available today: stand-alone, tethered, and integrated. Stand-alone PHRs do not connect with other EHR systems. Information is entered by the individual, who is responsible for its content, validity, and access. Individuals can then share the information with their health care providers should they wish to do so. Current medications, allergies, health problems, recent lab results, next of kin, advance directives, and insurance information are examples of data an individual might place in the record (Detmer, et al., 2008; Kupchunas, 2007; Tang, et al., 2006). Some stand-alone PHRs are offered free of charge by businesses that derive their revenue from sponsor advertising or data mining. Others are available for a fee. (Detmer, et al., 2008)

The strength of stand-alone PHRs is found in their widespread availability and the control they offer to individual users. Users do not need access to health care data from providers or insurance companies to create their PHR, and they can control what data are entered, and with whom they are shared. Users can store their data on the Internet, a personal computer, USB drive, CD, or smart card, and print them out as needed. These
strengths also lead to the limitations of stand-alone PHRs. The quality of the data depends on the user's computer competency, overall literacy, health literacy, and motivation for recording the data. Without linkages to existing datasets, users must reenter data into their PHR that already exists in their provider-housed records. Health care providers are reluctant to rely on patients' manually-entered data which may be inaccurate, incomplete, or out-of-date. Additionally, providers need access to their own past considerations and interpretations of the data as well as objective data to make clinical decisions. The security of personally-stored data also raises concerns. Portable consumer storage devices are easily lost or stolen, and can be destroyed in natural disasters such hurricanes, floods, and fires. Finally, stand-alone PHRs do not promote communication between provider and patient, a potential strength of other PHR formats (Detmer, et al., 2008; Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2010; Kupchunas, 2007; Simborg, 2010; Tang, et al., 2006).

Tethered PHRs are patient portals into a provider-based EHR (Detmer, et al., 2008; Steinbrook, 2008; Tang, et al., 2006). The provider organization makes some portion of the electronic data available to the individual, often free of charge, but sometimes for an annual fee. Fletcher Allen's PHR, MyHealth, is a tethered product, whose functionality is embedded in PRISM. The strengths of tethered PHRs are found in this organizational sponsorship that is responsible for data security, storage, and integrity. Strengths also include the breadth and quality of their data, and their enhanced functionality. Because the data in the tethered PHR are not entered by the patient, they have the potential for being more accurate, complete, and current than stand-alone data.
Tethered PHRs may provide functionality such as release of test results to the patient, email communication for medical questions, prescription renewal, appointment scheduling, and pre-appointment form completion and information collection through questionnaires. On the other hand, the provider organization, not the individual, controls the data in a tethered PHR. Individuals who see providers from a variety of health care organizations may find that their data are spread among various tethered PHRs that do not communicate with each other, or that part of their information is not available. Because the data come from the EHR, the patient's ability to add, annotate, or append information can be problematic. In some applications, including MyHealth, patients must call or email the provider asking that information be included or corrected. In others patients can add information which is displayed in a separate section of the record.

Patient portals to health insurance claims data provide a variation on the tethered approach (Detmer, et al., 2008; Halamka, Mandl, & Tang, 2008; Steinbrook, 2008). Insurance billing is already automated, and can provide data with minimal effort. However, billing data lack detailed clinical information and use language that is not readily understood by large segments of the non-clinical population. In addition, historical data continuity is lost when people change insurance companies.

Integrated PHRs are hybrid systems that connect various health care data sources including EHRs, insurance claims, pharmacy data, home diagnostics, and patient-provided data (Detmer, et al., 2008; Steinbrook, 2008; Tang, et al., 2006). Their strength lies in their ability to capture the full array of an individual's health data, eliminating the manual data entry of stand-alone systems, and the isolation of tethered systems.
However, they are complex systems which require standards for interoperability, data transmission, user identification and security.

Actual implementations of integrated PHRs are in their infancy, with few, if any applications available on the market. A task force examining the current state of PHRs identified 91 applications available in 2010, which could be broken down as follows: stand-alone: 54%; tethered: 26%, both stand-alone and tethered options provided: 11%; not categorized: 9% (Jones, et al., 2010).

**Personal Health Record Potential Benefits and Barriers**

Combining the best of all definitions, PHR proponents envision a single, robust, portable, patient-controlled, self-populating, secure, integrated PHR with anytime, anywhere access to the patient and other designated individuals that covers a person's health from birth throughout life. (Detmer, et al., 2008; Leonard, Casselman, & Wiljer, 2008; Lober, et al., 2006; Steinbrook, 2008; Urowitz, Wiljer, Apatu, Eysenback, DeLenardo, Harth, Pai, & Leonard, 2008). The PHR contains links to relevant health information, enhances communication between patient and provider, improves patient safety, and reduces health care cost. Ultimately it may change the predominant hierarchical physician-centered health care culture to a partnership model. Despite their transformative potential, the growth and adoption of PHRs is not assured. Patient issues include software usability concerns, questions about the usefulness of provided functionality, barriers to access, and the need for both computer and health literacy to be able to use a PHR effectively. Provider barriers include the challenges posed by incomplete and potentially inaccurate records, and time and resource concerns. Security and technological barriers must also be addressed. Whether the benefits will be realized
and the barriers overcome has yet to be determined, and is the focus of ongoing PHR research.

Providing health information to patients may empower them to become active participants in their care (Detmer, et al., 2008; Kaelber, et al., 2008; Leonard, et al., 2008; Urowitz, et al., 2008). PHRs may help individuals monitor and manage their diseases, communicate with relevant health care providers, and adhere to clinical protocols, recommendations, and lifestyle changes. This may become especially important for the estimated 40% of the population world-wide who have a chronic condition defined as a lifelong illness or disease with long-term implications (Leonard, et al., 2008).

A retrospective audit of diabetes patients at the Cleveland Clinic examined 11 quality of care measures for those who used their tethered PHR with those who did not, including eye and foot exams, immunizations, laboratory tests, smoking cessation, and blood pressure and body mass index monitoring (Tenforde, Nowacki, Jain, & Hickner, 2011). While there was a small, marginally significant positive association between PHR use and some of the outcome measures, the study measured association and not causality. The researchers could not determine whether the PHR empowered the users to become active participants in their care, or whether those who used the PHR had a different baseline level of health care involvement.

New York City HIV/AIDS patients in a study of PHR usage and outcomes reported feeling empowered by having access to their health care data (Gordon, Camhi, Resse, Odlum, Schnall, Rodriguez, Valdez, & Bakken, 2012). They also reported that viewing health data they did not understand motivated them to use the Internet to seek additional information about their conditions. However, researchers found no significant
differences in outcomes, perceived quality of medical care, emergency room visits, or hospital admission rates between PHR users and nonusers.

Communication between patients and providers may be improved through the PHR’s asynchronous modality (Detmer, et al., 2008; Hess, Bryce, Paone, Fischer, McTigue, Olshansky, Zickmund, Fitzgerald, & Siminerio, 2007; McGeady, Kujala, & Ilvonen, 2008; Tjora, Tran, & Faxvaag, 2005). Working patients may find this a convenient, more efficient, and easier way to discuss sensitive topics, and afford them the ability to re-read advice. Asynchronous communication gives providers time to research options and contemplate their answer. It eliminates the need for a third party, such as a nurse, to relay messages to the patient, and provides a self-documenting mechanism that may increase provider productivity. Patient requests that are filled out electronically can be structured to provide all the necessary information, eliminating the need for call-backs common in voice mail systems. For those with chronic conditions, health coaches may provide online consultations; data from home monitoring devices may be uploaded to the PHR, with abnormal results flagged to the provider; recommended office visits may be scheduled and tracked; and online support groups promoted.

The Clinical Report is a patient status reporting tool embedded in a web-based PHR being developed for use by advanced stage cancer patients, their care givers, and the oncology clinic team at the University of Wisconsin. In a study of the system, patients, and their caregivers completed the report weekly, ranking symptoms on a Likert scale. Clinicians used the information to prepare educational resources for the clinic visit, identify the need for rapid interventions, and as references in clinical case meeting discussions. Clinicians appreciated the system's asynchronous reporting. With the
information provided before the clinic visit, less visit time was spent gathering data
leaving more time to address deeper concerns. Clinicians were better prepared to discuss
patient and caregiver concerns because they were made aware of them ahead of time
(Dubenske, Chih, Dinauer, Gustafson, & Cleary, 2008).

Having one complete, accurate, up-to-date location for patient health information
may improve patient safety. It can provide immediate, accurate, current data in
emergency situations. It can help reduce medication errors by providing built-in logic that
crosschecks for allergy and drug interactions (Detmer, et al., 2008). Allowing patients to
view, update, and verify the accuracy of their medication lists may help keep medication
lists current and accurate. In a recent national survey two-thirds of PHR users reported
that the ability to make sure information is correct was a very or somewhat useful feature
of their PHR – the highest score of all the functionalities queried, and 12% reported
finding missing or incorrect information in their chart (California HealthCare Foundation,
2010). By storing information from all providers in one place, the chance of missing or
conflicting information is reduced (Steinbrook, 2008). An integrated PHR provides
continuity when a patient moves or changes providers (Lober, et al., 2006).

Costs may be reduced through the elimination of redundant tests, reduction of
medication error lawsuits, better management of chronic conditions, substitution of
online consultations for face-to-face appointments, less time spent gathering and
recording patient information during office visits, and the prevention of loss of patient
data due to natural disasters (Detmer, et al., 2008; Leonard, et al., 2008; Steinbrook,
2008; Tang, et al., 2006). Clinicians may find that providing a tethered PHR helps retain
current patients and attract new ones. One quarter of the respondents in the National
Consumer Survey on Health IT reported that the use of their PHR made them feel less likely to switch doctors (California HealthCare Foundation, 2010).

PHRs may change the way clinical research is conducted (Mandl & Kohane, 2008). If they become widespread, PHRs will become large, up-to-date health care databases. Data from multiple sources will reside in the same record, allowing researchers access to rich data without the need to acquire multiple consents and develop elaborate matching algorithms. They may replace provider recruitment by allowing patients themselves to search for and enroll in studies researching their conditions or concerns. Boston researchers used Beth Israel Deaconess Medical Center's tethered PHR to recruit participants for a study aimed at identifying undiagnosed mobility difficulty, chronic pain, and depression (Leveille, Huang, Tsai, Allen, Weingart, & Iezzoni, 2009; Leveille, Huang, Tsai, Weingart, & Iezzoni, 2008). PHR participants were contacted by email four weeks before a scheduled visit to their primary care provider, and invited to participate. Recruitment results were not as successful as researchers had hoped. Of the 4,047 patients invited to participate, ultimately 241 subjects were enrolled, far fewer than the 600 targeted by the researchers. Fewer providers than anticipated agreed to participate and many potential subjects did not open the study invitations in their PHR.

The most wide-reaching change that PHRs may promote is a shift in the medical culture from a hierarchical physician-patient relationship to a shared model, where physician and patient jointly own and manage health care (Detmer, et al., 2008; Smith & Barefield, 2007; Urowitz, et al., 2008). The information and functionality provided may empower patients to take an active role in managing their care. PHRs can provide links to
educational information and tools to help patients make informed decisions about their care and the ability to communicate with their provider about these decisions more easily.

The potential of PHRs will not be realized if they are not used. Barriers to PHR adoption have been identified. For consumers to fully engage in their PHR they need to understand the need for and accept responsibility of maintaining and coordinating their health information (Tang, et al., 2006). This shift has been seen in other industries, from hospitality, where travelers now book and manage their own vacation plans, to finance, where online banking and investment firms enable customers to track and manage their money. A usable interface that provides consumers with easy-to-use tools to perform the functions that they deem appropriate is essential, and as of yet, in regard to PHRs, neither the interface nor the pertinent functionality is well defined or understood (Tang, et al., 2006).

Using a PHR requires access to computers and the Internet, neither of which is uniformly available. Blacks and Hispanics are less likely than the national average to own a computer or to have Internet access; Internet access is lower for those with lower incomes; and rural Internet use is lower than urban use (Chang, Bakken, Brown, Houston, Kreps, Kukafka, Safran, & Stavri, 2004). A study of PHR adopters from a large health care system in the northeast found that adopters were more likely to be White than Asian, Hispanic or Black; more likely to have commercial insurance or to self-pay than to be covered through Medicare or Medicaid; and more likely to live in a high income than low income area (Yamin, Emani, Williams, Lipsitz, Karson, Wald, & Bates, 2012).

Fox and Purcell (2010) found that adults with one or more of five chronic health conditions: high blood pressure, lung conditions, heart conditions, diabetes, and cancer,
are significantly less likely to access the Internet than healthy adults. The more chronic conditions one has, the greater the gap: 81% of those with no chronic conditions, 62% of those with one condition, and only 52% of those with two or more conditions reported using the Internet. These results remained significant when controlling for age, race, education, and income. However, Yamin et al. (2012) found that those with chronic conditions were more likely to access their PHR than those with no chronic conditions.

But access alone is insufficient. Reading and writing skills, computer competency, and health literacy are also required (Detmer, et al., 2008; Leonard, et al., 2008). Twenty percent of Americans may face one or more of these barriers (Chang, et al., 2004). Access barriers also exist for those with cognitive and physical disabilities (Lober, et al., 2006). A study of PHR use among people living with HIV and AIDS in New York City found that those with Internet experience were 2.7 times more likely to use the PHR than those with no experience (Gordon, et al., 2012).

Health literacy is related to general literacy, but includes additional skills including knowledge of common health-related vocabulary such as diabetes, cholesterol, and protein; abbreviations such as mg, and mcg; familiarity with structure and genre of health-related material such as insurance forms and drug labels; and an understanding of how the health care system works. Health literacy is a necessary skill for PHR use. Users must be able to access, comprehend, and act upon their health information for the PHR to be useful to them. (Detmer, et al., 2008; Ishikawa & Kiuchi, 2010; Jeppsen, Coyle, & Miser, 2009; Jordan, 2011; Leonard, et al., 2008; Morris, MacLean, Chew, & Littenberg, 2006; Powers, Trinh, & Boswirth, 2010; White, 2008).
The 2003 National Assessment of Adult Literacy which surveyed 19,000 US residents aged 16 or more living in households and prisons included a set of health literacy-related measures. In the assessment three basic literacy categories (prose, document, and quantitative literacy) in three health care categories (clinical, preventive, and navigation of the health care system) were addressed. Overall, 12% of respondents were proficient, 53% intermediate, 22% basic, and 14% below basic in their health literacy skills (White, 2008).

Compared with those of adequate health literacy, those with low literacy have increased risk of hospitalization, higher rates of depression, less routine preventive care such as mammograms, pap smears, flu or pneumococcal immunizations, and higher health care costs. They have poorer understanding of their chronic diseases, poorer disease management skills, higher levels of disease indicators, and worse self-reported health. They frequently do not understand prescription labels or complex instructions and have poor understanding of written or spoken medical advice. Low health literacy is most common in older patients, those with lower education, immigrants, racial and ethnic minorities, those with lower incomes, females, and those who have been incarcerated (Berkman, DeWalt, Pignone, Sheridan, Lohn, Lux, Sutton, Swinson, & Bonito, 2004; Ishikawa & Kiuchi, 2010; Jeppsen, et al., 2009; Jordan, 2011; Morris, et al., 2006; Powers, et al., 2010; White, 2008).

Heart failure patients with lower health literacy have more heart failure symptoms, lower quality of life, lower general heart failure knowledge, and lower overall self-efficacy than heart failure patients with adequate literacy. They were less likely to own a scale, weigh themselves daily, manage their diuretic, or to know what to do if their
weight goes up (Macabasco, DeWalt, Broucksou, Hawk, Baker, Schillinger, Ruò, Bibbins-Domingo, Holmes, Erman, Weinberger, & Pignone, 2011).

PHR use is lower for those with low health literacy. Kaiser Permanente, a managed-care health insurer, uses Epic's EHR. Its PHR is available to all of its patients. Among its 40,000 diabetic patients, those with lower health literacy have poorer diabetic outcomes. They are less likely to use the PHR even when controlling for computer access and educational attainment. The reasons for their lower rates are unclear but may be due to a lack of awareness of PHR, a lack of motivation to learn to use it, lack of Internet access or computer training, competing time demands, or difficulty navigating or understanding the PHR (Sarkar, Karter, Liu, Adler, Nguyen, Lopez, & Schillinger, 2010).

Interventions for those with low health literacy can include simplifying instruction forms, use of patient health care teams to provide simplified education and ensure that patients understand and retain what is being said, and aggressive educational interventions (Jeppsen, et al., 2009). In the clinical setting there is a need to quickly identify those with low health literacy. Several screening tools have been developed. They fall into three main types. Tools using direct testing of ability have patients read and pronounce words, read passages where words have been omitted and identify the omitted words, and read and analyze nutrition labels. Self-reporting tools ask patients to rate their experience with various types of health information. Finally, proxy measures such as educational attainment may be used. While none of these methods measures the full array of health literacy skills, they may be useful in identifying patients for whom interventions might be useful (Jordan, 2011).
The need for diligent security to protect sensitive health care information is widely cited as a barrier to PHR adoption (Lober, et al., 2006). Possible consequences of security breaches include the publication of personal health information, denial of insurance coverage for those with expensive conditions, identity theft, and direct marketing campaigns to those with specific conditions (Fredrickson, 2008). However, consumer studies indicate that this may not be as great a barrier as theoreticians present. While the majority of Americans including those using a PHR are concerned about the security of their health information in general, the majority of PHR users are not as concerned about the privacy of the information contained in the PHR (California HealthCare Foundation, 2010; Fredrickson, 2008; Hassol, Walker, Kidder, Young, Pierdon, Deitz, Kuck, & Ortiz, 2004). Patients using an asynchronous physician communication in Norway recognized and were comfortable with the fact that online communication is not 100% secure (Tjora, et al., 2005). Users had access to three forms of communication, and their choice of which to use was dependent on the sensitivity of the information being communicated. Regular email was the method of choice for short routine communication. A secure system that involved sending a message to the provider's system, receiving a PIN number via telephone, and then entering the PIN to access the system was rarely used except for sensitive communication. Finally, respondents waited for face-to-face encounters to discuss extremely confidential information and for discussions where they felt the need to receive non-verbal as well as textual information.

Provider barriers to PHR adoption include the challenges posed by incomplete records, and time and resource concerns. Widespread knowledge about PHRs and their
potential is lacking. In the fall of 2007, 25% of physicians surveyed in Nebraska and South Dakota had not heard of PHRs, and 60% did not know if any of their patients used PHRs (Fuji, Galt, & Serocca, 2008).

Currently, because health information is stored in hospitals, clinics, and doctors’ offices, it is fragmented. Different providers have different information with different levels of completeness and timeliness. Because of the lack of ubiquitous EHR usage, even if a provider's records are electronic, they may not be complete (Urowitz, et al., 2008). Providers are justifiably reluctant to use systems that do not contain accurate information.

The shift in the provider-patient relationship espoused by PHR proponents towards a shared model of control is a barrier for some providers (Detmer, et al., 2008; Urowitz, et al., 2008). Their role will expand to include helping patients find and understand health-related data from multiple sources, and encouraging them to make informed decisions.

Some providers express concerns for the increased work involved in answering email (Greenhalgh, et al., 2010). Implementation of Kaiser Permanente's secure email functionality with its PHR led to a two-month spike in office visits and telephone calls to the office when the application was introduced. After that time, both telephone rates and office visit rates decreased (Zhou, Garrido, Chin, Wiesenthal, & Liang, 2007).

Proponents of PHRs suggest that health costs will be reduced through their use. Kaiser Permanente physicians reported anecdotally that PHR use decreased face-to-face physician office visits partially through increased use of less expensive health care
encounters such as laboratory tests, health education classes, non-physician office visits and telephone calls (Greenhalgh, et al., 2010; Zhou, et al., 2007).

For users to adopt a PHR it must provide perceptible value, and its costs must be justified relative to its perceived value (Leonard, et al., 2008). However, a closer look at who pays and who gains uncovers some major contradictions. PHRs are expensive to build and maintain. The costs of PHRs, especially tethered PHRs, are generally borne by health care organizations. However, the savings are realized by patients and payers (Detmer, et al., 2008; Tang, et al., 2006). What is valuable to the patient may not be valuable to the clinician. For example, while diabetic patients may find a feature for recording daily weight and exercise a useful behavior modification tool, clinicians need summary tools to reduce the daily data volume. The diabetic patients examining the University of Pittsburgh patient portal ranked all potential portal features at least somewhat useful, yet only 2 of 17 were willing to pay for access (Hess, Bryce, McTigue, Fitzgerald, Zickmund, Olshansky, & Fischer, 2006). In fact, under fee-for-service billing common in US health care, providers may not receive payment for electronic communication with their patients. Thus, they are paying for a system that lowers their income. Recent changes in reimbursement for e-visits (sometimes dubbed mouse calls) may help reduce this barrier.

On a national and global level, interoperability issues with PHR adoption abound. There are needs for standards in a myriad of areas including data interchange, common data set elements, consumer terminology, authentication processes, security standards, privacy standards and certification. (Detmer, et al., 2008). PHRs require the integration of health information from disparate sources, and software to clean, format, and map the
data needs to be developed. Who will bear the costs for the development remains to be determined.

There is a small, but growing community of PHR users. The National Consumer Survey on Health IT (California HealthCare Foundation, 2010) found that 7% of American adults have used a PHR; among those with three or more chronic conditions, the number was 8%. Three types of activities were of value to the users: accessing information from their medical record – including verifying information in the record and looking up test results; convenience – including renewing prescriptions and scheduling visits; and communication with providers. Respondents, especially those with two or more chronic conditions including heart failure, noted positive benefits of their PHR use: more than half reported that using the PHR made them feel they knew more about their health and more about the care their doctors provided; one-third reported that their PHR made them feel more connected to their doctor and led them to take action to improve their health.

Although the technology is in its infancy, PHR clinical research is being conducted and published. Three studies are reported here. Automatic patient messaging delivers standard messages to PHR patients following a triggering event. Possible triggers include monitoring symptoms of oncology patients or managing post-surgical patients for infection. MedCheck's trigger is a new prescription or prescription change, and its goal is to reduce adverse drug events. Ten days after the trigger, MedCheck sends an email to the patient asking if they have filled the prescription and if they have had any problems. MedCheck routes the answer to their physician. Thus, MedCheck continues the clinical encounter, enabling the provider to provide an intervention if necessary. In a
retrospective study of 267 charts of patients who opened the MedCheck message, researchers identified 21 adverse drug effects, 17 of which were identified through MedCheck (Weingart, Hamrick, Tutkus, Carbo, Sands, Tess, Davis, Bates, & Phillips, 2008). For this type of application to be effective, physicians must review and answer their messages in a timely manner.

Keeping the medication list accurate in EHRs is a challenge. Researchers at a large integrated regional healthcare delivery network tested a workflow that used the PHR to improve medication documentation within the EHR. Patients were sent a secure message to their tethered PHR showing their EHR's current medication list prior to an upcoming visit. They were asked about any discrepancies between the list and what they thought they should be taking, including differences in dose, and missing or additional medications. They were also asked about adherence problems, possible side effects, and prescription refill needs. Their answers were incorporated into the EHR, and displayed to the provider within the medication screen during the office visit. The screen allowed the provider to verify and easily move information from the patients' responses to the EHR. Three weeks after the visit, participants and a control group whose pre-visit review did not include medications were interviewed and differences between their medication regimen and that reported in the EHR were identified. While both groups had a high discrepancy rate, those who completed the pre-visit medication review had a lower rate (42%) than did the control group (51%). Results suggest that the PHR message encouraged patients to review their medications and their responses similarly encouraged their providers to update the medication list and to discuss medication adherence and potential side effects. The intervention seemed well-accepted by the patients (71%
completed the pre-visit questions). During the office visits providers failed to open the medication module and view patients' responses in 23% of the cases, pointing to larger workflow and compliance issues at the clinics (Schnipper, Gandhi, Wald, Grant, Poon, Volk, Businger, Williams, Siteman, Buckel, & Middleton, 2012).

A study that included a PHR in an intervention to reduce blood pressure found web-based tools useful, but only in conjunction with personal communication (Green, Cook, & Ralston, 2008). In a 12-month clinical trial, tethered PHR patients with uncontrolled hypertension were told they had high blood pressure and encouraged to work with their physician to control it. They were registered to use a tethered PHR, and given pamphlets on the PHR and high blood pressure. They were randomly assigned to three interventions: a) no further instructions, b) home monitoring, and c) care management. The home monitoring and care management groups received a tour of the PHR and its functions, and a home blood pressure monitor with instructions. The care management patients were assigned a pharmacist who, after an initial phone call, communicated with the patients through the PHR. Together they developed an action plan and communicated about the patient's adherence to the plan. Use of the PHR alone did not have a significant impact. The impact was significant only when the PHR was coupled with human interaction between the patient and pharmacist.

In summary, PHRs are an emerging technology. As of yet there is little agreement about what constitutes a PHR. Definitions, features, and platforms need to be established. Proponents see many benefits to their use including enhanced patient-provider communication, improved patient safety, and reduced health care costs. Patients with chronic conditions may find PHRs to be a useful disease management tool. However,
research is needed to validate these claims. Access barriers, security issues, the
challenges of providing an easy-to-use interface, and provider reluctance are all hurdles
that must be overcome before widespread use of PHRs can be expected. A discussion of
technology acceptance models is warranted.

Acceptance of Technology

The potential of PHRs will only be realized if they are accepted and used.
Acceptance of a new technology has been the focus of research in many areas. Two
major bodies of research are the diffusion of innovation and the Technology Acceptance
Model (TAM).

The diffusion of innovation model uses Tarde's adopter classification scheme first
described in the early 1900s (Davidson & Heineke, 2007; Geibert, 2006; Rogers, 2003).
Adoption begins with a small group of innovators, followed by a slightly larger group of
early adopters. The innovation becomes more wide-spread as the early majority accepts
it. They are followed by the smaller late majority who are more adverse to risk but do not
want to be left behind, and so wait for respected peers to go first. The last to adopt the
innovation are the laggards who bring up the rear. Rogers' (2003) Diffusion of
Innovations research expands Tarde's. He defines diffusion as a four element process "by
which (1) an innovation (2) is communicated through certain channels (3) over time (4)
among members of a social system" (Rogers, 2003, p. 11).

The innovation is an idea, practice, or object that is perceived as new (Rogers,
2003). Innovations have five characteristics which make them more or less likely to be
adopted:
1. Relative advantage describes whether or not the innovation is perceived as being better than its predecessor. Better may be defined by economics, convenience, satisfaction, or social prestige. PHR’s suggested benefits, such as convenience, improved communication and safety, and cost reduction are all examples of potential advantages that may accrue from widespread PHR usage.

2. Compatibility describes the users’ perceptions of how the innovation matches their values, past experiences, and needs. Healthy individuals may feel they have less need for a PHR than those with chronic conditions for whom having access to accurate health information in the Emergency Department may mean the difference between life and death. Similarly, those with past experiences of Internet security breaches may have different reactions to PHRs than those without them.

3. Complexity describes the users' perception of how difficult the innovation is to use. Simpler innovations are adopted more quickly than complex ones that involve developing new skills. The user interface of the PHR is an important component of its perceived complexity.

4. Trialability describes the users’ ability to experiment with the innovation before adoption. Innovations that allow such trial are accepted more rapidly than those that do not.

5. Observability describes the visibility of the innovation to others. The more visible, the more rapid the acceptance. Discussions and demonstrations with friends and neighbors can help promote an innovation.
Of these five, relative advantage and compatibility are the most important (Rogers, 2003).

Information about the innovation needs to be communicated (Rogers, 2003). Mass media is effective for introducing and creating awareness of an innovation. However, interpersonal channels, both face-to-face and increasingly Internet-based, are more effective in persuading a person to adopt. Most people don't base their decision on objective scientific studies, but rather on the subjective evaluation of others who have adopted the innovation. Social networks, modeling, and imitation are important processes in acceptance. The more similar the adopter and potential adopter, the greater the likelihood adoption will occur.

Adoption follows a five step pattern that usually occurs in a time-ordered sequence: a) knowledge: one learns about the innovation and how it functions; b) persuasion: one forms a favorable or unfavorable opinion about it; c) decision: one decides to adopt or reject it; d) implementation: it is put to use; and e) confirmation: the user reinforces or rejects the innovation decision (Rogers, 2003). People move through the sequence at different speeds. The rate of adoption describes the speed of the adoption within society. A plot of the number of adopters over time results in an s-shaped curve. We start with a few innovators. Over time these are joined by a growing group of early adopters. The curve climbs more steeply as the early majority follow. As the late majority adopts the innovation, the rate of adoption begins to level off, and finally flattens as the remaining late adopters (laggards) are brought on board. While the s-shaped curve is constant, its slope, which describes how fast the innovation is diffused, varies. Kaiser Permanente's PHR adoption rates following the classic S-shaped curve (Silvestre,
Valerie, & Allen, 2009). Some object to Tarde's adopter categories, finding them stereotypical, value-laden, and inadequate to describe the complex nature of technological adoption.

Finally, the social system defines the individuals, groups, or organizations in which the innovation occurs (Rogers, 2003). The structure of the social system can help or hinder adoption. Its formal structure, for example the structure described on an institution's organization chart, is less influential for diffusion than its informal interpersonal networks. Social systems have norms of established behavior, and opinion leaders who conform to and exemplify these norms. The most innovative individuals in a system often deviate from these norms, and have low credibility within the group. Opinion leaders, on the other hand, have high credibility, and their adoption or rejection of the innovation will influence the behavior of the group.

The decision to adopt an innovation can be made by an individual, by consensus, or through an authoritative mandate. The choice of a patient to use a PHR is an individual decision. The choice of a physician to participate may be an individual decision, but is more likely to be a consensus decision within a medical office, or an authority decision mandated by a health care organization. Authority decisions generally have the fastest rate of adoption, but they can also lead to resistive behavior (Timmons, 2003).

Adoption has consequences for the social system. As well as the anticipated uses, individuals often reinvent the innovation, using it in unanticipated ways, leading to both desirable and undesirable outcomes. Such is the nature of innovation, which due to its newness carries a certain degree of uncertainty and risk (Timmons, 2003).
Greenhalgh et al. (2004) identified several individual variables that can influence EHR adoption: general individual traits associated with willingness to try and use innovations including tolerance of ambiguity, intellectual ability, motivation, values, and learning styles; context-specific psychological antecedents including the innovation's ability to meet identified user needs; user ability in terms of specific skills necessary for system use; how the value attached to the project by other users aligns with the meaning attached by the individual; and how the decision to adopt the EHR is made, whether individually, authoritatively, or collectively.

TAM predicts an individual’s acceptance and use of a particular software application based on the user’s perception of its ease of use and its usefulness, two of the five characteristics identified by Rogers. Users are more likely to use a program when they believe it will improve their job performance and that it will not be too difficult to use. The identification of these two variables as key determinants of user acceptance are found in many theoretical frameworks including self-efficacy, expectancy, behavioral decision, diffusion of innovation, marketing, and human computer interface theories (Davis, 1989). In his seminal publication on TAM, Davis presents the model, a validated tool for its measurement, and results from two studies using the tools. In each study both variables were significantly correlated with an individual’s use of the studied software. Ease of use was found to be an antecedent to usefulness, that is, the effect that perceived ease of use has on technology usage is due to its contribution to the perceived usefulness of the software. Because of its reliable measurement tool and "parsimonious theoretical base," (Lucas, Swanson, & Zmud, 2007, p. 206) TAM has been widely used in the study of individual adoption of technology. The model has been cited in over 1,000 articles and
has proven to be robust in studies of various types of software including email, groupware, expert systems, spreadsheets, and electronic health systems, and in various cultures including the United States, Japan, and Saudi Arabia (Venkatesh, Davis, & Morris, 2007).

Silvestre, Sue and Allen (2009) studied adoption of Kaiser Permanente's PHR using a modified TAM model in which they examined perceived system quality as well as ease of use and usefulness. They found that perceived usefulness and quality were positive significant predictors of actual system use, while perceived ease of use was not.

Over time, theoreticians have expanded the TAM model to include additional usage determinants. Venkatesh, Morris, Davis, and Davis (2003) compared eight models that together utilize 32 constructs with four moderating variables to predict software acceptance. They studied acceptance in four industries over a period of six months, asking users to evaluate their intentions, attitudes, and usage four times during the study, and used the results to evaluate the strength of each of the eight models. The models were able to explain between 17 and 42% of the variance in acceptance. From the results they identified four direct factors that influence usage, and four moderating variables that were able to explain 70% of the acceptance variance. They then validated their model, termed the unified theory of acceptance and use of technology, in two additional industries. The four unified theory determinants include a) performance expectancy – the degree to which an individual believes the software will help job performance; b) effort expectancy – the system's ease of use; c) social influence – the degree to which an individual perceives that those with influence feel the system should be used; and d) facilitating conditions – the user's perception that organization infrastructure exists to support system
use. Facilitating conditions are important as a software platform is rolled out, but become less important as users learn and gain experience with the system.

Adoption determinants are moderated by the user's gender, age, and experience, and whether or not the adoption is voluntary or mandatory. Generally, those who are younger, male, and have more experience have a greater rate of technology adoption (Venkatesh, et al., 2003). Venkatesh et al. (2003) found that social influences had no effect in voluntary adoption situations. In mandatory settings, social influences were important in the early stages of adoption, but their role diminished over time. This seems to contradict Rogers' (2003) theory that stresses the importance of the social setting in the diffusion process. In PHR adoption, the choice of adoption by an individual patient is voluntary. For the provider, while usage may be voluntary, it may also be a mandatory part of a PHR implementation.

Trimmer, Beachboard, Wiggins, and Woodhouse (2008) studied seven resident physicians' intentions to use electronic medical records from a unified theory of acceptance and use of technology perspective. The residents worked in a family practice office that had electronic medical record software, and were asked about their experience with it, and how important having similar software would be in their choice of a practice location upon completing their residency. The seven were unanimous in their favorable performance expectations of the software's ability to improve their ability to practice medical care. In terms of effort expectancy, they described the ease of use of some system functionality (reviewing past clinical data, e-prescribing, and connectivity), and drawbacks of others (cumbersome data entry, system efficiency, and workflow and training issues). Socially, the residents were aware of which of their peers supported, and
which disliked the application, and they felt the facilitating conditions for its use were favorable. All seven felt that having an electronic medical record would positively influence their practice choice decision. The overriding factor for this intention was in its ability to improve patient health care.

TAM is not without its critics. Some argue that the limited number of variables studied in the original TAM model, perceived usefulness and ease of use, ignore other important user beliefs and values, such as trust in online applications, or presence in social networks (Benbasat & Barki, 2007). Others claim that the unified theory of acceptance and use of technology’s expansion of TAM has resulted in an unwieldy model in need of simplification (Bagozzi, 2007). Methodologically, TAM's primary usage data are self-reported, although system logs ascertained actual usage in the development of the unified theory of acceptance and use of technology (Straub & Burton-Jones, 2007). Using self-reports to measure both the independent and dependent variables can lead to common rater bias; when respondents rate a program’s perceived usefulness and ease of use either positively or negatively, it is unlikely that their rating of intended use will be different. As Straub and Burton-Jones (2007) explain, "Why would a reasonable person use a technology that s/he did not find to be useful?" (p.225). Additionally, both TAM and the unified theory of acceptance and use of technology examine software used for one's job. In looking at PHR adoption, the provider will be using the PHR in a work-related capacity. However, patient adoption will be for non-work-related reasons. While TAM addresses acceptance of technology, acceptance has been narrowly defined as being the degree of use during adoption of the software (Schwarz & Chin, 2007; Straub & Burton-Jones, 2007). The unified theory of acceptance
and use of technology study examined usage for a period of six months, but even this provides a different view from that of studying acceptance throughout the usage lifecycle, as the user learns, adapts, and optimizes the software use. TAM also does not examine the context or the consequences, intended or not, of the adoption of the application (Bagozzi, 2007; Benbasat & Barki, 2007). Like Roger’s diffusion of innovation theory, TAM’s focus is on an individual’s acceptance of technology. Extrapolation to acceptance of software within an organization must be made with caution (Lucas, et al., 2007; Venkatesh, et al., 2003).

PHRs are in their infancy, although their use is growing; in 2008 a national survey found 2.7% respondents had a PHR, while a national survey conducted in 2010 found the number to be 7% (California HealthCare Foundation, 2010). In the latter survey, respondents in some typical early-adopter groups had higher participation rates than the 7%: those in households with incomes over $75,000 (13%), those with a college education (12%), men ages 29 to 45 (11%), and, as we have already seen, those with three or more chronic conditions (8%).

Group Health Cooperative is a mixed-model health care system in Washington and Idaho serving over 300,000 patients. They implemented the Epic EHR and its associated PHR in 2001. Between January 2004 and March 2005, 29% of the 124,000 adult patients who were eligible to use the PHR elected to do so. Researchers interested in the adoption of secure message within the PHR compared those enrolled in the PHR who used the functionality to those enrolled patients who did not. Rates of secure messaging were higher among women than men, and among those with commercial insurance rather than Medicaid, and among those aged 50-65. Provider use of secure
messaging varied widely; between 3% and 52% of all their patient encounters were through secure messaging. Patients whose providers had a greater overall use of secure messaging were more likely to use secure messaging themselves. Finally, patients were assigned a morbidity score ranking of their expected need for health care due to acute and chronic conditions. Sicker patients were more likely to use secure messaging (Ralston, Rutter, Carrell, Hecht, Rubanowice, & Simon, 2009).

Working within a TAM framework, researchers in New Zealand interviewed ten patients with one or more long term conditions on their use of a tethered PHR (Day & Yulong, 2012). Patients reported that the PHR was useful and convenient, especially for reviewing results and ordering prescription refills. They viewed the PHR as a source of truth for drug names, diagnoses, and laboratory results, and used it to prepare for appointments. However, they found the journaling tool that allowed them to post data they were monitoring difficult to use, and most chose to continue recording on paper.

Usability

Perceived ease of use is a major factor in technology adoption. The International Organization for Standardization, a leading body in defining usability standards, addresses four characteristics of usability: effectiveness, efficiency, satisfaction, and learnability (Abran, Khelifi, & Suryn, 2003). Shneiderman and Plaisant (2005) outline four usability goals for software developers: ascertain the users' needs; ensure reliability; promote standardization, integration, consistency, and portability; and complete the project on time and within budget. Usability design has been studied extensively over the past three decades, yielding a body of literature and best practice recommendations. The U.S. Department of Health and Human Services (2006b) has compiled the research into
research-based web design and usability guidelines that can be used by designers, usability specialists, managers, and researchers. Some guidelines are general, for example *understand and meet user’s expectations*, while others drill down to the minutia of creating a usable interface, such as *use mixed-case for prose text*.

Usability effectiveness can be measured by the percentage of tasks accomplished; efficiency by task completion time, the time spent on errors, or the number of available commands used or not used; satisfaction through user comments and evaluations; and learnability through the time it take to learn the functionality (Abran, et al., 2003; U.S. Department of Health and Human Services, 2006b). Web-based applications intended for universal usability, including PHRs, will be accessed by users with a diversity of abilities, backgrounds, and motivations. They will have varied physical and cognitive abilities, computer access, computer knowledge, and literacy skills (Shneiderman & Plaisant, 2005). Testing with specific cohorts is needed to validate the usability for them.

In addition to computer skills, those using PHRs also need experience with medical health concepts and terminology. PHRs need to address medical jargon and terminology (Britto, Jimison, Munafo, Wissman, Rogers, & Hersh, 2009). In building a prototype PHR, De Clercq, Hasman, and Wolffenbuttel (2003) based informational screens on forms used in a medical practice that were routinely discussed with the patient. However, inside the PHR, without the benefit of a clinician to interpret the data with them, patients reported difficulty understanding the information. Providing the right level of support is a key usability issue.

Usability studies are crucial in the development process. An iterative design approach of creating a prototype, testing it, making changes, and retesting until pre-
determined performance benchmarks are met is recommended (U.S. Department of Health and Human Services, 2006b). This approach can lead to sites that are more effective, more efficient, and yield greater user satisfaction. Britto, et al. (2009) performed usability testing on Cincinnati Children's Hospital Medical Center's tethered PHR, MyCare Connection with 16 parents of children with chronic diseases. Participants self-reported their computer skills, computer usage, and knowledge of their child's condition. They were then recorded using the PHR to perform scripted tasks. Researchers found that using the scenario-based testing with novice users allowed them to uncover problems with terminology, navigation, task completion, satisfaction, and ease of use.

In their development of a diabetes patient portal designed to provide diabetes self-management education, researchers at the University of Pittsburgh Medical Center used focus groups to solicit feedback (Hess, et al., 2006; Hess, et al., 2007). Features of the portal, which is tethered to two EHRs, included the ability to schedule appointments, review health information, and communicate with providers electronically. Features designed to encourage diabetes management included a daily logbook for recording exercise, weight, and blood glucose levels, the ability to graph lab results, links to diabetes information, a frequently asked questions page, and behavioral recommendations. Pre-implementation focus group participants were asked to rank 15 portal features. All features were ranked at least somewhat useful. Most useful were the daily log, a calculator for estimating diabetes control for the past three months, and links to educational websites. Least useful were chat rooms for diabetic patients, electronic bulletin boards for sharing information, and schedules for health cooking classes (Hess, et al., 2006). Post-implementation focus groups felt the portal's access to medical records,
and scheduling and tracking features provided them with a sense of empowerment. They were frustrated with inaccurate information, slow responses from their providers, and lab data that their providers did not release to the PHR for them to view. Barriers to effective use of the system included difficulty with user-names and passwords, and being unaware of the features of the site. Access to educational sites, which was ranked high in the pre-implementation groups, was not viewed as useful by the post-implementation group, perhaps suggesting that simply providing links to educational information is not sufficient to encourage their use.

Usability testing can also be used to analyze an existing application. Most published usability evaluations of PHRs fall into this category. They were not performed as part of the development cycle; rather, they assessed completed software and aimed to understand influences on PHR adoption. In their systematic review of usability studies of health information systems, Peute, Spithoven, Bakker, and Jaspers (2008) analyzed 52 studies and found that under 25% were performed before the software was released, while 73% were post-implementation analyses of user satisfaction or re-engineering needs.

Two studies have evaluated aspects of the usability of Epic's PHR, the PHR in use at Fletcher Allen. Geisinger Health Systems introduced their PHR in 2001. Users who had registered, activated their account, and logged into the PHR at least once between 2001 and 2003 were invited to participate in an on-line survey. They define this patient group as early PHR adopters. Approximately one-third of the invitees (1,421 people) replied and completed the survey. On a scale of 0 (hard) to 100 (easy), average ease of use scores for PHR functions (ease of registering, logging in, renewing prescriptions, first
time e-mail and subsequent email) ranged between 78 and 85, with women finding the system somewhat easier to use than men. Patients felt they could understand their medication information and test results (average score 80), although those with more education found the results more understandable. Providers were also invited to participate, and 31 (13%) did so. Communication mode preferences were markedly different between the patients and the providers. For most categories of communication, patients preferred online/email or in person communication, and providers preferred written or telephone communication (Hassol, et al., 2004).

Group Health Cooperative examined functionality and satisfaction through a paper survey mailed to a random sample of patients who used their PHR. Overall, 94% were satisfied or very satisfied with their PHR. By function, highest marks went to medication refills (96%) and secure messaging (93%) followed by test results (86%), appointment scheduling (79%), educational information (80%), and the provider directory (74%) (Ralston, Carrell, Reid, Anderson, Moran, & Hereford, 2007).

While large surveys may provide a general picture of what PHR features are used and overall satisfaction, they do not provide detailed information about specific populations use, learning over time, or function usability. This study worked with a small population of heart failure patients. First, like Britto, et al. (2009), the usability of the PHR for novice heart failure patients was examined. A limitation of many usability studies is their emphasis on first-time use of the system (Shneiderman & Plaisant, 2005). After three months patients were again interviewed to examine a more experienced user view of the product.
Heart Failure

A basic understanding of the causes and treatment of heart failure is provided to place the proposed study in its clinical context. A thorough description of heart failure is beyond the scope of this literature review. Heart failure is not a disease, but rather a set of symptoms caused by the heart's inability to pump strongly enough to meet the body's metabolic demands. This causes a buildup of blood and fluid in the lungs and other parts of the body leading to fatigue, dyspnea (difficulty breathing), cough, and fluid retention; although not all symptoms are present in all patients. The heart's ventricles are cardiac muscles that move blood through the body. The right ventricle pumps oxygen-depleted blood to the lungs, and the left pumps the newly oxygenated blood to the rest of the body. Heart failure results from the inability of either ventricle to either fill with or eject blood. Typically, heart failure is caused by the inability of the left ventricle to empty adequately. Causes of heart failure include hypertension, heart attack, coronary artery disease, heart valve disease, congenital heart disease, infection of the heart valves and muscles (endocarditis or myocarditis), and diseases of the heart muscle (cardiomyopathy) (American College of Cardiology Foundation & American Heart Association Task Force on Practice Guidelines, 2009; Clark, et al., 2008; Fletcher Allen Health Care, 2007; Heart Failure Society of America, 2006; Institute for Clinical Systems Improvement, 2007; National Pharmaceutical Council, 2004).

Heart failure is life-long and progressive. Its progress can be slowed or stopped by treatment, but it is generally not reversible. The severity of heart failure symptoms fluctuates in a given patient, and medication and life-style changes can reduce heart

1 The term "heart failure" is preferred over the older term "congestive heart failure" because not all heart failure patients have congestive volume overload.
failure symptoms even when they do not affect the underlying cardiac pathology.


Functional limitation caused by heart failure is assigned to classes that are measured by the amount of effort needed to elicit symptoms: Class I: exertion that would limit normal individuals; Class II: ordinary exertion; Class III: less than ordinary exertion; and Class IV: at rest (American College of Cardiology Foundation & American Heart Association Task Force on Practice Guidelines, 2009). Heart failure treatment goals include reducing symptoms, improving functional status, improving quality of life, and increasing survival (National Pharmaceutical Council, 2004).

Five million Americans have heart failure, and over 500,000 new cases are diagnosed each year. Heart failure accounts for 12-15 million office visits and 6.5 million hospital days annually, and these numbers are rising. It is especially prevalent among the elderly and is the most common cause of hospitalization for people over 65. Eighty percent of heart failure hospitalizations are to those over 65, and Medicare spends more on heart failure than any other diagnosis. It is a common, costly, disease that limits a patient's functional capacity and quality of life, and can be fatal (American College of Cardiology Foundation & American Heart Association Task Force on Practice Guidelines, 2009).

Typically heart failure is identified in one of three ways: a) patients complain of decreased exercise tolerance due to dyspnea or fatigue, b) they complain of fluid retention causing cough or edema in the lower extremities, or c) heart failure is identified during other tests and procedures such as a chest x-ray or electrocardiogram (EKG).
Diagnosis is based on a complete history and physical exam, standard laboratory tests, and diagnostic tests such as a two-dimensional echocardiogram with Doppler flow studies to determine whether cardiac abnormalities are present and which chambers are involved. During initial evaluation of heart failure an attempt to determine the cause of heart failure is important because some conditions are treatable or reversible. The initial evaluation also identifies coexistent conditions that may contribute to or exacerbate symptoms, and provides baseline data. Ongoing evaluation of heart failure patients includes clinical assessment to identify symptoms, their functional consequences, and their impact on activities of daily living; monitoring of fluid status, electrolytes, and renal function; evaluation of short and long term risks of disease progression and prognosis; and selection and monitoring of treatment (American College of Cardiology Foundation & American Heart Association Task Force on Practice Guidelines, 2009).

Common factors that lead to hospitalization for heart failure patients include non-compliance with the treatment plan, excessive alcohol or illicit drug use, uncorrected high blood pressure, medication changes, acute myocardial ischemia, atrial fibrillation and other arrhythmias, pulmonary embolus, endocrine abnormalities such as diabetes, and infections such as pneumonia or viral illnesses. Hospitalization accounts for a large proportion of the cost for caring for heart failure patients, and is associated with high morbidity and mortality especially among the elderly. The readmission rate within six months is 50%, and the risk of mortality within 12 months is 25-30%. (American College of Cardiology Foundation & American Heart Association Task Force on Practice Guidelines, 2009).
The Joint Commission (2009) is a nonprofit agency that accredits over 16,000 health care organizations in the US. It has four core performance measures for hospitals that apply specifically to heart failure patients: a) patients or their caregivers receive written educational material that addresses activity level, diet, discharge medications, follow-up appointments, weight monitoring, and what to do if symptoms worsen; b) left ventricular systolic function is evaluated before hospitalization, during hospitalization, or is planned for after discharge; c) patients with left ventricular systolic dysfunction are prescribed angiotensin converting enzyme inhibitors (ACE-inhibitors) or angiotensin receptor blockers (ARBs) at discharge; and d) heart failure patients who smoke are given smoking cessation counseling during their hospitalization. Improving compliance rates on these items is intended to improve the outcomes for hospitalized heart failure patients.

Heart failure education for both the patient and family is critical. Failure to understand how best to comply with discharge instructions can cause heart failure exacerbation leading to a subsequent readmission, and education about heart failure 's precipitating factors and compliance with medication and dietary advice can reduce readmission rates (American College of Cardiology Foundation & American Heart Association Task Force on Practice Guidelines, 2009; McAlister, Stewart, Ferrua, & McMurray, 2004). Fletcher Allen's discharge brochure uses the common mnemonic DAMES to stress these core self-care activities: Diet, Activity, Medications, Everyday weight monitoring, and Symptom monitoring and follow through (Fletcher Allen Health Care, 2007). Further information then expands each section.

One approach to working with heart failure patients is disease management which recognizes that heart failure is a chronic illness that spans home, outpatient, and inpatient
settings; and that most patients have multiple medical, social, and behavioral challenges that can best be met with a multidisciplinary team. Disease management provides a system for coordinated communication and collaboration between the patient, management team, and physician. Interventions stress the clinician-patient relationship and a care plan that includes intensive patient education and counseling; encouraging patients to be active participants in their own care; emphasizing prevention of heart failure exacerbation through the use of evidence-based practice guidelines; close monitoring with vigilant follow-up; outcome measurement, evaluation, and feedback; optimization of medical therapy; assistance with social and financial concerns; and collaboration between the patient, management team, and physician. Coupling intensive, focused discharge education and planning with well-coordinated follow-up care has led to positive results in heart failure Patients. (American College of Cardiology Foundation & American Heart Association Task Force on Practice Guidelines, 2009; Krumholz, Currie, Reigel, Phillips, Peterson, Smith, Yancy, & Fazon, 2006; National Pharmaceutical Council, 2004)

**Rural Health**

Fletcher Allen defines itself as a provider of health care for a rural region. There is no standard definition of rural used in health-related research. What definition is chosen will affect the research process and can impact the results (Vanderboom & Madigan, 2007).

There are two primary federal definitions used in health policy: the Census Bureau classification system and the Office of Management and Budget definition. The Census Bureau defines urban areas by their population density. Urban areas consist of an
urban center with a population of 50,000 or more and a density of at least 1,000 people per square mile, and surrounding areas with a density of 500 people per square mile. Urban clusters are population concentrations outside the urban area with between 2,500 and 50,000 inhabitants. Anything not defined as an urban area or urban cluster is rural. These area designations do not follow political boundaries such as state or county lines; they are instead more or less densely settled areas as they might appear from the air. The Office of Management and Budget definition is based on county population. Counties or county clusters with at least one urban area with a population of 50,000 or more are defined as a Metropolitan Statistical Area, while those with 10,000-50,000 people are defined as Micropolitan Statistical Areas. Again, anything not within one of these urban areas is defined as rural. Other classification schemes exist that provide finer distinctions of rural; however, they are often of limited value for research due to the difficulty of finding sufficient participants in the smaller groups for an adequate sample size. Fletcher Allen serves a population in Vermont and northern New York. By either the Census Bureau or Office of Management and Budget definition, over 60% of Vermont's population lives in a rural setting (Census: 62%; Office of Management and Budget: 67%). However, it must be noted that Fletcher Allen is located in Burlington, the largest population center in the state. Although both the Census Bureau and Office of Management and Budget definitions define rural geographically, it can also be argued that rural is a culture, way of life, and state of mind (Vanderboom & Madigan, 2007).

Fletcher Allen's use of the term rural has not been rigorously defined. When searching for a definition, the author was referred to the Vice President for Planning and Business Development, the Director of Government Relations, and the Government
Relations Specialist. None could provide an official definition. Email responses to the query included

I do not know whether we "quantified" the term "rural" in the development of our vision statement; rather, my understanding was that it was a recognition of the fact that Vermont – with the exception of the Burlington area – is primarily rural in nature (M. O'Donnell, personal communication, February 10, 2011).

I believe that technically we have only one "Metropolitan Statistical Area" (MSA) in Vermont, as defined by the U.S. Office of Management and Budget, which includes Burlington and South Burlington. That would also support the notion of the rest of Vermont being "rural." (M. O'Donnell, personal communication, February 10, 2011)

While Burlington is not considered "rural" we serve a rural population in northern New York and Vermont, so our vision recognizes that the needs of the people are sometimes different in a rural setting and as such we will strive to understand that and respond (D. J. Scalise. personal communication, February 10, 2011).

Those living in rural areas face health challenges related to geographic distance and lack of services. Compared to urban populations, rural populations tend to be older, and less educated. They tend to have lower incomes, less access to both primary and specialized health care, and poorer health. They have lower overall literacy and health literacy rates, and they are less likely to receive their health information from the Internet (Zahnd, et al., 2009). Geographically, it has not been economically feasible for private firms to provide broadband access to remote areas without government assistance, leaving many rural residents without high speed Internet capabilities (McCarthy, 2007; Vermont Telecommunications Authority, 2009).

Patients with heart failure who live in rural areas have poorer outcomes than their urban counterparts. The reasons are complex and interrelated. Most heart failure research has been done in urban settings, and the resulting clinical recommendations may be better suited to urban dwellers. Rural patients are older and sicker and have less access to care.
They are more isolated and have less social support. Telecommunication strategies that link patients to providers have proven effective in heart failure care (Clark, et al., 2008). Whether PHR technology can be an effective tool remains to be seen.

**Conclusion**

PHRs are an emerging health technology that allow patients to access and coordinate their medical records. There is not yet a consensus on what platform is best suited for delivery of a PHR nor the functionality that should be included therein. For PHRs to be adopted they must be easy to use, be understandable, and provide useful functionality to patients. Theoretically the field holds a lot of promise, but the hard work of building usable systems and validating their efficacy through clinical research has yet to be done. Heart failure is a costly chronic disease. Managing heart failure involves a team including the patient, disease management clinicians, and physicians. Outcomes are better for urban patients than those living in rural areas. An examination the potential benefits of a PHR in the disease management of heart failure patients living in a rural setting fits into the PHR research agenda. Whether PHRs can be of benefit to heart failure patients, and what specific features, if any, can help them with their disease management were addressed.
Chapter 3

Methodology

PHRs are a new and growing technology. While many theoretical benefits and risks to their use have been posited, there is little research to provide validation for either. To examine the potential benefits of a PHR in the disease management of rural heart failure patients, three research questions were posed:

1. How usable is the PHR for heart failure patients?
2. What PHR features do heart failure patients find useful?
3. Can a PHR be useful in the disease management of heart failure patients?

Research Design

A descriptive mixed methods design that combined quantitative and qualitative approaches was used. Descriptive research collects data to answer questions about current conditions. It is used to assess preferences, attitudes, concerns, or interests of a defined group of people (Gay, Mills, & Airasian, 2006), in this case, rural heart failure patients using Fletcher Allen’s tethered PHR, MyHealth. Data were collected through two face-to-face semi-structured interviews, observations of a usability study of participants performing specified tasks in MyHealth, computer-generated reports of participants'
MyHealth usage, and an interview with the heart failure nurse on the participants’ disease management team.

Interviews were conducted, one as the participant was enrolled in the study and given access to MyHealth, and a second after approximately three months. Interviews allow deep conversations with participants, allowing the researcher to explore a wide range of views and concerns, and encouraging respondent reflection and consideration. They allow researchers to gather information that might otherwise be hard to capture, for example the why of an action or opinion. In studying usability, interviews are useful to understand users' goals and needs. Semi-structured interviews provide a balance between structured interviews that leave the researcher little leeway in pursuing topics as they arise, and unstructured interviews that can be time-consuming and unproductive (Gay, et al., 2006; Lazar, Feng, & Hochheiser, 2010).

Portions of each interview were highly structured, including questions asked in published studies, to allow a comparison of rural heart failure patients with more general PHR users. The remaining semi-structured interview questions allowed the interviewer and participant to explore emergent topics, expand on answers, seek and provide clarification, and offer further explanation. The techniques were used to develop a rich understanding of the salient characteristics of the participants’ PHR experience. Several grounded theory methods were employed: initial coding and categorization of data; concurrent data collection and analysis; and constant comparative analysis (Birks & Mills, 2011). Initial coding and categorization of early interviews were used to identify concepts and themes. As themes emerged they were explored more deeply in subsequent interviews whose coding and categorization further refined the themes and informed
future interviews. The iterative process of comparing and analyzing data followed by further data collection describes constant comparative analysis.

Because interviews provide self-reported data, they are subject to participants' perceptions and recall. It is useful to compare these data with actual usage reports (Lazar, et al., 2010). Self-reported views on MyHealth were combined with observational data from the usability study, reports of actual MyHealth usage generated from the system, and the experience of the heart failure nurse managing their care.

**Procedure**

Fletcher Allen’s PHR, MyHealth, which is tethered to its EHR, PRISM became available to patients in June, 2011. Basic functionality in the system includes

- Medical Information which provides a view of portions of PRISM including: current health issues, test results, medications, allergies, immunizations, medical history, and hospital admission data, but excluding provider notes;
- Message Center which includes inbox and sent messages folders, and sections for contacting the doctor's office and requesting prescription refills;
- Appointments which allows users to request an appointment, view scheduled appointments, and cancel upcoming appointments;
- Health Library which provides a link to Healthwise patient information; and
- Billing and Insurance which allows users to pay their bills and update their insurance information.

Fletcher Allen follows national best-practice guidelines by providing heart failure patients with a disease management approach to their illness through a system of
coordinated communication and collaboration between the patient, management team, and physician. The heart failure nurse on the management team, working with the investigator and PRISM staff, identified disease management information and activities that could be delivered through the PHR and these were added to MyHealth for participants’ use. These included

- a daily journal flow sheet that allowed the patient to record their daily weight, blood pressure, energy, breathing, and swelling scores;
- standardized heart failure questionnaires, including the Minnesota Living with Heart Failure Questionnaire and the Self-Care of Heart Failure Index;
- heart failure resources which included Fletcher Allen Cardiology Department patient education material; and
- expanded communication features allowing users to contact the heart failure nurse directly, rather than just the Cardiology clinic.

The number of participants needed to complete valid usability testing is an ongoing debate. Osborn, Mayberrry, Mulvaney, and Hess (2010) summarized 26 articles on web sites to improve diabetes outcomes where the number of participants ranged from 3 to 12; Britto et al. (2009) used 16. In this study, after Institutional Review Board approvals from both the University of Vermont and Nova Southeastern University were obtained (see Appendices A and B), 15 patients were enrolled, a group large enough from which to draw meaningful conclusions, yet small enough to complete the study in a timely fashion.

The heart failure nurse made the initial contact with potential participants during a scheduled appointment. She identified patients with access to the Internet, and the ability
to use a computer without help. While such patients are not representative of the entire heart failure population, they may represent early adopters of PHR technology. She described the study and gave them an informational brochure (see Appendix C). With their permission, the investigator contacted them and discussed the study in more detail. Those willing to participate were enrolled, their initial interview scheduled, and a welcoming letter and the informed consent (see Appendix D) emailed to them for their review. All interviews and subsequent analysis were conducted by the investigator.

At the beginning of the interview the informed consent and HIPAA consent forms (see Appendix E) were reviewed and signed. During the initial interview MyHealth accounts were set up for those who were not already enrolled and participants were given access to the expanded heart failure resources. Three months after the initial interview, participants were contacted and a final semi-structured interview discussing their PHR experience was scheduled.

A description of the procedures used to gather data on each research question follows. Research Question 1: *How usable is the PHR for heart failure patients?* Participants completed a 25-minute usability study during their initial interview to measure their ability to use the tool’s interface. They were asked to perform basic MyHealth tasks using test patient data (see Appendix F). For two-thirds of the participants, this was their initial exposure to MyHealth. It provided baseline data on the PHR’s usability. Effectiveness was measured by the ability of the participants to complete and comprehend specific tasks in MyHealth; efficiency by timing the participants’ work on the tasks; and their satisfaction through two standard measures of
usability – the After-Scenario Questionnaire and the System Usability Scale survey which are described in detail in the instrumentation section that follows.

The usability of a tool is not an absolute, but must be viewed in the context of its use, the users, their tasks, and the appropriateness of the tool for the task (Brooke, 1996; Lewis, 1993). So while the test patient was developed with the heart failure nurse to contain information a typical heart failure patient might see, the information and tasks were defined by the investigator, and may not have represented relevant content or tasks for the participants. Thus, a detailed discussion of usability occurred during the second interview.

Research Question 2, What PHR features do heart failure patients find useful? Usability and usefulness, while related, address different aspects of computer usage. Various PHR activities may be usable but not useful to heart failure patients, and vice versa. Three measures were used. First, a computer-generated report of the dates, times, and MyHealth activities accessed by each participant was obtained. Second, in the final interview, questions about PHR usage found in the literature were asked. Third, in the final interview, the topic was discussed more fully with the participants.

Research Question 3: Can a PHR be useful in the disease management of heart failure patients? Semi-structured questions were asked in the final interview to elicit participants' disease management practices and techniques, and how they did or did not incorporate the PHR. The heart failure nurse was also interviewed for her perspective on its usefulness.
**Instrumentation**

Instruments included methods for collecting descriptive statistics, usability data, comparisons of national data, and questions to elicit a deeper understanding of the participants’ PHR use. Descriptive statistics included age, gender, rural status, health literacy, and computer expertise, all of which may all play a role in PHR adoption.

To determine which participants live in rural areas, US Census Bureau data were used. Participants were designated as urban, mixed, or rural based on the major town in their ZIP code. To validate the data, participants were asked if they lived in an urban, suburban, small town, village, or rural area. Those answering suburban or small town were classified as living in a mixed area, and those answering village or rural were classified as rural. ZIP codes of patients with a heart failure diagnosis seen in the Cardiology clinic between April 2010 and March 2011 were also obtained and classified (see Appendix G for details).

Health literacy was measured using the public-domain Single Item Literacy Screener which was developed to be a quick health literacy screening tool. It asks respondents *How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?* with five possible responses. Those answering always, often, and sometimes are identified as having inadequate health literacy. The screen tool was validated against the Short Test of Functional Health Literacy in Adults. Overall, it has a moderate ability to identify patients who need help reading health related information. It has been criticized for not taking into account visual problems, dyslexia, aging, gender, language, cultural, contextual, or setting factors. (Morris, et al., 2006).
A reliable, validated, quick one-question measure of computer literacy has not been developed. The definition of computer literacy is evolving as information technology evolves. Definitions have incorporated understanding basic terminology, programming ability, operating system concepts, and application use. It has become apparent that computer literacy must be evaluated relative to the context in which it will be applied (Easton & Easton, 2004). Self-assessment is used extensively to assess computer knowledge and skills, and while it is useful for attitudinal data, its accuracy in providing information on knowledge and competence is less reliable, especially among novice users who tend to over-rate their computer expertise (Ballantine, McCourt Larres, & Oyelere, 2007). While there are validated computer literacy instruments available, their length and content made them unsuitable.

Yet Rubin and Chisnell (2008) stress the need for an operational definition of computer expertise when conducting usability studies. Time and frequency of computer use have not proven sufficient in their usability studies. They present the example of a subject who spent 60 hours per week playing a game accessed by a desktop shortcut. Their revised measure includes the frequency of use of four specific web-based applications: researching health information, taking part in online auctions, playing web-based games, and paying bills online. The problem is that someone could be an expert Internet user and not access these specific types of websites.

A modification of the Rubin and Chissnell (2008) measure was developed that asked the participants to identify their overall computer use frequency and confidence and then asked them to do the same for the four applications they use most often. Thresholds for expert users for both the subjective overall scores and the combined
individual scores were developed. During the usability study, the investigator assigned an additional subjective computer expertise rating based on the participants’ facility with the mouse, accessing links, and general ease with webpage navigation (see Appendix H for details).

The usability test included eight tasks: health summary, results, daily journal, messaging, questionnaires, appointments, heart failure prevention education resources, and prescription refills (see Appendix F). Participants were asked to complete a set of tasks in a sample chart. Andrew MyHealth, the study patient, was developed in conjunction with the heart failure nurse. Andrew was designed to have a health profile similar to those of the participants (see Appendix I). He had robust problem and medication lists. His results included an echocardiogram stress test, and blood urea nitrogen (BUN) and potassium labs. Participants completed the usability tasks in Andrew MyHealth’s MyHealth account on a development website, to keep the test patient out of Fletcher Allen’s actual EHR.

Participants began with the health summary topic after which they completed as many of the remaining tasks as they could in their allotted 25 minutes on a rotating basis. Participant 1 started with results, participant 2 with the daily journal, and so on. No one completed all eight tasks.

After completing each task, participants completed the three items in the standard usability After-Scenario Questionnaire and other questions specific to MyHealth in the same format (see Appendix F). The After-Scenario Questionnaire items address three components of user satisfaction: ease of task completion, completion time, and the adequacy of support information. The items were assessed using a seven-point Likert
scale ranging from 1 (agree) to 7 (disagree). The After-Scenario Questionnaire is a reliable, valid, and sensitive usability instrument (Lewis, 1993). For reporting and analysis, After-Scenario Questionnaire items can be combined into an After-Scenario Questionnaire mean, with a range of 1, most satisfied, to 7, least satisfied. No one accessed the help or FAQ features of MyHealth, and thus the adequacy of support question, Overall, I am satisfied with the support information (online-line help, messages, documentation) when completing the tasks was not relevant, and the After-Scenario Questionnaire score used is the mean of the two questions: Overall, I was satisfied with the ease of completing this task, and Overall, I was satisfied with the amount of time it took to complete this task.

Following completion of all their usability tasks, and again in the final interview, participants completed the ten item System Usability Scale survey. The System Usability Scale, developed for Digital Equipment Corporation in 1986, provides a short satisfaction assessment. Item scores are combined to provide an overall score ranging from 0, least, to 100, most satisfied (Brooke, 1996). Bangor, Kortum, and Miller (2008) suggest using a "university grade analog" for interpretation giving a score of 90-100 an A, 80-89 and B, and so on. To establish baseline scores, they evaluated 206 usability studies with 2,324 respondents obtaining an overall mean score of 70.14, with a mean of 68.05 for the web-based applications.

During the final interview, questions matching two published studies (California HealthCare Foundation, 2010; Hassol, et al., 2004) were asked to allow a comparison of the rural heart failure participants with more general PHR users. Hassol, et al. asked respondents about the understandability of medical information and test results,
completeness of their health information, accuracy of their medical history, and their data confidentiality concerns. The California HealthCare Foundation (2010) asked respondents to rank the usefulness of PHR features.

Finally, semi-structured interview questions were developed that asked participants to elaborate on answers given to the various surveys and questionnaires. Additional themes were discussed including participants’ disease management strategies, wellness levels, issues they encountered using the PHR, additions they felt would make the PHR a better tool, and their future plans with the PHR.

Data Collection and Analysis

Interviews were conducted between December 2011 and July 2012 in a quiet, private space, usually a small conference room at Fletcher Allen. Two were conducted in participants’ homes. All interviews were taped and transcribed.

The usability test accessed the MyHealth website via Internet Explorer 8. Testing was done on a Dell Inspiron laptop with a 14 inch (35.6 cm) display with a resolution of 1366 x 768, and an external keyboard and mouse. To maximize the viewing area, all toolbars that could be closed were, and the taskbar at the bottom of the screen was hidden. Many participants found the text on the website too small to read easily when it was displayed at 100% resolution. When this was the case, the browser was "zoomed" to 125%. Participants’ key clicks, typing, and comments were recorded using Captivate, a screen recording application.

Quantitative data from the usability study and descriptive questions were recorded and analyzed, and a list of usability recommendations developed (see Appendix F).
Qualitative data from the interviews was coded, categorized, and analyzed, and emerging themes expanded upon in subsequent interviews.

**Summary**

Electronic PHRs are a relatively new technology. Their uses and benefits, abuses and pitfalls have not yet fully emerged. Heart failure is a common, debilitating, expensive disease. An exploratory-descriptive study was designed to help assess the usability and usefulness of a tethered PHR and the role it might play in the disease management of heart failure patients. Standard PHR functions and specific features developed in consultation with a heart failure nurse were made available to the participants. Data were collected through interviews and a usability study. Usability recommendations and emergent themes were identified and explored.
Chapter 4

Results

PHRs are a component of EHRs that provide a patient-centered medical record. PHR functionality falls into two broad areas: access to personal medical information such as health problems, medical history, allergies, medications, and test results; and electronic tools for secure provider-patient communication, prescription refills, and appointment management. An exploratory study was designed to examine ways a PHR might be useful in the disease management of chronic illnesses such as heart failure, and in patients in rural areas.

MyHealth is a tethered PHR that provides patient access to portions of Fletcher Allen Health Care's EHR. Heart failure patients living in northern Vermont and New York used MyHealth for three months and shared their views on its usability, usefulness, and disease management value. Results are presented as follows: first, participant demographics and descriptive statistics are examined; second, participants' responses are compared to national data; and third usability, usefulness, and disease management uses of the PHR are discussed.
Demographics and Descriptive Statistics

Fifteen patients with a clinical diagnosis of heart failure who were being seen at Fletcher Allen Health Care’s Cardiology clinic were enrolled between December 2011 and April 2012. Potential participants were selected by the clinic's heart failure nurse based on her subjective evaluation of their computer skills and there being a clinical benefit to her monitoring their daily heart failure data. Nine participants (60%) were male and six (40%) female. They ranged in age from 51 – 74, with a mean age of 63.8. Two dropped out during the study. Their results are included in the usability study, but not in the analysis of how useful MyHealth was, nor its effect on disease management. All but one participant had adequate health literacy based on the Single Item Literacy Screener. Five participants had been using MyHealth for between 2 and 10 months before the study; the others were enrolled during their first interview. Of the 13 completing the final interview, five were newly diagnosed heart failure patients, while eight had been living with heart failure from 1 to 20 years.

The rural-urban mix of heart failure patients seen in the Cardiology clinic between April 2010 and March 2011 was 37% rural, 41% mixed, and 22% urban. Participants were more urban (27% rural, 33% mixed, and 40% urban) based on ZIP code densities. Self-reported data (33% rural, 40% mixed, and 27% urban), while less urban that the ZIP code density designation, were still more urban than patients from the clinic in general. The higher number of urban participants may reflect the fact that Fletcher Allen is located in Burlington, an urban area, and patients living nearer to Fletcher Allen may have been more willing to participate in the study. (See Appendix G).
Computer expertise varied by definition. Thirteen participants (87%) were experts based on their overall frequency of use and confidence. This scale corresponded more closely to the subjective rating of the interviewer (60% expert) than did either overall confidence alone or the more detailed score based on frequency and confidence in various computer activities. The investigator reassigned four participants whose use and confidence scores classified them as expert, to intermediate based on their difficulty manipulating the mouse or scrolling, double-clicking when only a single click was needed, and overall tentativeness (See Appendix H). All participants had the computer skills needed to navigate the MyHealth website independently.

Participants used different types of computers for their day-to-day use. Several used more than one type of computer. Five participants used desktop computers, nine used laptops, and two used iPads. Among the laptop users, four had a 14 in. (35.6 cm) screen, three a larger screen, and the screen size for two is unknown. Larger screen sizes reduce the amount of scrolling needed in MyHealth, and the portability of the iPads made them useful for recording daily journal numbers as they were collected.

Comparison with other PHR Data

Geisinger Health Systems, an integrated provider network in north central Pennsylvania, conducted an online survey of patients using their tethered PHR to evaluate their experiences and attitudes (Hassol, et al., 2004). Their 1,352 respondents were younger, more likely to be female, and had used the PHR for a longer period of time than the study participants. Their health problems were not reported. Participants using MyHealth responded more positively to the same questions about completeness and accuracy and had fewer confidentiality concerns than the Geisinger group (p<0.05). The
groups were similar in their ratings of the understandability of the medical information
and test results in their respective PHRs, as shown in Figure 1.

**Figure 1. Geisinger and MyHealth PHR Attitudes.**
Geisinger Means and MyHealth Confidence Intervals

A national survey of PHR users asked respondents to rank the usefulness of PHR
features (California HealthCare Foundation, 2010). The study participants found
scheduling appointments less useful, and managing their health information in one place
more useful than the national respondents (See Table 1). A lack of reported standard
deviation in the national data precludes deeper analysis.
Table 1. Usefulness of PHR Features - National Data and Participants

Percent ranking the Feature Very or Somewhat Useful

<table>
<thead>
<tr>
<th>PHR Features</th>
<th>National Respondents (N=266)</th>
<th>Participants (N=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making sure information is correct</td>
<td>64%</td>
<td>55%</td>
</tr>
<tr>
<td>Looking at Results</td>
<td>57%</td>
<td>54%</td>
</tr>
<tr>
<td>Renewing Prescriptions</td>
<td>52%</td>
<td>45%</td>
</tr>
<tr>
<td>Sending/Receiving Messages from Physician</td>
<td>50%</td>
<td>62%</td>
</tr>
<tr>
<td>Scheduling Appointments</td>
<td>48%</td>
<td>15%</td>
</tr>
<tr>
<td>Managing Health Information in one place</td>
<td>44%</td>
<td>78%</td>
</tr>
<tr>
<td>Sending/Receiving Messages from the Heart Failure Nurse</td>
<td></td>
<td>77%</td>
</tr>
<tr>
<td>Receiving email notice of MyHealth message</td>
<td></td>
<td>67%</td>
</tr>
<tr>
<td>Completing the Heart Failure Daily Journal</td>
<td></td>
<td>50%</td>
</tr>
<tr>
<td>Using Heart Failure Resources</td>
<td></td>
<td>31%</td>
</tr>
<tr>
<td>Paying Bills</td>
<td></td>
<td>15%</td>
</tr>
</tbody>
</table>

**Usability**

The MyHealth website was created and is maintained through a collaborative process between the software vendor and several Fletcher Allen groups: a steering committee, PRISM programmers, marketing, and the web development team. Each group is responsible for different aspects of the site. The underlying software from the vendor provides the backbone functionality for the site. For example, it can flag abnormal values in the patient-entered daily journal numbers, but only if the data are numeric. Thus, to flag both systolic and diastolic blood pressure values as abnormal, patients entered their data in two separate systolic and diastolic fields, rather than as the more familiar two numbers separated by a slash format (140/68). Other types of data cannot be flagged. Nor can the program flag a new score based on its deviation from previously entered scores. For example, it cannot flag a swelling entry of *moderate* that followed a consistent series of *scant* entries. Decisions about what to include in MyHealth were made by the steering committee that was composed of Fletcher Allen physicians, lawyers, business managers,
and senior leaders. This style of decision-making is common. In a study of 17 organizations with PHRs, 88% used a committee structure for decision making, and only 35% included patient representation on their committee (Collins, Vawdrey, Kukafka, & Kuperman, 2011). The PRISM programmers implemented the decisions. Marketing was responsible for the overall site look and feel, which was designed to match other Fletcher Allen sites. They designed the header and specified the wording of nonclinical text in the webpages. The web development team was responsible for implementing marketing’s design. Any changes to MyHealth involve collaboration between these groups as well.

Usability of MyHealth was measured through eight usability tasks that participants completed during their initial interview, System Usability Scale scores from the initial and final interviews, and comments made during the final interview. In general, participants found MyHealth easy to use. During the usability tasks they understood the information in the study patient’s chart and often related it to their own health issues. For example, when looking at medications, one participant commented "Lasix – I took Lasix initially."

Participants were very forgiving. Even when they spent a great deal of time on a task, had to retrace their steps, and ultimately may even have needed help to complete it, they still said they were satisfied with MyHealth. Investigators at Duke University Health System reported similar findings for their usability evaluation (Segall, Saville, L'Engle, Carlson, Wright, Schulman, & Tcheng, 2011). The disparity between needing help and high satisfaction underscores the need for applying various data collection methods during usability testing.
Table 2 displays a summary of efficiency and effectiveness usability measures for the eight tasks. A complete discussion of each task is presented in Appendix F.

Participants were satisfied with the time and ease of completing the tasks, with no mean score higher than 2.3 on a scale of 1 (satisfied) to 7 (not satisfied).

**Table 2. Usability Task Efficiency and Effectiveness Statistics**

<table>
<thead>
<tr>
<th>Task</th>
<th>N</th>
<th>Mean Minutes to Complete Task (SD)</th>
<th>Mean Time Satisfaction (SD)</th>
<th>Unassisted Completion Rate</th>
<th>Mean Ease Satisfaction (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appointments</td>
<td>5</td>
<td>2.2 (SD 0.4)</td>
<td>1.0 (SD 0.0)</td>
<td>40% (2)</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>Heart Failure Daily Journal</td>
<td>9</td>
<td>4.5 (SD 5.2)</td>
<td>1.6 (SD 0.8)</td>
<td>22% (2)</td>
<td>1.7 (SD 1.1)</td>
</tr>
<tr>
<td>Heart Failure Prevention Resources</td>
<td>6</td>
<td>3.0 (SD 1.4)</td>
<td>2.2 (SD 2.2)</td>
<td>33% (2)</td>
<td>2.0 (SD 1.8)</td>
</tr>
<tr>
<td>Medical Information</td>
<td>15</td>
<td>3.6 (SD 2.1)</td>
<td>1.2 (SD 0.5)</td>
<td>87% (13)</td>
<td>1.1 (SD 0.3)</td>
</tr>
<tr>
<td>Messaging</td>
<td>6</td>
<td>4.7 (SD 2.2)</td>
<td>2.0 (SD 1.8)</td>
<td>33% (2)</td>
<td>2.3 (SD 1.7)</td>
</tr>
<tr>
<td>Prescription Refills</td>
<td>7</td>
<td>1.8 (SD 3.7)</td>
<td>1.1 (SD 0.3)</td>
<td>86% (6)</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>Questionnaire</td>
<td>6</td>
<td>6.3 (SD 3.4)</td>
<td>1.2 (SD 0.4)</td>
<td>17% (1)</td>
<td>1.5 (SD 0.8)</td>
</tr>
<tr>
<td>Results</td>
<td>6</td>
<td>3.0 (SD 2.2)</td>
<td>1.0 (SD 0.0)</td>
<td>83% (5)</td>
<td>1.2 (SD 0.4)</td>
</tr>
</tbody>
</table>

* Based on answer to the question: *Overall, I was satisfied with the amount of time it took to complete this task* (1=agree, 7=disagree).
** Includes those who completed with no problem, or who self-corrected errors.
*** Based on answer to the question: *Overall, I was satisfied with the ease of completing this task* (1=agree, 7=disagree).

The time to complete each task was not useful in and of itself, as some tasks inherently took longer. The standard deviation provides a measure of dispersion in the results. For example, the heart failure daily journal had a mean completion time of 4.5
minutes, but a large range of times (4 to 14 minutes) as indicated by the standard
development of 5.2. The mean time satisfaction score provides a measure of the participants’
views of how long the task took. The lowest time satisfaction (2.2) was for the heart
failure prevention resources. These resources were difficult to find both because of their
label, HF Prevention Resources (participants did not recognize the initials HF as meaning
heart failure), and their location in the medical record portion of MyHealth rather than
with the educational materials. On the other end of the spectrum, all participants gave the
appointments and results task the highest time satisfaction rating.

The percent that completed each task independently provides a measure of the
effectiveness of the activity for new users. Participants were most independent with
accessing medical information, renewing prescriptions, and results. Participants had more
difficulty finding the activity or correctly completing the other tasks. When requesting an
appointment, three of the five participants sent the appointment request to the wrong
provider. Their high satisfaction ranking is likely due to the fact that they were unaware
of their error. When completing the questionnaire, participants had difficulty in several
areas: finding the questionnaire, opening it, and completing it. When sending a message,
participants found the name of the activity and the message choices inadequate, sent the
message to the wrong provider, and were unclear what would happen next.

Most usability problems arose due to issues of screen layout, lack of clear and
consistent site conventions, and instruction clarity. These themes are discussed here.
Specific recommendations for each task are provided in Appendix F.
Screen Layout

Usability testing was conducted on a laptop with a 14 in. (35.6 cm) display and a screen resolution of 1366 x 768 pixels. During testing many participants found the text too small to read easily and the browser was zoomed to 125% for them. However, the problem seemed to be limited to the testing environment. When asked during the final interview, no one reported difficulty reading the text from their home monitors.

On the test computer, 24% of the available vertical space was used by the header. The icons for Tweet and Facebook alone used 6% of the total available space. This portion of the screen was lost for content display. On the home page, only 70% of the vertical content is viewable without scrolling (see Figure 2). From the home page users could navigate to the Medical Information or Billing and Insurance sections via icon links, tabs, or buttons. None of the participants used the buttons which were located at the bottom of the page; none scrolled down and saw them.

The column on the left of the home page used important screen real-estate. The first link was to the current page, and served no purpose. The final link, log off, was available in the header, and thus, was redundant. The middle three links were to account settings that would rarely be accessed and could be moved to a tab in the header. The Health Library search function was the most useful section of the column, but was displayed too far down to be seen without scrolling. In his final interview, one participant described his confusion this way:

The two main things are Health and Billing. That’s all well and good, but there’s other stuff on the left side that’s also equally accessible, or maybe equally if not more important, but it doesn’t appear to be one of your main options.
Removing the necessity of scrolling would enhance the Home Page. Reducing white space between bullets, and reducing the height of the header by shrinking the Fletcher Allen logo, moving links to social media to the bottom of the screen, and moving the MyHealth Online title to the left beside the page tables are possibilities. Moving the settings links in the left column to a tab would free up real estate for useful content as well as making these activities available from any webpage.

**Site Conventions**

Following standard webpage conventions and applying consistent navigational prompts increases user satisfaction (Krug, 2006). Participants stumbled in situations
where MyHealth did not follow standard conventions or was inconsistent. Three examples include the design of buttons, link and label design, and using clear labeling.

Usability guidelines recommend that "when pushbuttons are used, ensure that they look like pushbuttons" (U.S. Department of Health and Human Services, 2006b, p. 144). Giving buttons a raised or 3-D appearance that looks like they can be clicked will make their intent clearer to the user. The buttons in MyHealth were green rectangles with white text (see Figure 2). They looked like labels rather than buttons. While participants were able to ascertain that they were buttons, it was not clear and intuitive.

What was and was not a link in MyHealth was also unclear (see Figure 3). Some links followed standard conventions and were blue and underlined. However, MyHealth section labels were also blue, and some were links while others were not. On the Home page, they were not links. In addition, some links were not displayed in underlined, blue text. On the Home page, bullets in bold black text on the left were bullets, while bullets in plain black text under the Medical Information and Billing & Insurance titles were not. Many participants tried to click these non-linking bullets. Finally, some unfamiliar icons were unlabeled links. The lack of consistency made it difficult for the participants new to MyHealth to easily navigate the site.

**Figure 3. Inconsistent Links on MyHealth Home Page**
Consistent, standard labels that are familiar to users aid in navigation and user satisfaction (Krug, 2006). There are many instances in MyHealth where the terms caused issues ranging from momentary confusion to the inability to complete the desired action. For example, participants had difficulty finding their daily journal which was labeled *Health Tracker*, clicking a button labeled *Back to the Home Page* brought users back to the main Medical Information page, not the Home Page; and when editing questionnaire responses, the button to return to the review page was labeled *Jump to Preview*, which surprised several participants. One participant described his experience this way:

Some of the terminology that you’ve set up I think is not consistent with other websites, like contact us, support, things like that. I’ll give you an example. Two years ago when we were in Florida we were looking to buy a car and so I went online to various dealers that I noticed around. And they had a very, very similar look and feel to them. You could look up what was available, used, new, contact us, da da da, whatever you wanted to find. They all had the same types of things. And they were all pretty much intuitive to look at. I don’t find a lot of the language that’s used in MyHealth intuitive to the consumer. It might be to the clinicians… but the language isn’t consistent. … Anyways, look and feel and maybe terminology that would be more consistent with what you find on other web sites… might help.

*Instruction Clarity*

There are complex rules governing what clinical information is displayed to patients in MyHealth. The software vendor provides functionality that allows institutions to make decisions from global to very granular levels. For example, at the global level, Fletcher Allen chose not to display any provider notes in MyHealth. Patients wishing to see their doctor’s notes have to follow the hospital’s release of information process through the Health Information Management department.

Displaying lab results required a much more granular approach to meet the institution’s objectives. The Fletcher Allen laboratory analyses samples from across Vermont and northern New York. Both Fletcher Allen and non-Fletcher Allen providers
use the lab. They can either draw samples in the clinic and ship them to the lab, or have
the patients go to the lab for the specimen collection. When the lab completes a test, the
results are communicated to the provider. Providers working in Fletcher Allen clinics or
hospitals receive the results of tests they order in PRISM through their In Basket, an
e-mail-like function. As well as calling the patient or sending a letter, if the patient has a
MyHealth account, the providers can choose to a) release the results to MyHealth, with or
without comments; b) withhold the results from MyHealth; or c) do nothing which causes
the results to be released to MyHealth according to the standard release time frame that
was defined by the MyHealth steering committee. Non-Fletcher Allen providers may not
have access to PRISM’s In Basket. Results of tests they ordered are faxed to them. They
communicate with the patient and file the result in the patient’s chart according to their
office procedures.

Patients whose labs have been processed at the Fletcher Allen lab have PRISM
records that receive the results, and are eligible for MyHealth accounts. The lab results
are available in PRISM regardless of who ordered the test. However, non-Fletcher Allen
providers do not have the opportunity to release, withhold release, or comment on the
results because they do not have access to PRISM’s In Basket functionality. Therefore,
the steering committee decided MyHealth would only display results of labs ordered by a
Fletcher Allen provider. Similarly, until a patient has a MyHealth account, the provider
will not have chosen to release, withhold, or comment on a result. Therefore, it was
decided that labs resulted before a patient's MyHealth account was activated would also

---

2 Whether or not they do is based on Fletcher Allen policies governing access to PRISM and the office
practices of the providers. Many providers in the Burlington, VT area have their own clinics, but are on the
Fletcher Allen medical staff. They have full access to PRISM. Others can be granted read-only access to
the system, and do not have access to the InBasket.
not be displayed, although Fletcher Allen ordering providers could manually release them one patient at a time if they chose to do so. The software allows for this level of granularity in MyHealth, and it was implemented by the PRISM programmers. This level of analysis, decision-making, and implementation was followed in all areas of MyHealth.

The challenge for marketing was to present users with succinct, clear information about MyHealth. In the case of test results, the decision is explained on the Test Results screen:

Note: MyHealth Online only displays test results from providers who use Fletcher Allen's electronic medical record. If you are unsure if your doctor uses Fletcher Allen's electronic medical record, please contact your doctor.

However, most local providers have access to PRISM, and use it to look up results and read specialist notes. The definition "providers who use Fletcher Allen’s medical record" did not adequately discriminate between providers whose results would or would not be displayed.

Similar levels of granularity are found in the timing of result release, with whom the patient can communicate and schedule appointments, and which medication renewal requests can be made. In many of the cases, marketing's message, either on the page or in the FAQs, was not specific enough for participants trying to understand the rules behind the site and how they applied to their data.

Compounding the confusion, during the usability test, participants rarely read the instructions and none went to the help link. When they did read the instructions they skimmed them rapidly, and even when they read the answer to their questions aloud, they did not apply it. Participants not only missed instructions, they also missed the comments the provider added to help them interpret their lab results – a key feature of MyHealth test results release (see Figure 4).
One participant found and followed the result’s About this Test link, but still did not notice the doctor’s office comments:

I’ll tell you what, I read almost everything on that page, and I’ll tell you and I’ll be honest with you, I don’t think I did [see the comment]. I just think I skipped over it. And it’s in red compared to the black. And that’s really what you want. You read all that technical stuff. But you really want to know is "What did the doctor think?"

During a presentation of preliminary findings from the usability testing, PRISM staff expressed their frustration at users not reading the information provided. Krug (2006) describes the phenomenon aptly:

When we’re creating sites, we act as though people are going to pore over each page, reading our finely crafted text, figuring out how we’ve organized things, and weighing their options before deciding which link to click.

What they actually do most of the time (if we’re lucky) is glance at each new page, scan some of the text, and click on the first link that catches their interest or vaguely resembles the thing they’re looking for. There are usually large parts of the page that they don’t even look at. (p. 21)
He goes on to explain that people scan because they are usually in a hurry, they know they do not need to read everything, and they are good at it – they have been scanning newspapers, magazines, and books all their lives. He recommends that webpages create a clear visual hierarchy through text size and placement, and that text be reduced to a bare minimum (he graphically names his point "omit needless words"). Applying these recommendations to MyHealth might make salient instructions more available to users.

Another MyHealth area needing clarity was what would happen next. Three examples are provided. First, when a questionnaire was submitted, the system replied "Thank you. Your questionnaire has been submitted." There was no text indicating that the submitted questionnaire would be stored in the patient’s PRISM record. One participant stated "I assume that if it has been submitted that it’s been returned to the center." Second, when sending a message to the clinic, the send button was not visible without scrolling. Several participants typed their message and because they did not see the send button assumed it had been sent. They moved to the next task, and the message was lost. A pop-up asking if they wanted to send or cancel the message as they left the page without sending it would have prevented the error. Finally, when requesting an appointment, three of the five participants completing the task did not specify the correct clinic – they requested the appointment with the default provider instead. When they sent their request the system replied "Thank you, your message has been sent." Adding to whom the message was sent may have helped the users identify their error. Instructions for what would happen next, "A member of your doctor's staff will get back to you within one business day," were provided on the opening appointment screen (see Figure 5) but not the final screen, leaving participants unclear what would happen next. One participant
stated "There was no email notification or anything else". Another explained, "It’s like email, you assume they’ll get it." Shortening and adding the instructions to the final screen and presenting them as they are needed, might help alleviate the what-will-happen-next confusion.

**Figure 5. MyHealth Request an Appointment Initial Screen Text**

![Request an Appointment](image)

© 2012 Epic Systems Corporation. Used with permission.

*Learning to Use the Site*

During the final interview participants were asked if they had difficulty using the site. None reported any difficulty. MyHealth has a help line whose phone number is displayed in the screen header. One participant called for help logging in. The problem was his password, which was reset quickly and efficiently.

When asked how they learned to use the site, participants described "exploring" the site and "trying things out." One participant, an intermediate computer user, had initial help from her daughter:

Subject: My daughter was there once but from there I figured it out.

*Interviewer: How did you figure it out?*
Subject: Just going back into it. Actually looking on the screen to see what was there, and connecting the dots.

Several participants described the usability test as their training. In describing his learning experience one participant explained:

That’s when I was here with you. Remember how I was going around trying to figure out how to get to where? Finally I had to ask you. That was it. Other than that, I was fine.

Another described it this way:

*Interviewer: How did you learn to use it? What kind of support was there?*

Subject: Well, you taught me how to use it.

*Interviewer: Well, I sat in the background.*

Subject: Yes, and just playing with it. Cause I probably went on the next day and played with it some more… you know, "Do I remember stuff I did yesterday?" Like the first day I said "Oh my god, I can’t remember how to get on, I can’t remember how to get into the daily journal," and then I pressed on one of the buttons and got the drop down. "OK there it is." So the first day I really squirreled around a little bit trying to remember it.

Some participants reported MyHealth behaved in unexpected ways, and in doing so provided an explanation for the results they encountered. While their explanations were not always accurate, they did provide a framework within which the participant could continue to view MyHealth a reliable tool. For example, when setting up the daily journal for a patient, the heart failure nurse specifies a range of normal weight, blood pressure, and pulse values for the patient. If the patient’s numbers are outside of this range, the data are considered abnormal. The patient is alerted, and the results sent to PRISM are flagged. One participant’s weight exceeded the maximum normal value. Not knowing how the abnormal value was defined, he speculated that a three pound variance from his initial reading caused the abnormal reading. This was consistent with his MyHealth experience, although not actually how the determination is made. Another
participant did not learn how to initiate a message to his provider. He did not believe it was possible. But he did know that he could reply to a message he received. He made sure he did not delete the last message from any provider so he would have a means of continuing his communication. These two examples typify participants making meaning of the results they encountered. Further exploration of user’s meaning-making is an interesting question, but is beyond the scope of the study.

Summary

Overall, participants were satisfied with MyHealth’s usability. For the eight usability tasks completed, on a scale of 1(high) to 7 (low), mean satisfaction scores ranged from 1 (Prescription Refills) to 2.4 (Heart Failure Prevention Resources) (See Figure 6). Further details on each task are provided in Appendix F.

Figure 6. Mean Satisfaction Scores for MyHealth Usability Tasks

* Likert Scale Ranges from 1 (High) to 7 (Low)
After completing all their tasks, participants completed the 10-item System Usability Scale. They completed the scale again in their final interview, after using MyHealth for at least three months. The survey produces a combined score ranging from 0 (least satisfied) to 100 (most satisfied). A rule-of-thumb interpretation analogy is the common grading system, 90-100 is an A, 80-89 a B, and so forth (Bangor, et al., 2008).

Mean scores for the System Usability Scale were 78.3 in the initial interview and 80.4 in the second. These compare favorably to Bangor et al.'s mean of 68.05 for 1,180 participants rating various web-based applications. Individual System Usability Scale scores ranged from 50 to 100 in the initial interview and 40 to 95 in the second. There was no significant difference between the initial and final scores (p=0.88). In seven cases participants scored MyHealth more positively in the final interview, in five they scored it more negatively, and one participant’s score was unchanged (see Appendix J).

General areas for MyHealth usability improvement include screen layout, site consistency, and instruction clarity. Implementation of the improvements will involve the software vendor, and the various Fletcher Allen teams responsible for MyHealth. Specific recommendations are found in Appendix F. In final interviews participants reported being able to use PRISM to complete tasks relevant to them, although some had developed inaccurate explanations of why the system worked the way it did. MyHealth was usable for the participants. Technology acceptance models predict that acceptance is based on usefulness as well as ease of use, the topic addressed next.

**Usefulness**

Both interview and MyHealth usage data (see Appendix K) show that feature usefulness varied by participant. What one participant may have found extremely useful,
others found irrelevant. Two big drivers were whether the participant’s primary care provider (PCP) was using MyHealth, and existing routines which participants were using successfully. When participants did modify their practices and use MyHealth, they did so for reasons of convenience, increased access to information, and improved communication with their clinics. Following a discussion of the PCP issue, the usefulness of various MyHealth features will be addressed. The heart failure daily journal feature will be addressed in the discussion of disease management.

Fletcher Allen and non-Fletcher Allen PCPs

A PCP is a provider who oversees the general health of patients, following and monitoring their health problems, and coordinating care between any specialists associated with their care. Patients’ health issues, allergies, immunizations, medications, and routine tests and procedures are managed by the PCP. PCPs working in Fletcher Allen clinics use PRISM to document their patient care, and those data are found in MyHealth. For participants with a Fletcher Allen PCP, MyHealth should have contained complete and up-to-date information. The same was not true for those with non-Fletcher Allen PCPs. Their information was not documented in PRISM. Participants were patients of the Fletcher Allen Cardiology clinic that used PRISM. That data flowed to MyHealth. However, health issues, allergies, medication changes, and immunizations that were diagnosed or implemented by a non-Fletcher Allen provider had to be added to PRISM manually when the patient reported them during a Fletcher Allen clinic visit. Until the patient reported them, PRISM, and consequently MyHealth were not up-to-date. While the lack of a unified EHR has broader implications for health care in general, for participants, the fact that MyHealth was a tethered PHR, linked to PRISM meant that
those whose care was not fully provided by Fletcher Allen clinics may have had incomplete information in MyHealth which could limit its usefulness. Six of the participants did not have a Fletcher Allen PCP.

Despite the PCP limitation, most participants reported that their medical problems, immunizations, and allergies were accurate. Medications tended to be accurate as well, although medications with frequent dosage changes such as warfarin (Coumadin) were less so. From the participants’ reports it appeared that the Cardiology department was doing a good job of keeping their patients’ records up-to-date, even when the information was verbally reported by the patient and hand-entered into PRISM during an appointment.

Results were more of an issue. Labs and tests ordered by non-Fletcher Allen providers and those resulted before the patient activated their MyHealth account were not displayed in MyHealth. These two factors caused confusion and reduced the usefulness of participants’ results in MyHealth.

As well as restricting the display of results, MyHealth also limited communication, medication refills, and appointment scheduling, and notification to Fletcher Allen providers the patient had seen in the past year. These restrictions were less of an issue. Most participants understood that MyHealth was a Fletcher Allen website and hence you could only communicate with Fletcher Allen providers, although they felt that expanded capabilities would enhance the system. The difference with results stems from the fact that the Fletcher Allen laboratory performed the test and the results are in PRISM, just not in MyHealth. Usefulness of specific MyHealth features is described next.
Results

When they were available, participants used MyHealth to access their results in different ways. Some liked the immediacy of being able to see their results in MyHealth. One participant, a nurse by occupation, described using the results to prepare for upcoming appointments:

Every six months I have certain blood work done and I like to see it before I get to the doctor’s office. I’m always looking and comparing [back to previous results].

Her views contrasted sharply with another participant who didn’t feel competent to interpret his results:

I always do blood tests just before I go see my doctor, so I get the results from the doctor. They wouldn’t mean anything to me anyway.

Another participant preferred to wait and hear the results from the provider in case they were abnormal:

There’s the whole bit about interpreting what the results are… that might be a little tricky. Because an average person might not be able to look at certain numbers or even descriptions without going "oh no, oh no," [if the results were abnormal] and then just stress for ten days until their appointment.

He felt more comfortable receiving a personal interpretation by his provider:

I don’t like things that are too automatic without it having been looked at by actual eyes. It feels better to me that somebody’s actually scanned the set of numbers and goes "That looks about right." That’s all it takes.

The ability to refer back after discussing the results with the provider was useful:

It’s good to be able to go back and refer to [the results] and see the flow of things. When you have a doctor’s appointment you only get one isolated element, but if you go back and look at your history, then you can see what’s going on… [It’s] very useful, or reassuring. Because now you can see. He talks to you about it, but now you can come back and look.

One participant began by getting his results during a visit, and as he learned how to interpret them he began to look in MyHealth before the visit:
[Before, my doctor] would show me the results "This was a little high, this is looking pretty good" and then when I did go in [to MyHealth] to see it I could understand it better. [Now] I like seeing them, now that I understand what everything means and what to look for. I’m sure if something was really drastically wrong they would call me right off. But at least I can go in there and see [today’s] results.

This did not mean he no longer needed the provider’s opinion; he still wanted the personal interpretation from the provider, "I want to know what he thinks, his input on what’s going on." This was true for everyone, they expected their doctor to monitor and interpret their results, "It’s more important for me to know that someone else has looked at my test results."

Another participant liked seeing the actual values of his lab results, rather than just learning that his results were normal.

It was very useful to be able to see [the results]. It kind of tells me where I am in the grander scheme of things rather than just going "yes, you were good." For example I do my blood sugar twice a day and I can tell where I am. I’m supposed to be between 70 and 110 – to me that tells me that they want me to be at about 90. So if I gave you the option of doing my test and you said "oh, you’re good, you’re good," your version of good might be 109 –"you’re good, it’s within [the range]," or it might be 71 – "oh, you’re good." That doesn’t tell me [what I want to know]. By being able to see my results, I know where I am – "oh, gee, I’m good because I’m on the average, I’m right in the middle." So that helps me. Or if I’m right on the top end, then I have to think back; have I been taking my medication exactly right; have I been taking it with food when I’m really not supposed to be? If I’m on the high end of the scale then I can change up either the way I take my medication or what I’m eating to help me.

Participants' ability to understand the results played an important part in how they were accessed. The nurse was comfortable looking at her results, others learned what their values should be and then felt comfortable looking at them, and using them to monitor trends or change their daily habits.

There are three levels of interpretation available in MyHealth: 1) the actual lab values from the laboratory; 2) links to Healthwise patient information on the tests and
their values; and finally 3) the provider can add a comment to the results, although this is not required and they were not easily seen during the usability study. One participant spoke of the contrast between the actual values, which he felt were too hard to understand and the Healthwise information which was too general. He really wanted an explanation of what the results meant to him and his heart failure, the interpretation offered by the provider. Overall, MyHealth results were useful for preparing for an appointment, reviewing information following an appointment, and noting trends over time.

**Appointments and Prescription Refills**

MyHealth displayed past and upcoming appointments with Fletcher Allen providers, and had functionality that allowed users to request an appointment with a provider with whom they have had a visit in the past year. Participants received reminders of various appointments and notifications of new appointments in the Message Center. When these notices were posted, the system also sent an email to their designated email address alerting them of the MyHealth message.

Participants found different aspects of the appointment section useful. While some liked the convenience of scheduling on the computer, "[I like] the appointment thing. You don’t have to get a phone, you just go up there [to the computer] and do it," others were happy with their non MyHealth ways, "I want to talk to a person about something like that. I really like to keep my schedule right – I have a book where I write all my things down." Another had not realized this was an option, but was going to try it because she did not like the person that answered the phone in the office, and with MyHealth she would not have to speak with her. Many participants reported that they made future appointments at the end of their previous appointment, and thus had little use
for the feature: "I stop on the way out. That’s what they tell you to do. I follow directions well!" Finally, non-Fletcher Allen providers could not be scheduled in MyHealth, "I have my normal doctor that I go to, and I was making appointments with him, and he’s not part of [MyHealth]."

The ability to see upcoming appointments can be helpful:

My husband and I both had appointments in April and they both got changed. [He asked,] "Are you sure we don’t have an appointment tomorrow?" and I thought, "No, it’s been changed." I double-checked myself by going in [to MyHealth] and looking.

The message about the upcoming appointments could also be helpful, "There’s nothing wrong with getting a reminder about an upcoming appointment. I have enough appointments so that it’s hard to keep track." However, there were two specific instances in which participants did not like the feature. The first was for frequently recurring appointments. One participant went to cardiac rehab three times a week. Three times a week he received an email telling him he had a message in MyHealth – the message informing him of his rehab appointment. The other, mentioned by several participants, was the system’s email notifying them of their new appointment, the one they had just set up at the end of their office visit. They would set up the appointment, come home, and have a MyHealth message. This was viewed as an annoyance, not a useful feature.

Most participants did not use the appointment feature, and relied on methods they had already established for scheduling and keeping track of appointments. Nevertheless, there were participants for whom it was one of the MyHealth features they liked best. MyHealth does not have an "opt out" choice for receiving notification emails. Adding the option to suppress emails for specific appointment types such as recurring appointments or ones made in the past 24 hours, might be a patient-satisfier.
As with appointments, only medications prescribed by a Fletcher Allen provider could be renewed through MyHealth, and some liked the convenience of requesting refills through MyHealth while others had existing processes that worked well for them, generally calling the provider or the pharmacy. Four participants (31%) reported this feature as one of the best in MyHealth.

The Message Center

Patients can send messages to any provider’s office with whom they have had a scheduled visit in the past year. Participants could also send messages to their heart failure nurse. Three participants (23%) listed the feature as one of the best in MyHealth. They liked the asynchronous aspect of messaging, both because it allowed them to prepare their questions, "You can take more time to do it and do it thoughtfully," and because they were not interrupting the clinic, "I think that’s a huge benefit to be able to feel like you’re not bugging someone by phone. They can look at it when they are free and get back to you."

Participants understood that messaging would take time, and used the phone when they needed an answer more quickly. "[The phone] is my safeguard. Because I’m not going to worry all day long, I can just find out," described one participant. Another explains:

It’s useful if I have a question and I don’t need to know the answer right away. I’ll see it the next day. But I have Protime\textsuperscript{3} and I want to know [the results] that day. I don’t look at MyHealth for the answer, I want them to call me, and if they don’t call me, I’ll call them and ask them.

Participants were able to send messages to the heart failure nurse. Participants sent her messages about their condition that they said they would not have sent to their

\textsuperscript{3} A blood test that measures how long it takes blood to clot, used to regulate warfarin dosing.
provider, for example, notification of warfarin dose changes prescribed by the PCP, and questioning the need for a second echocardiogram when one had recently been done. The heart failure nurse reported that these messages were useful to her, and participants commented on the importance of her replies,

I think the most valuable [aspect of MyHealth] is the contact with [the heart failure nurse]. I think having a contact person and knowing you have one contact person is the most valuable, because you have a sense that someone cares about you.

*Other Useful Features*

Other features participants found useful include educational materials, viewing their medication list, and paying their bills online.

Educational material was available through Healthwise links and through the heart failure prevention resources link developed for the study. Usability testing indicated that participants had difficulty finding the heart failure prevention resources and that they confused it with the Healthwise search feature. Thus it is not possible to separate the usefulness of the two. One participant reported referring back to the resources to refresh her memory. Another looked up information for a friend who was newly diagnosed with heart failure.

Two participants found the medication list and its associated Healthwise links to be a valuable combination:

*Interviewer: So the things you used and liked best were*

Subject: Descriptions of medications and what they’re for, because sometimes I know what shape they are, but I’m not sure what I’m taking them for.

*Interviewer: So that educational stuff you actually used in a number of ways?*

Subject: I ran out of something one day and said "Oh my god, I can’t get the prescription until tomorrow. What was that pill supposed to be doing for me?" and [I used MyHealth].
Interviewer: You could have called the office and asked them.

Subject: But that’s a little embarrassing – "I’m taking this pill but I don’t know why."

And

Interviewer: So it seems like you think MyHealth is a useful thing.

Subject: Yes, it is, I mean think about it. Where do you get to have all your medicines – where do you see that? I see them right there – boom, boom, boom, boom. This does this, this does that, this does this. So I know. I guess in the past I wouldn’t have known what they did. That’s the reality of it all. So [now] when I order it, I know what I’m ordering.

A third spoke of learning the medical names for generic terms through his med list, "I know what Coumadin is. I now know what warfarin is."

Bill paying was not useful for participants fully covered by Medicare and supplemental insurance. As with other features, for those that had bills to pay, some were comfortable with their current processes, "I pay it online from my financial institution online... So, it’s nice that you’ve got the feature ... I just don’t see the benefit to it personally." Others found it useful, "Oh yeah, because I used to either call, and never get through, or mail them. And that was a hassle. I hardly ever write a check now, ever." In an example of an unexpected use of the system, one participant, when asked if he used the bill-pay feature, replied:

No, but it did help me to remind myself to send the bill that I do have to my sister in California. She’s the one who pays. It’s a very sideways reminder to me to do something completely different than what is designed to do. It was useful. My sister liked it; she didn’t have to bug me about it.

Health Team Communication

Beyond the usefulness of individual features, participants reported that MyHealth changed the way they communicated with their health team. This anecdotal evidence may be describing the shift from a hierarchical to a shared provider-patient relationship.
proposed by Detmer et al. (2008) and Urowitz et al. (2008). Viewing test results before, during, or after a visit, and feeling comfortable sending messages to the heart failure nurse are two aspects already discussed.

Participants also described how MyHealth changed their communication in terms of connectedness, "I feel more connected, because my record’s all right there, I can see it;" feeling informed, "I think I’m more informed, and they’re being more informed as they’re becoming more familiar with me;" and having more access to the team, "I’m not worrying about having to call this doctor today and that doctor tomorrow and, oh dear, I forgot to call that one. When I need to send a message I send it, and it’s not long before they respond."

**Disease Management**

Disease management promotes coordinated communication and collaboration between heart failure patients and their health care team. The approach includes patient education; monitoring to prevent exacerbation of heart failure symptoms; outcome measurement, evaluation, and feedback; medical treatment optimization; and encouraging patients to be active participants in their care. Being active participants in their care is a big job for heart failure patients. This section begins with a discussion of some of the strategies participants use for participating in and managing their care. The PHR has tools that could be used to promote heart failure disease management. Following a summary of tools discussed in more detail in the usefulness section, daily monitoring outcomes within the PHR are discussed. The section ends with the thoughts of the heart failure nurse who monitored the participant’s data in the PHR.
Subject Management of Their Heart Failure

The mnemonic DAMES is used to stress core self-care activities for patients with heart failure: Diet, Activity, Medications, Everyday weight monitoring, and Symptom monitoring and follow through.

Participants’ diet monitoring included managing salt and fluid intake, and food journals to help with weight loss. One participant has a sodium level *app* on her IPhone that she uses to look up the sodium levels in foods. Another cited the difficulty in obtaining low sodium foods in the local grocery store as a challenge of living in a rural area. A third was hospitalized with low sodium levels, and wished his non-Fletcher Allen labs were in MyHealth, because he had not been called and told his latest sodium lab values. A fourth discussed her strategy of selecting the "best" chip from the bowl at a party and learning to be content with that. A participant with a fluid restriction described his process for monitoring: "I’ve measured out two liters in glasses that I have at home and I know I can have six of those a day. So I just try to pace myself." Another includes his fluid intake as part of a larger diet journal, "I have a journal – a food journal that I’ve been keeping with my diet that tells all the meals that I’ve been eating, what my blood sugars were, and how much water I drank."

Restricted activity was also monitored. One participant described his life changes brought on by activity restrictions:

*Interviewer: Exercise?*

Subject: I try not to exercise because I had a pace maker put in. They stopped the heart and put in a pace maker defibrillator and did an ablation. So I’m totally reliant on the pace maker now. I tried working. I went back to work. I was working half days, and it wasn’t going well, and now they want me to just relax and take it easy this summer and see how it’s going and see if I’m going to be able to go back to work at all next year.
Interviewer: Are you going to cardiac rehab or something like that?

Subject: No

Interviewer: They don’t want you to do anything?

Subject: Not much, no. I can do a little bit, like I might go out and do some weed whacking for a little while.

Interviewer: That’s ok?

Subject: Well I work for a doctor and we had to buy a battery operated weed whacker because I couldn’t handle the motorized one – it’s too heavy for me. By the time I got it going [I was out of breath]. The [electric whacker’s] battery goes for half an hour. So I weed whack for half an hour and then I rest for a while. I might get on the riding mower and mow on that for a while, or I just go and sit down, and then later on I might do more. What used to take me an hour and a half to do now takes me at least 3 hours to do.

Another participant also reported restricted activity following the implant of his cardioverter-defibrillator:

I’ve only had this thing in since June 8th or 9th. They told me 4-8 weeks [before going back to rehab] on or about July 25th. So August 1st, back I go. I gained so much ground, and then this happened, and now I have to start back at square one.

Following a long Vermont winter, one participant was glad to be outside. Her description of her joy of working in her yard is tempered by the reality of her condition:

I’m feeling really good. Yes. I’ve had energy and I love to do lawn work. I’m still struggling with my gardens trying to get them [looking good for the summer]. It takes me longer than it used to. I rest more. I take a chair with me, you know. And I get tired and I sit in the chair. I don’t have the energy I had before I had my heart problems but I do have lot more energy than [I did].

The M, for medications in DAMES covers a wide range of management issues. It includes developing and following a system for making sure the correct medications are taken at the correct time. One participant keeps all her papers from the doctor in a folder and "every once in a while I go back and double check and make sure I’m doing it right. Cause once in a while I’ll miss something." She goes on to explain her system for knowing she’s taking the right medications:
I have a… system with my pills: there’s two fat ones, two oval ones, two teeny ones, and if there’s something missing I know to come back to that system that I’ve learned. Some people do colors, I do size. "Oh, that one’s missing, that’s because it’s a vitamin and I ran out." So I’ve learned that system works for me for keeping track of medications.

Participants organized their medications into boxes, "And I have pill boxes. I do my pills once a week," or bottles, "because I have so many [medications], I have seven pill bottles—with Sunday to Saturday written on the top. And I fill up each bottle for the whole week, and so in the morning all I have to do is open up that one bottle."

Medication monitoring also includes getting refills. One participant called in his prescriptions, then walked to the pharmacy as his morning exercise, took his blood pressure with the store’s monitor, and picked up his pills. When prescriptions expired, he was happy to let the pharmacy call the doctor’s office to get them renewed, "And so if my prescription has expired it just comes up. 'Do you want us to contact the doctor, press 1 or 2’ … So I do, and the next day the prescription’s waiting for me." Another participant monitored her refills, and those of her husband, more closely, preferring to do the renewal monitoring herself:

_Interviewer: Some people tell me that if it’s been a year, and the med’s expired, the pharmacy will call the doctor._

Subject: Yes, they’ll do that.

_Interviewer: But you’re calling the doctor’s office?_  

Subject: Well, if I realize it I do it. If I missed it, they [the pharmacy will] catch it… [But] I try to keep track of it. Only because my husband, he has lots of meds too, and he’s never checking them and I bring them in and they go "well this one’s expired," and then I’m embarrassed.

Pharmacies offer a host of ways to have prescriptions filled: walk in, phone calls, e-prescribing from the clinic, email from patients, and mail order. One participant describes his use of them all to get renewals for his many medications:
[Renewing prescriptions online from MyHealth] was fine. It was almost right off – if I would [request the refill] in the morning, a message [in MyHealth] would be there in the afternoon or evening saying it’s been sent [to the pharmacy]. And then within no time at all I’ll get a call from Rite Aide saying… Well actually I don’t get those calls anymore because I signed up for the online Rite Aide. They’ll send an email when the med’s been put up and stuff. My wife got right off that [the phone calls from Rite Aide] because my little chihuahua she starts howling when that Rite Aide automated thing comes on – she don’t like that. So my wife got right off that and I don’t get calls from them anymore. They send me emails. The only thing I don’t like [with the Rite Aide email] – I wish I knew what it was, because I have so many meds. Probably seven times out of ten I know what it is because I’m getting low on things, but I’ve gone over to Rite Aide before and had things put up when I’m not even ready for it yet. It’s the automatic thing. So I have to write them down, whenever I have a bunch of them I have to pick up. I have four or five I have to pick up every month. Now I’m getting to the point when I get them every three months [in the mail] - and that’s better. It’s a little more expensive but you don’t have to run to the pharmacy all the time.

Not all rural pharmacies have all of these features:

[Renewals] can be tricky with my little drug store. I asked if they do e-script, and they do, but they don’t. It’s like yes, but maybe they didn’t check it as often as they should.

Dosing changes can also disrupt the renewal cycle:

[The pharmacy’s] intention is to give me a 30 day supply. There’s one or two where it ends up being a 60 day supply just because they don’t know that I take it only once a day, instead of twice a day…It’s been changed a number of times [explains his dosage changes]. So they think I take 20 mg twice a day, but I only take it once a day…It can be really frustrating.

And if one runs out of a medication, knowing what the medication is for is important in ascertaining how important it is. One participant reported using the information in MyHealth, and another, quoted previously, that the missing vitamin was not an issue.

Finally, being aware of the purpose of the medications, and dosing issues is also important. A participant with weight gain felt the problem was probably associated with changes in his diet including increased salt intake. He was planning to ask his doctor to increase the dose of his diuretic to help compensate.
Everyday weight monitoring, and Symptom monitoring and follow through, the final two DAMES categories, are interrelated. Weight monitoring is used to identify fluid retention, possibly caused by diet or medication changes, which can lead to symptoms of swelling and dyspnea. Fletcher Allen has a Heart Failure Journal it gives to new patients in which they can record weight, blood pressure, pulse, swelling, breathing, and energy levels (See Appendix L). It includes an area for reference values for monitoring, and instructions about what to do when symptoms deteriorate.

Participants’ daily monitoring varied. Three participants, one with a recent heart failure diagnosis and two long-term heart failure patients, did not record any daily monitoring. All felt that their health was stable, so there was not a need to monitor their condition more closely or to write it down:

I don’t keep track. I mean, I do in my mind. If there was a significant difference I would go back and see why, but as far as writing it down, I don’t do that at all. On account of I don’t like details.

and

Weight? I don’t worry about my weight, and I have a-fib and I know when my heart is in it. I’m on meds for it. It’s controlled.

At the other end of the spectrum, five participants, two newly diagnosed, did monitor and record their weight and other vital signs daily. In between were participants who either reduced the frequency or stopped monitoring over the course of the study. A change in routine with or without a change in health condition, was often identified as the precipitating factor: the participant who felt better and began working in her garden did not follow the same morning routine; the participant with the new device who was put on restricted activity no longer went to cardiac rehab where he had been monitoring; another participant moved and was still setting up his new house; another lost his computer,
where he had been monitoring, in a lightning strike. Reduced monitoring was a result of feeling better:

So the first few months after the condition presented itself a year ago I was pretty diligent about everything and stayed on until things seemed like they were pretty stable, and then I would just check it less often. I got my pacemaker in mid-November and after I got that I again became very diligent – twice a day, at least once a day and that again stayed going for a few months. But once I got to a certain point I started to see the same readings and numbers, so I started checking every other day instead of twice a day. That was just something that after a few months of seeing no trend, just the same thing, I’d check it and that’s kind of the way it is now. I’m a couple, three times a week and I’ll put on the cuff and step on the scale. So I don’t do it as often as I was asked to, but I still stay on and look for major changes and stuff like that.

Participant’s health management went beyond DAMES. They monitored and trended their lab results; kept lists of questions for their doctors – either on paper or on their smart phone; and kept folders or binders of material from their providers. They kept track of their appointments, not only when, where and with whom they were scheduled, but also what was planned and its relevance. Two participants reported cancelling their appointment for a routine echocardiogram because they had had one recently due to a change in their condition. Another spoke of how much harder it was for her to manage her diet and daily monitoring while she was travelling. Others spoke of their support systems and how they decided when to share their symptoms, and when they chose to keep it to themselves so their loved ones did not worry. Participants also monitored and managed their pace-makers and other implanted devices. One rural participant told of falling during the night and landing on his pacemaker. He called Fletcher Allen and had the device tested over the phone, but nevertheless sat up through the night worried that if the device failed while he was asleep that he would not wake up. Another dreamed her defibrillator went off, but then worried that perhaps it was not a dream. She spoke of
working through the decision of whether or not to call and whether or not to trust her heart and implant.

*MyHealth and Disease Management*

MyHealth has tools that can help promote disease management activities. Patients can look up health information, see some of their test results, view their medications and a description of what the medications are for, manage their Fletcher Allen appointments, and send and receive non-urgent messages from their Fletcher Allen providers and heart failure nurse. Different participants found these tools more or less useful in their disease management.

The MyHealth heart failure daily journal was developed specifically for the study. It replicated Fletcher Allen’s hard-copy daily journal (see Appendix L), with places for patients to enter weight, blood pressure, pulse, and energy, swelling, and breathing levels. Data was transmitted to PRISM, where the heart failure nurse monitored the results. When participants were given access to the journal, the heart failure nurse established their individual normal ranges for weight and blood pressure. Values outside of these ranges were flagged when the data were sent to PRISM and participants were given instructions to call their provider. Normal ranges for the other values were unable to be set due to underlying functionality limitations.

The heart failure nurse gave each participant access to the MyHealth daily journal when they enrolled, and she promoted its use with the participants, feeling it was a key heart failure disease management device. All but two of the participants accessed the daily journal in MyHealth; however, use of the tool varied widely. Those who did not monitor their daily weights and symptoms before the study began did not incorporate the
daily journal into their routine. Others tried the feature, but then reverted or switched to non-electronic recording methods. Finally, some entered their data into MyHealth, more or less faithfully. Beyond their feeling the need to monitor at all, the decision to record the data in MyHealth or on paper was a balance between the inconvenience of using MyHealth and the reassurance afforded by the heart failure nurse’s monitoring of the results.

Participants’ computers were not placed near their scales or blood pressure cuffs. Most who recorded in MyHealth first obtained and recorded their weight, blood pressure, and pulse on paper, some in a notebook or designated legal pad, others on a scrap. Then they turned on their computers, logged into MyHealth, and transcribed the data. Some participants were on their computers frequently, and incorporated the process into their daily computer routines. However, many participants chose instead to enter a batch of data every few days. Thus for most participants it was not convenient to record their numbers in MyHealth.

I did that in the [paper] journal. I didn’t do it on the computer… For two reasons, one is that the journal is right here in my lap, and [the other is that] the computer was upstairs.

One participant accessed MyHealth on her iPad, which she brought with her when she weighed herself, just as the other participants brought their paper and pencil. Then she brought the iPad with her as she checked and recorded her blood pressure, pulse, and other values. She was the only paperless user. She recognized the convenience:

And if I didn’t have the iPad then I probably would feel it’s a pain in the butt. I mean if I had to go and find a computer and log in and you know… So I guess the ease of my iPad has made a big difference… Our computer at home is old, so if I had to do it through that I would not be happy.
Another also recognized the potential and suggested that a MyHealth smart phone app would make recording more convenient.

The decision about whether to put up with the inconvenience and enter the daily journal data into MyHealth was related to how useful participants felt the heart failure nurse monitoring to be. A participant that did not find it useful explained, "I didn’t feel like it was giving me anything more than I could see by looking at my pad." A participant who did find it useful explained:

Interviewer: Do you think that advantage outweighs the hassles that you went through?

Subject: Oh yes, definitely, because that way [the heart failure nurse is] probably more familiar with checking patterns and seeing how things are going.

Many participants wished the MyHealth daily journal had a place for user comments or additional user-specified data items. The comment might be used to further clarify a value or speak to why it changed, for example,

I could just say, "My pressure was 72/44 and I was dizzy," or you could say, "My pressure was 80/50, but I’m not dizzy," or that sort of thing.

Additional data items mentioned included blood glucose levels, calories consumed, and miles walked. Most wanted the data to be viewable by their health care team. However, another participant, a diligent MyHealth recorder wanted a private space:

making more room somehow for my personal information – like if something is different with other things besides the heart. For example, I take my blood sugars every day too. It would be nice for me to be able to record. Not that the doctor or anybody else wants to see that all in the same place but I would.

The messaging features in MyHealth, combined with the daily journal information, created a supportive, collaborative environment for some users:

If I wasn’t on MyHealth I would not have communicated. I would have just... you know... but because it was there and I’d say "Gee it would be nice to send her a note and let her know how I’m doing on my diet" and plus, she was keeping
an eye on my results in MyHealth too, so if MyHealth had not have been there she would not have been looking at that. And so I think it’s been a help and I think it’s a big help really.

And

I liked doing that [getting messages from the heart failure nurse about my daily journal]. Again, it just puts me more in touch, and it’s always nice to get an "Atta boy, you’re doing good."

When asked if MyHealth changed their health behavior, several participants answered positively:

- Yes, when everybody could see what I was doing I was a lot more compliant… Its works good, it really does, and it's very helpful and it’s a big sense of security. It makes it easier for them [Cardiology] too because they can keep a daily track of what’s going on with you and it’s not like me going every 6 months and you have to catch up on what’s happened for the last 6 months.

- Yes. I got used to [the daily journal]. It’s become a routine. [Before the study] every once in a while I would take my blood pressure and see if it’s ok, and I’d say, "Ok, cool." Weight wise, I don’t think I weighed myself that much. But my wife’s bought a brand new scale and we’re both using it. It’s kind of like put into my daily routine now.

- Interviewer: Has MyHealth changed your health behavior?

  Subject: Yes, because I’m more aware of what I’m doing, which choices I’m making.

  Interviewer: Is that because of the daily journal?

  Subject: I think so because I’m more familiar if I made a change to medication there, if I exercised or not there, if I see a pattern in the way I’m doing things or what I need to do to change something.

  Interviewer: So do you think it’s a useful tool for that?

  Subject: I do.

  Interviewer: For managing changes in your behavior?

  Subject: I think so because if my weight is going up a little bit then I know that I need to do something different with the diet or exercise.
Interviewer: You have it written down on paper too. Do you think that that – the paper – is just as good, or do you think that putting it in MyHealth is more of a motivator?

Subject: I think probably putting it into I’ll call it a journal is more helpful.

Interviewer: Why is that?

Subject: It’s more personal I think. It’s easier to see.

Interviewer: Do you go back sometimes in MyHealth and just look at all that data that you entered?

Subject: Yes, I do. It’s an incentive.

These sentiments were echoed by the heart failure nurse during an interview on her experience with MyHealth.

Interviewer: Did it help you with your practice?

Nurse: I think it did. I really liked to be able to see those things, that information, the journal in particular right in the patient’s chart where the rest of their records were and if there was an issue or change in patterns…I could see their blood pressure and weights and everything. It’s definitely a very slick tool….You can see how something like this could be also used for other types of programs like weight loss, smoking cessation, [and] diabetic control.

Provider Engagement

There was no active physician involvement in the study design. The chairman of the Cardiology Department approved the study, and the Cardiologists and mid-level providers were informed of its occurrence, but there was no physician involvement in the development of the heart failure daily journal, or in the decision to allow participants to communicate directly with the heart failure nurse. To set up participants with the daily journal, an order was placed in PRISM. The heart failure nurse placed the order, but it had to be cosigned by a provider. The Cardiology chairman cosigned the orders.

The lack of provider knowledge, engagement, and participation in the study was a weakness. The daily journal information was sent to the heart failure nurse's In Basket,
email-like functionality within PRISM, for her review. Because she placed the initial order and monitored the data as they were returned, and because of the small number of participants, the heart failure nurse was aware of who was recording their daily numbers. The data also flowed in to a Heart Failure daily journal flow sheet and episode of care that all clinicians could access. However, there was no way to easily identify such patients in PRISM. Clinicians had to a) open the flow sheet activity, find the specific flow sheet, and see if there were any results; or b) notice and open the episode of care report.

Cardiologists were unaware of the flow sheet or which patients were using it. The heart failure nurse felt that had the providers played an active role in promoting the daily journal, adherence might have been better. When one participant told her physician that the data were in PRISM, he did not know where to find it or how to retrieve it. She brought up MyHealth on her iPad so he could review the data. The lack of provider awareness limited the usefulness of the daily journal.

**Conclusion**

Fifteen heart failure patients were enrolled and completed an initial usability study. Participants were generally satisfied with the usability of MyHealth, although issues of screen layout, consistent application of site conventions, and unclear instructions were identified. Thirteen participants completed the study. As a group, compared to other published studies,

- they felt that their health information was more correct, that their medical history more accurate, and they had fewer security concerns; and
they found managing all their information in one place and sending messages to their physician more useful, and scheduling appointments, making sure their information was correct, and renewing prescriptions less useful.

Individually, different participants found different features more or less useful, depending on how well the feature fit their current habits and needs as well as whether their PCP was documenting in PRISM.

Participants described the myriad of details they needed to manage their condition. Some of the activities were encompassed in the DAMES acronym, and many others that needed attention fell beyond its spectrum. The daily monitoring of weight and other vital signs varied by user. Some monitored and recorded faithfully, other did not. A third group monitored at the beginning of the study, but lessened the frequency or stopped altogether as time went by. Participants who used the communication tools found them useful and felt more connected with their health care team.

The final chapter will examine these results in light of the research questions and place them within the context of the literature.
Chapter 5

Conclusions

PHRs are an emergent subset of the EHR industry, and a small, but growing number of Americans have PHRs. To date, no clear standards for content, format, delivery, ownership, or data sharing exist. Three types of PHRs are currently in development. 1) Stand-alone PHRs are owned and managed by the patient, and are not integrated with other health information. Patients determine the scope and content of the PHR, enter the data, and are responsible for data accuracy and security. 2) Tethered PHRs are patient portals into provider-based EHRs. A tethered PHR is owned and managed by a provider organization that shoulders the development and ongoing operational costs, determines the scope and content of the information available, and is responsible for the data integrity, security, and storage. 3) Integrated PHRs are hybrid systems that include information from multiple data sources and patient-entered data to provide a complete picture of the patient's health. Complex interoperability, data transmission, and security issues need to be addressed before large-scale integrated PHRs are feasible.

Theoretical benefits and risks of PHRs have been articulated. For example, those with chronic diseases such as heart failure and those living in rural areas may find a PHR's information, educational materials, data sharing, and communication capabilities
to be useful disease management tools. However solid research to support or refute this claim has yet to be completed.

Heart failure patients from northern Vermont and New York used MyHealth, a tethered PHR for three months. They tested its usability during an initial interview, and provided feedback on their experience at the end of the study period. They felt the system was usable and provided useful features that they incorporated into their health management strategies. The usefulness of the features varied by user and depended upon how it fit into the user's existing routines, values, and concerns. Their experiences validate some of the PHR benefits found in the literature, but do not support others.

This chapter begins by discussing the results of three research questions. Limitations of the study are then described. Implications and recommendations of the research place the findings in a broader context. Finally, a summary of the entire project concludes the report.

**Research Question 1: How usable is the PHR for heart failure patients?**

Participants were all intermediate to expert computer users. During the three month study period, all were able to use MyHealth to complete activities they found useful. In the initial usability study and in final interviews, participants identified items that could be improved. These can be classified into three broad areas: redesigning the screen layout to move prominent features to the fore and reduce scrolling; following standard webpage conventions consistently throughout the site, and modifying the text to provide clarity and an instruction hierarchy that can be easily scanned and interpreted. All three areas have a large body of best-practice research that can be referenced to make the site more usable.
Most of the usability issues found throughout the site can be viewed on the home page (see Figure 2, page 75). On a 14 in. (35.6 cm) display with a screen resolution of 1366 x 768 pixels, the banner uses 24% of the available screen real estate. A large Fletcher Allen Logo, and links to Fletcher Allen social media are in large part responsible. Fletcher Allen’s marketing team was responsible for the header design, and it reflects their focus. MyHealth is a tethered PHR, funded and promoted by Fletcher Allen and Fletcher Allen’s branding of the site is appropriate. However, the large header reduces the usability of the application. The inability to view the entire home page without scrolling meant that participants did not see the Health Library search feature or the buttons to the two main sections of the site. A redesign of the page might solve the problem.

Participants were able to use the site with practice, but did not find it completely intuitive on first encounter. MyHealth’s overall design matches that of other Fletcher Allen websites. Headings are blue but are not links; buttons have white labels on green text and have a flat, not a 3-dimensional appearance. Bulleted lists are marked with a green triangle. Some are links, others are not. Some links are displayed in the traditional blue underlined style. Others are blue but not underlined. Moving the mouse over the page reveals its clickable portions: buttons and icons change to a darker hue, links become underlined, and underlined white links in the blue area at the bottom of the page become un-underlined. A consistent design that is apparent without having to move the mouse around the screen would meet usability guidelines and improve the experience of new users to the site.

---

4 See www.fletcherallen.org
Providing the right instructions at the right time in the right format is a challenge for web developers. Users tend to scan webpages and make quick decisions about relevant content and links. Designers can take advantage of this by using font characteristics to provide a hierarchy of information on the screen and reducing text wherever possible. MyHealth’s instructions would benefit from such reorganization. Users did not "see" the instructions on the page. They did not read the entire text to learn the details before clicking and starting a task, and then did not know what would happen at the end. Interpretation of test results from the provider was overlooked. PRISM programmers expressed their frustration with these findings because the instructions are there if only the users would read them. Understanding basic web behavior and designing toward it might reduce the amount of overlooked text reducing stress for both users and programmers.

MyHealth is a website built by committee. The software vendor, a steering committee, PRISM programmers, and Fletcher Allen marketing and web development staff all played a part in its implementation, and all are involved in its ongoing development. To date, patients have had no formal voice in the process. There was no patient usability testing completed as part of the MyHealth development and implementation.

After MyHealth was implemented, patient concerns and complaints were received by various communication channels in the organization, and depending on the channel were referred to a physician on the steering committee, PRISM programmers supporting the application, or the hospital’s patient advocacy department. There has been little formal interaction between these groups to collate or address the issues in a systematic
way. Relying on voiced complaints, while important, does not provide a balanced view of MyHealth’s usability. The usability study of the heart failure participants was the first systematic examination of MyHealth by patients by the organization. Implementation of recommendations will require a concerted diligent effort by various organizational groups involved in the process to hear, understand, accept, and address the issues identified by the patients. Usability improvement is an iterative process. Ongoing systematic patient feedback will remain vital as the recommendations are implemented.

The usability concerns about health literacy in PHR use found in the literature were not evident. Participants who found the wording of test results difficult used the Healthwise links to access basic information about the tests. Participants relied on their health team to explain the implications of their results on their health. Those with a health background and those who had had heart failure for a period of time and were familiar with the tests were able to interpret them in MyHealth. Others waited to hear the results from their provider. Regardless of approach, all expected their health providers to examine and reflect on their results and make appropriate health care changes as warranted.

Despite the issues identified, participants were able to learn to use the system, primarily through trial and error, which is how they describe learning to use any website. They did not call the support number printed on the website, and only rarely contacted the investigator with questions. Finally, they were satisfied with the system. In the initial usability test, on a scale of 1 to 7, with one being most satisfied, no task had a mean score of more than 2.4.
Research Question 2: What PHR features do heart failure patients find useful?

PHR proponents foresee a life-long, patient-controlled, self-populating, integrated PHR that contains patient-specific health data, provides links to relevant health resources, enhances patient-provider communication, and improves patient safety. As a tethered PHR in a world of fractured EHRs, MyHealth is not quite there. It is an institution-controlled, semi-self-populating application. It does, however contain patient data, links to educational material, and communication tools that patients found useful. More cautious PHR experts raise concerns about security, patient barriers caused by computer and internet accessibility and low computer and health literacy, provider acceptance, and usefulness of the PHR features. These issues were addressed during the interviews. Participants used features that met their needs and were convenient for them, and offered suggestions for enhancements.

It has been suggested that the PHR’s asynchronous modality may improve communication between patients and providers by offering a convenient and efficient method for communication, the opportunity to research and contemplate answers before responding, a nonthreatening way to discuss sensitive topics, the ability to store and reread advice, and the ability for patients to communicate directly with providers without a third-party to relay messages between the two. Communication can include consultations with health coaches and uploading of home monitoring devices with abnormal results flagging (Detmer, et al., 2008; Hess, et al., 2007; McGeady, et al., 2008; Tjora, et al., 2005).

Participants concurred with some of these benefits. They found MyHealth's asynchronous modality useful for communication that did not need an immediate
response. They appreciated its anytime, anywhere convenience. It enabled them to take the time to craft thoughtful messages, and to ask questions while not feeling that they were bothering their doctor. They recognized the limitations of asynchronous communication as well, choosing to communicate by phone when they needed an immediate answer.

The unique role of the heart failure nurse on their disease management team was apparent in participants' communication choices. They increased their communication with her, sending her messages about health updates such as warfarin dose changes and explanations of fluctuations in their daily numbers. They would not have called or sent a message to the office about these issues. MyHealth's ability to send messages asynchronously to their specific heart failure nurse was the feature that enabled the communication. The ability to send a message to a specific person through MyHealth was a unique feature of the study. Standard MyHealth setup routes all messages to the clinic's nurse pool, a configuration choice made by the steering committee. The ability to communicate directly with their nurse who they knew and with whom they had a relationship was the key that made the communication possible.

While MyHealth did not have the functionality to upload data monitoring devices, participants did hand-enter the data. Abnormal readings were flagged and communicated with the heart failure nurse. Some participants and the heart failure nurse found this a valuable tool for monitoring their condition.

Not all the purported benefits on asynchronous communication were found. There is no evidence that participants used MyHealth to discuss sensitive topics or that they saved and reread their messages. MyHealth did not eliminate the third party message
intermediary for patient-provider message as all messages went to the nurse pool. A nurse read them and either responded directly or forwarded the messages to the provider. Thus, at Fletcher Allen the MyHealth message workflow was designed to replicate the phone message procedure.

By having one complete, accurate, up-to-date patient record EHRs may improve patient safety by providing accurate data in emergencies, and crosschecking allergy and drug interactions (Detmer, et al., 2008). PHRs can play a role by allowing patients to view, update, and verify the accuracy of their records. MyHealth does not allow patients to update their own records. It is only up-to-date and complete for patients whose entire spectrum of care is provided for and documented in Fletcher Allen clinics. For others, information is updated in MyHealth at a Fletcher Allen office visit, or if patients specifically communicate the updates to a Fletcher Allen clinic whose staff updates PRISM. Participants reported that their MyHealth data were accurate, indicating that the Cardiology department is diligent about keeping PRISM current. The fact that the information was correct may account for the fact that participants were less likely to feel that verifying their EHR information was useful (55%) than a national sample (64%). Participants appreciated the EHR and its one source of truth for their health record.

Concerns over the security of MyHealth proved unfounded. Participants understood that any online application carries the risk of a security breech, but felt confident in Fletcher Allen's protocols or did not care who saw their record. Barriers to access including computer and internet access, computer literacy and health literacy concerns cannot be addressed. Participants needed access and basic computer literacy to
be enrolled. The patient education resources in MyHealth and a good relationship with their providers helped alleviate participants' health literacy barriers.

Lack of provider acceptance and use of the daily journal data were limitations. Disease management requires communication among the entire care team, and omitting the providers from the mix decreased the value of the data and the study. To extend and expand the use of the daily journal, a protocol and workflow that includes providers in the identification and follow up of appropriate patients, which data should be sent to the provider for review, and how that review will take place, needs to be developed. A better method for identifying who is using the daily journal needs to be developed, and training in how to access the data needs to occur.

Specific MyHealth features were more or less useful to specific participants based on their convenience over existing strategies, or their perceived benefit. Their MyHealth use corresponds well with the diffusion of innovation model's five characteristics of adopted innovations (Rogers, 2003):

1. Relative advantage: MyHealth was useful when participants felt the feature was better than their previous practice. Bill paying was better for the participant who used to call and never get through, but not useful for participants who used their bank's online bill paying services. For one participant renewing prescriptions through MyHealth spared her the embarrassment of having to ask the pharmacy to renew; for another having the pharmacy renew was much more convenient. For some, MyHealth's list of upcoming appointments and email reminders helped them manage their
schedules. For others the list was incomplete because their providers were not at Fletcher Allen clinics, and the email reminders were a bother.

2. Compatibility: Participants used MyHealth when it matched their values, past experiences, and needs. Participants used the computer for communication (email and Facebook), transactions (online banking), and information searching before enrolling. MyHealth was an extension of this use. Those that used the daily journal felt the need for the heart failure nurse to monitor their numbers and appreciated her professional oversight.

3. Complexity: Although some usability concerns were raised, participants were able to learn to use MyHealth to complete their desired tasks. Features that were deemed too complex did not have to be used. For example, one participant did not use the refill feature because he was unclear how the clinic would know which pharmacy to send it to. Participants reduced the complexity of the application by forming hypotheses about unexpected outcomes. These may not have been correct, but they allowed the users to work within a set of logical assumptions.

4. Trialability: Any Fletcher Allen patient can enroll in MyHealth and try it for themselves. Enrollment in the study allowed the participants to try MyHealth in a supportive environment. Their account was set up during the first interview, and their use was monitored. They had the investigator's contact information should something go awry.

5. Observability: Fletcher Allen promotes MyHealth use. Brochures are available at every clinic. Participants were given a more complete description
of MyHealth by the heart failure nurse and the investigator. They also tried parts of the application during the usability study. This may have made them more likely to use the application.

MyHealth use also corresponded to the four unified theory of acceptance and use of technology adoption determinants: performance expectancy, effort expectancy, social influence, and facilitating conditions. Participants fell into Tarde's early adopter group (Rogers, 2003), and represented the complexity described by Greenhalgh et al. (2004)

People are not passive recipients of innovations. Rather (and to a greater or lesser extent in different persons), they seek innovations, experiment with them, evaluate them, find (or fail to find) meaning in them, develop feelings (positive or negative) about them, challenge them, worry about them, complain about them, "work around" them, gain experience with them, modify them to fit particular tasks, and try to improve or redesign them- often through dialog with other users (p. 598).

MyHealth is a tethered PHR and the tension between Fletcher Allen and the participants' ownership and control was evident in the interviews. Those without Fletcher Allen PCPs could not see results that were available in PRISM. Participants wanted to add comments or additional data items to the daily journal, add appointments to non-Fletcher Allen clinics, record information for themselves that would not be shared with clinicians, and to communicate with a wider group of clinicians on a less-restricted list of topics. Some of this functionality could be added to MyHealth should Fletcher Allen decide to do so, others must await a more integrated health care system or interoperability among provider EHRs.

In summary, usability and usefulness go hand-in-hand in innovation adoption. MyHealth was both usable and useful to heart failure patients. Participants chose to use features that were more convenient than their existing methodologies or when the
features offered increased functionality. They appreciated the communication with their heart failure nurse and it may have deepened their relationship with her.

**Research Question 3: Can a PHR be useful in the disease management of heart failure patients?**

Managing heart failure is a complex task. Patients need to monitor their lifestyle, diet, activity, medication, weight, and symptoms. They need to manage their medications and appointments. They need to know what is normal for them, to be able to identify when they are not stable, and to know at what point to seek professional help. Participants had different methods for managing their heart failure and keeping healthy, and found the features of MyHealth to be of more or less use. Two key components to disease management within MyHealth were the ability to communicate with the heart failure nurse directly, and the heart failure daily journal. The journal let participants enter their daily monitoring into MyHealth and thus into PRISM where it was monitored by the heart failure nurse and viewable by the health care team.

Daily monitoring is a core activity for heart failure patients, yet participants found adherence over time difficult. Except for a participant with an iPad, using MyHealth to record daily numbers was an inconvenience. As participants weighed themselves and took their blood pressure, they recorded their values on paper. Then they had to log into MyHealth and record them again. The benefit of this increased work was the clinical oversight of the data. For those whose heart failure symptoms were stable or who were not anxious about their condition, the benefits did not outweigh the inconvenience. Some, in a compromise between oversight and convenience, chose to store up their data and enter it into MyHealth in batches. Others recognized the benefit, yet when forced to put
recording on hold by life's circumstances (illness, moving, computer failure, and the like) seemed unable to resume the process.

Those who were able to sustain the monitoring of their daily symptoms, whether or not they entered them into MyHealth, reported that establishing a routine was crucial. They had specific times of day for recording, and kept their data together in a journal. They referred back to previous entries for information and motivation.

The disease management capabilities of MyHealth could be motivational. The knowledge that the data were being monitored helped at least one participant adhere to his diet. Participants communicated directly with the heart failure nurse to explain their daily journal numbers and report on other health-related events. The heart failure nurse did not respond to all daily journal entries, but did communicate when numbers fluctuated and to provide encouragement. Participants acknowledged and appreciated these messages.

The heart failure nurse reported that the daily journal data were extremely helpful. She could detect changes and issues and found it convenient to have the data in PRISM with the rest of the participants' health information. Like the participants, she found it most useful for patients who were unstable and needed close monitoring. Provider involvement was lacking, limiting the usefulness of the daily journal.

There were no appreciable advantages to the PHR for rural heart failure participants. The phone was the technology of choice for both urban and rural participants with concerns that needed immediate attention. They expressed appreciation for the fact that they could reach a Fletcher Allen specialist at any time of day or night should the need arise. While some aspect of managing their health are harder for rural
participants, less health options at the local grocery and lack of e-prescribing at their rural pharmacy for example, the PHR was not viewed as a mitigating factor.

In summary the health information, daily monitoring, and communication features of MyHealth can empower heart failure patients to be more active participants in their care, but not all patients at all times. How and when patients chose to use the PHR was complex and dynamic.

Limitations

The study had several limitations. While the small sample size was appropriate for exploratory research, the results need to be validated through a larger, more comprehensive study. Participants all had computer and Internet access and basic computer skills. They were recruited from one Cardiology clinic serving patients in northern Vermont and New York. While it may be argued that Vermont and northern New York are rural areas, participants came from towns of various sizes. Neither US Census data nor participants' subjective definitions placed all participants in a rural environment. Their responses, attitudes, and preferences may not be generalizable to broader rural or general patient populations. In addition MyHealth is just one of the many PHRs available today. Its usability and features may not be generalizable to other PHRs.

Participants used the PHR for three months. Users' PHR usage patterns change over time. Zhou et al. (2007) found a two-month spike in office visits and telephone calls after the introduction of a PHR. Over time both decreased. The three month timeline may not have been long enough for participants to establish their PHR routine.

Finally, the nurse serving all the heart failure patients at the Fletcher Allen Cardiology Department provided the clinical perspective. The clinic's cardiologists were
not part of the study team. While the voice of the nurse is an important one in PHR research, the lack of physician input is a limitation.

**Implications and Recommendations**

PHRs are useful and usable for computer literate heart failure patients. As predicted by adoption theories, patients will use PHR features that they find usable and are more convenient than other ways of performing the same task or that have added benefits. Use of the daily journal for recording and monitoring weight, vital signs, and heart failure symptoms can be useful, but adherence to daily monitoring is hard to maintain over time. Making recording more convenient by expanding the PHR to mobile applications, incorporating physicians in the process of initiating and promoting the daily journal, and targeting patients most in need of active monitoring may improve usage.

At Fletcher Allen there is interest in extending the use of the daily journal and expanding its use to include enrolling hospitalized heart failure patients as they are discharged. One vision is that patients would be enrolled in MyHealth and the daily journal in the hospital. They would learn to record their data as part of their DAMES education, establishing the MyHealth entry as part of their DAMES routine. They would then be actively monitored through MyHealth until they were stable, and able to record, monitor and evaluate their symptoms independently. Implementation of the vision will involve coordination between the heart failure nurse, cardiologists, inpatient nurses, and hospitalists. As not all heart failure patients are followed by the cardiology clinic, or even by a Fletcher Allen PCP, outreach will need to extend to other clinics as well. Organizational buy-in, active coordination and monitoring, a designated heart failure nurse or team, and clinician engagement and education will be necessary.
The PHR could be used in the management of other chronic conditions such as asthma, cystic fibrosis, diabetes, and obesity, or to support families and caregivers engaged in hospice and palliative care. Development and implementation should focus on providing a convenient value-added tool, with clinical oversight, provider acceptance, and communication practices that allow for the development of a deep, personal relationship between client and clinician.

MyHealth is a PHR tethered to Fletcher Allen's EHR. Implementing a tethered PHR in a large health care organization involves input from disparate teams. At Fletcher Allen these included a steering committee, marketing, web development, and PRISM programming teams. It is important that the teams work together and adhere to established best-practice guidelines. Incorporating iterative usability testing with patients from a wide variety of backgrounds throughout the development process and following best-practice usability standards are two important practices not followed in Fletcher Allen's implementation.

Although tethered PHRs are owned and paid for by health care organizations, including patients in policy decisions might lead to a more useful application. If the organization wants to move from a hierarchical model of physician-patient interaction to a shared model, sharing the decisions about what types of data will be shared in the PHR and with whom patients can communicate seems essential. Patient input through surveys of PHR patients could be used to evaluate the completeness and usefulness of PHR functions, and overall PHR satisfaction.

As patients used the tethered PHR they envisioned a system with untethered capability that would allow them to add their own fields and comments to the daily
journal, communicate with out-of-service providers, enter additional test results, and access the data on their smart phone. They envisioned an integrated PHR. Development needs to continue toward this goal.

Finally, it is imperative that the interoperability of EHR systems be addressed. Without so doing we risk substituting a system of fractured stand-alone paper charts for one of fractured stand-alone EHRs, and the transformative power of bringing health records into the electronic age will be compromised.

**Summary**

PHRs are an emerging health care technology that allow patients to access and in some cases manage their health records. PHRs can be stand-alone systems managed entirely by individual patients; tethered systems owned by organizations using EHRs who manage and control security, access, and content; or integrated systems that receive updates from a variety of systems. PHR advocates speculate on the potential benefits of patient access to their health care information, enhanced asynchronous communication between patients and clinicians, and convenience of online appointment scheduling and prescription refills, although little actual research has been conducted. Potential barriers to PHR use include lack of computer and internet access, poor computer or health literacy, security concerns, and provider disengagement.

As medical care improves and lifespans increase, the number of people with one or more chronic conditions is rising. The PHRs' information and communication features may help those with chronic conditions monitor and manage their disease, communicate with their health care team, and adhere to clinical recommendations. One such chronic condition is heart failure, a life-long progressive set of symptoms caused by the heart's
inability to pump strongly enough to meet the body's metabolic demands. Over five million Americans have heart failure and Medicare spends more on heart failure than any other diagnosis. It is a costly, debilitating disease. Heart failure management involves diet, activity, medication, weight, and symptom monitoring and management.

In our increasingly urban environment, those living in rural areas face unique challenges due to their distance from services. Compared to their urban counterparts, those living in rural areas tend to be older, less educated, poorer, and sicker. Rural heart failure patients have poorer outcomes than those living in cities, although telecommunication strategies for linking rural patients with providers have proved helpful. There is little research on the effect of PHRs on rural health.

The potential of PHRs will only be achieved if they are used. PHR users form a small but growing segment of the population. Two key features for adoption of any technology, including PHRs are ease of use and usefulness. Fletcher Allen Health Care, an academic medical center in northern Vermont implemented an EHR (PRISM) in 2009 and a tethered PHR (MyHealth) in 2011, providing the opportunity to examine the usability, usefulness, and disease management potential of a PHR for heart failure patients living in a rural area through this exploratory study.

The Cardiology heart failure nurse identified MyHealth features that would support patients' heart failure management. In addition to existing MyHealth features, new functionality was proposed to allow patients to communicate directly with the heart failure nurse and to enter daily symptom monitoring information (weight, blood pressure, pulse, energy, swelling, and breathing levels) into MyHealth. The new functionality was developed and tested, and made available. Following Institutional Review Board
approval from the University of Vermont who oversees research at Fletcher Allen, and from Nova Southeastern University, 15 participants were enrolled for a period of three months.

A descriptive mixed methods design that combined quantitative and qualitative approaches was used. Data were collected through two face-to-face semi-structured interviews, observations of a usability study of participants performing specified tasks in MyHealth, computer-generated reports of participants' MyHealth usage, and an interview with the heart failure nurse.

Issues identified in the eight-task usability study primarily fell into three broad categories: a) screen layout; b) applying a consistent, standard format to buttons, labels, and links; and c) providing concise, clear instructions in a hierarchical format that supports quick scanning for relevant material rather than careful reading for nuance. The issues can be resolved by applying existing best-practice guidelines to the site.

Participants used MyHealth features that were more convenient than other methods, or had some additional benefit. Which features met these criteria varied by user; what one found useful another found irrelevant. Explanations for why a feature was used fit well with theoretical models of technology adoption.

There was no appreciable difference in the PHR experiences of rural and urban participants. Both relied on the telephone for emergent issues, reserving MyHealth for asynchronous tasks.

Living with heart failure requires management of diet, activity, medication, and symptom monitoring. Participants had various management methods. The heart failure nurse promoted the recording of daily symptoms in MyHealth with participants as they
were enrolled in the study. Eleven of the thirteen participants used the MyHealth daily journal at least once, but most found it difficult to record in the journal daily. For all but the participant using an iPad, recording was not convenient because their scale, blood pressure cuff, and computer were not co-located. They had to write down their results and then login to the computer and report them. Some entered their data in batches rather than daily. Others lost computer access for various reasons and once it was restored did not resume recording. When asked why they recorded, subjects cited the comfort and security of having the heart failure nurse monitoring the data, and the fact that the data were now in their EHR. Participants who were stable and comfortable with their heart failure did not see the same benefit to the MyHealth daily journal as did those who were newly diagnosed or whose symptoms were unstable. Participants liked the ability to communicate with the heart failure nurse directly and sent her messages about their health status which they would not otherwise have communicated.

In spite of the fact that participants did not uniformly use the daily journal, the heart failure nurse found the data extremely beneficial. She suggested that a greater involvement from the physicians might have improved its use. The lack of physician participation is a limitation of the study. Moving forward, Fletcher Allen is planning to continue to use the daily journal with patients for whom clinical monitoring is warranted. Physicians will be involved in patient selection and monitoring.

The study expands the knowledge of PHR use and adoption by addressing useful functionality and disease management tools among a group of patients with heart failure living in northern Vermont and New York. The patients were able to use the application to complete tasks they found useful. The increased communication and disease
management tools were useful for some participants and very useful for the heart failure nurse. These tools could be expanded to help patients with other chronic diseases.
Appendix A

University of Vermont Institutional Review Board Approval

CHRMS: M11-232

Protection of Human Subjects Assurance

Title: Personal Health Records and Disease Management for Rural Heart Failure Patients
Principal Investigator: Karen Baron
Institution: University of Vermont and State Agricultural College, Burlington, VT 05405

This institution has an approved assurance of compliance on file with the Department of Health and Human Services which covers this activity.

Assurance number for University of Vermont and State Agricultural College: FWA 00000723
IRB number: IRB 00000683 Expiration Date: July 31, 2012
(Fletcher Allen Health Care Assurance number: FWA 00007277)

Certification of IRB Review

This activity has been reviewed and approved by an IRB in accordance with the requirements of 45 CFR 46, including its relevant Subparts; and, when applicable, with the requirements of 21 CFR 50 and 21 CFR 56.

Date of approval MAY 25 2011 Date of expiration MAY 24 2012

IRB Review Type: Expedited review

Institutional Signature/Date: 5/25/11
Name and Title of Official: David A. Kaminsky, M.D., Associate Chair, Committee on Human Research in the Medical Sciences
Appendix B

Nova Southeastern University Institutional Review Board Approval

NOVA SOUTHEASTERN UNIVERSITY

MEMORANDUM

To: Karen Baron, Ed.S.
   Graduate School of Computer and Information Sciences

From: David Thomas, M.D., JD
   Vice-Chair, Institutional Review Board

Date: July 14, 2011

Re: Incorporating Personal Health Records into the Disease Management of Rural Heart Failure Patients – Research Protocol No. 06201105Exp.

I have reviewed the revisions to the above-referenced research protocol by an expedited procedure. On behalf of the Institutional Review Board of Nova Southeastern University, Incorporating Personal Health Records into the Disease Management of Rural Heart Failure Patients is approved in keeping with expedited review categories #6 and #7. Your study is approved on July 14, 2011 and is approved until July 13, 2012. You are required to submit for continuing review by June 13, 2012. As principal investigator, you must adhere to the following requirements:

1) CONSENT: You must use the stamped (dated consent forms) attached when consenting subjects. The consent forms must indicate the approval and its date. The forms must be administered in such a manner that they are clearly understood by the subjects. The subjects must be given a copy of the signed consent document, and a copy must be placed with the subjects’ confidential chart/file.

2) ADVERSE EVENTS/UNANTICIPATED PROBLEMS: The principal investigator is required to notify the IRB chair of any adverse reactions that may develop as a result of this study. Approval may be withdrawn if the problem is serious.

3) AMENDMENTS: Any changes in the study (e.g., procedures, consent forms, investigators, etc.) must be approved by the IRB prior to implementation.

4) CONTINUING REVIEWS: A continuing review (progress report) must be submitted by the continuing review date noted above. Please see the IRB web site for continuing review information.

5) FINAL REPORT: You are required to notify the IRB Office within 30 days of the conclusion of the research that the study has ended via the IRB Closing Report form.


Cc: Dr. Ling Wang
   Dr. Trudy Abramson
   Ms. Jennifer Dillon
Appendix C

Recruitment Brochure
YOUR RESEARCHERS

Karen Baron is the Training Coordinator for Fletcher Allen's electronic health record – PRISM. She's excited about PRISM's expansion to MyHealth Online – your access into PRISM, and how it can help you monitor and maintain your health.

She's been working on her PhD at Nova Southeastern University for several years. Her interest is in using technology to enhance education and learning.

Cindy Wolkin, RN BSN is program coordinator and nurse educator of the Heart Failure Program of University Cardiology Associates at Fletcher Allen Health Care.

HOW DO I PARTICIPATE?

The Cardiology Department's heart failure nurse, Cindy Wolkin, will introduce the study to you. If you are interested in participating, she will pass your contact information onto Karen Baron, the study researcher.

Ms. Baron will contact you by phone and discuss the study in more detail with you. If you are willing to participate, she'll send you the study enrollment forms and schedule your first interview.

Questions? Contact us at:

- Cindy Wolkin at (802) 847-4283 or by email at HF@vtmednet.org
- Karen Baron at (802) 847-7763 or by email at karen.baron@vtmednet.org

MyHealth Online:
A Tool to Help Manage Your Heart Failure?
Help us find out by participating in our MyHealth Online Study

Fletcher Allen Health Care
In alliance with The University of Vermont
WHO CAN PARTICIPATE?
Fletcher Allen Health Care Cardiology Department patients who
- have heart failure
- have access to a computer
- have the necessary basic computer skills to use MyHealth Online

WHAT IS MYHEALTH ONLINE?
MyHealth Online is your view into PRISM, Fletcher Allen’s new electronic medical record. When you access MyHealth on the Internet you can review your health information, communicate with your doctor, schedule office visits, and renew your prescriptions.

MyHealth Online is available to all Fletcher Allen patients.

WHAT ABOUT MY HEART FAILURE?
You can record and track your daily weights, blood pressure, energy, breathing, and swelling in MyHealth Online. MyHealth's graphs can help you monitor them. Because they are in your chart, your Heart Failure nurse can view them too.

Your Heart Failure nurse can send you questionnaires through MyHealth and monitor your answers. The two of you can email through MyHealth's secure messaging feature.

MyHealth Online can let you know about upcoming Heart Failure classes and support groups.

IS IT USEFUL?
Is MyHealth Online useful? You can help answer this question by participating in our MyHealth Online and Heart Failure study.

WHAT IS INVOLVED?
The study begins with an hour interview with Karen Baron. In the initial interview we'll discuss your computer experience and then have you look at a sample patient's MyHealth Online chart. You'll be asked to complete several tasks in the chart and rate their usefulness. Then you'll be given access to your own MyHealth Online chart.

Over the next three months, you'll be able to use MyHealth Online as often as you'd like.

After three months, you'll meet with Karen Baron again and discuss your thoughts about MyHealth Online with her. The Heart failure features of MyHealth Online are being developed specifically for this study. Your input will help determine which of them become available for all heart failure patients in the future.

Institutional Review Board
Approval Date: JUL 14 2011
Continuing Review Date: JUL 13 2012
Appendix D

Informed Consent Form

Informed Consent

Title of Research Project: Incorporating Personal Health Records into the Disease Management of Rural Heart Failure Patients

Principal Investigator: Karen Baron, Ed.S.

Local Faculty Sponsor: Cate Nicholas, Ed.D.

You are being invited to take part in this research study because you are
- a Fletcher Allen Health Care Department of Cardiology patient with heart failure
- who has access to a computer and
- who has the basic computer skills necessary to use the program being studied.

This study is being conducted by a Fletcher Allen Health Care employee who is a student in the Graduate School of Computer and Information Sciences at Nova Southeastern University in Ft. Lauderdale, Florida.

We encourage you to ask questions and take the opportunity to discuss the study with anybody you think can help you make this decision.

Why is This Research Study Being Conducted?
The purpose of this study is to examine the usefulness of a computerized Personal Health Record called MyHealth Online. MyHealth Online is your view into PRISM, Fletcher Allen's electronic health record. It's accessible over the internet. This study will examine how easy it is for you to use the MyHealth Online program, what features are most useful to you, whether you find the information in the program understandable, and whether you feel the program can help you manage your heart condition.

How Many People Will Take Part In The Study?
Approximately 25 individuals will take part in this study

What Is Involved In The Study?
At the beginning of the study you will be asked about your computer experience. You'll be asked to examine a sample patient in the MyHealth Online Program on a computer. You will be asked to complete several tasks in MyHealth Online to see how easy it is to use. The computer will record your typing and mouse clicks. You will then be asked to complete a questionnaire that asks your opinion about the program. This session will be audio taped. It will take approximately one hour and will be done at the Fletcher Allen
Health Care main hospital, the Department of Cardiology at Tilley drive, or at a different location convenient to you.

Then you will be given access to your own information in the *MyHealth Online* program for three months and you will be asked to use the program in whatever ways you find useful. As you do so, the features you use will be automatically tracked allowing the researcher to identify which features you use and how often. It is important to note that the tracking will only gather information about which features you use and how often. It will not gather your health information nor the content of any electronic communication between you and your doctors or nurses that takes place in the *MyHealth Online* Program. During the three months, you will not be required to use the *MyHealth Online* program for a specific amount of time. How often you use *MyHealth Online* will be up to you.

After 3 months, you will again meet with the researcher. You will be asked about your involvement with the *MyHealth Online* program – which features you found useful, which features you did not, and why. This session will be audio taped. It will take approximately one hour and can be done at the Fletcher Allen Health Care main hospital, the Department of Cardiology at Tilley drive, or at a different location convenient to you.

During the study, the following information will be collected:
- Basic information about you including your name, age, medical record number, gender, and ZIP code
- Information and recordings from your initial and final interviews with the researcher
- A log of the dates, times, and sections of *MyHealth Online* you use during the study.
- The dates of any cardiology office visits and telephone calls to and from your heart failure nurse.

This study will **not** collect the content of your *MyHealth Online* use or communication between you and your heart failure nurse.

**What Are The Risks and Discomforts of The Study?**
The risks of participation in this study are minimal, meaning they are not thought to be greater than other risks you experience every day. There is the potential risk for an accidental breach of confidentiality. Professional standards will be followed to ensure that your confidentiality is being protected. You may find using a new computer program frustrating. If participating in this study becomes burdensome, you may stop at any time.

**What Are The Benefits of Participating in The Study?**
You may find that the information provided and the on-line communication available through the *MyHealth Online* program to be useful in your disease management. At the societal level, researchers are studying how to make Personal Health records such as *MyHealth Online* useful for patients with specialized health needs. Two groups identified for focused research attention are those with Heart Failure and those who live in rural areas. Your participation in this research study will contribute to this ongoing research question.
What Other Options are There?
You have the option not to participate in the study.

Are There Any Costs?
The only cost to you is the time it takes to participate in the study

What Is the Compensation?
You will not be paid for participating in this study.

Can You Withdraw or Be Withdrawn From This Study?
You have the right to leave this study at any time or to refuse to participate. You may discontinue your participation in this study by letting Karen Baron know by phone (802 847-7763), email (karen.baron@vtmednet.org) or in writing (Karen Baron, Fletcher Allen Health Care, PRISM ACC 2247, 111 Colchester Ave, Burlington, VT 05401). If you do decide to leave or you decide not to participate, you will not experience any penalty or loss of services you have a right to receive.

If your heart failure nurse feels that your participation in the study is in any way proving to be detrimental to your health, you will be notified of this fact and the reasons why by phone, email, and in writing, and will be withdrawn from the study.

Any information collected about you before you leave the study will be kept in the research records for three years from the conclusion of the study and may be used as a part of the research. In addition, since your feedback is important to the study, you will be contacted and invited to share it with the researcher if you wish to do so.

What About Confidentiality?
All information obtained in this study will be maintained in a confidential manner unless disclosure is required by law. The information will be stored in a locked file cabinet in the researcher's home office and destroyed by erasing computer files and shredding paper and audio tapes 36 months after the study is complete. Your information will be stored under a subject number generated for the study, not under your name. A key linking your name to your subject number is needed to link your initial interview, MyHealth use, and final interview. This key will be stored in the locked file cabinet in the researcher's home office and destroyed with the other documents after 36 months.

This research project will include audio recordings of your initial and final interviews. The audio recording will be transcribed by a transcriptionist hired by the researcher. The audio recording will be kept securely in the researcher's home office in a locked cabinet. The audio recording will be kept for 36 months and destroyed after that time by shredding. Because your voice may be potentially identifiable by anyone who happens to hear the recording, your confidentiality cannot be completely guaranteed. The researcher will limit access to the tape as described in this paragraph.
Upon request the Institutional Review Board and the researcher's dissertation chair (faculty sponsor) will be granted direct access to your original research records for verification of research study procedures and/or data.

The results of this study will be used in the researcher's doctoral dissertation and may eventually be published. Your name will not be revealed.

Contact Information

You may contact Karen Baron, the Investigator in charge of this study, at 802-847-7763 for more information about this study. If you have any questions about your rights as a participant in a research project or for more information on how to proceed should you believe that you have been injured as a result of your participation in this study you should contact Nancy Stalnaker, the Director of the Research Protections Office at the University of Vermont at 802-656-5040. You can also contact the Nova Southeastern University Human Research Oversight (Institutional Review Board or IRB) with questions regarding your research rights at 866-499-0790.

What Funding Sources does this study have?
There are no funding sources for this project. All costs associated with the study are being paid by the researcher.
Statement of Consent

You have been given and have read or have had read to you a summary of this research study. Should you have any further questions about the research, you may contact the person conducting the study at the address and telephone number given below. Your participation is voluntary and you may refuse to participate or withdraw at any time without penalty or prejudice.

You agree to participate in this study and you understand that you will receive a signed copy of this form.

________________________________________  __________________________
Signature of Subject                  Date

________________________________________
Name of Subject Printed

________________________________________  __________________________
Signature of Principal Investigator         Date

________________________________________
Name of Principal Investigator

**Principal Investigator:**  
Karen Baron, Ed.S.  
Fletcher Allen Health Care  
PRISM ACC 2247 (483 WP2)  
111 Colchester Ave  
Burlington, VT 05401  
karen.baron@vtmednet.org  
(802) 847-7763

**Faculty Sponsor:**  
Trudy Abramson, Ed.D.  
Nova Southeastern University  
GSCIS / NSU  
3301 College Avenue  
Fort Lauderdale, FL 33314-7796  
abramson@nova.edu  
1-800 -986-2247 extension 22070

**Local Faculty Sponsor:**  
Cate Nicholas, EdD  
Director, Clinical Skills Education  
College of Medicine  
UVM/FAHC Clinical Skills Laboratory  
237 Rowell  
106 Carrigan Dr.  
Burlington, VT 05405  
cate.nicholas@uvm.edu  
(802) 238-0698
Appendix E

HIPAA Consent Form

AUTHORIZATION FORM

AUTHORIZATION TO PERMIT THE USE AND DISCLOSURE OF PERSONAL HEALTH INFORMATION FOR RESEARCH PURPOSES

TITLE OF STUDY: Incorporating Personal Health Records into the Disease Management of Rural Heart Failure Patients

PRINCIPAL INVESTIGATOR NAME: Karen Baron
ADDRESS:
Fletcher Allen Health Care
PRISM ACC 2247 (483 WP2)
111 Colchester Ave
Burlington, VT 05401
karen.baron@vtmednet.org
(802) 847-7763

CHRMS NUMBER: M11-232

Purpose and Scope of Authorization

You have agreed to participate in the study identified above, and have signed a separate consent form that explains the study procedures and provides representations regarding the confidentiality of your personal health information.

This Authorization is required by privacy regulations that are a part of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”), and other applicable laws. Any health care provider who is subject to the HIPAA Privacy Regulations is referred to in those regulations as a “Covered Entity” (meaning, it is governed by those regulations).

This Authorization applies to each Covered Entity who maintains personal health information about you that is relevant to this research study. Fletcher Allen Health Care, Inc. (“FAHC”) is one such Covered Entity. As of the date that you sign this Authorization, others include

Principal Investigator

_____________________________________________________________
This Authorization legally permits FAHC and other Covered Entities, even if they are not identified by name in this document, to use and disclose your personal health information for this research study, but only in accordance with the restrictions set forth below. A Covered Entity might not be identified by name above because at the time you signed this Authorization, we may not have known that the Covered Entity maintained personal health information about you that was relevant to the research study.

The HIPAA Privacy Regulations use a special term to identify your personal health information – they call it “protected health information”, or “PHI”, for short. We refer to “PHI” below to mean your personal health information.

This Authorization gives you detailed information about how your PHI will be used, disclosed and protected in the context of this study, and answers the following questions:

- What PHI about you will be used or disclosed by a Covered Entity?
- Who within each Covered Entity may use or disclose your PHI?
- To whom may a Covered Entity disclose your PHI?
- How long will a Covered Entity be able to use or disclose your PHI?
- Will you be able to access your PHI associated with this study?
- What happens if you decide not to sign this Authorization?
- Can you change your mind and revoke this Authorization?
- What happens once your PHI has been disclosed by a Covered Entity?
- Will the results of the study be presented in publications?
- Who should you contact with any questions or concerns regarding your privacy rights?

1. **What PHI about you will be used or disclosed by a Covered Entity?**

The following PHI may be used by a Covered Entity, or disclosed to authorized persons by a Covered Entity, in connection with your involvement with this research study.

- Basic personal demographic information, including name, address, medical record number, date of birth, occupation, marital and family status, and similar information.
- Pre-existing health information pertaining to you that the researchers will need to use in connection with the performance of the study, such as, inpatient medical records, outpatient medical records, primary care physician’s notes (such as internists, family practitioners, obstetrician-gynecologists), specialist’s notes (such as surgeons, oncologists, cardiologists, and others as needed). We will review your records as few years back as necessary to gather the pertinent information to perform this study. We will not access mental health records as it is not relevant to this study.]
- All of the health information resulting from the tests, procedures, medications and other treatments you will receive in the course of this research study.
These tests, procedures, medications and treatments are set forth in the consent form that you signed, and can be found under the What Is Involved In The Study?

- section of the consent form. More specifically, the types of tests, procedures, medications and other treatments include:

  - Relevant medical diagnoses (your Heart Failure diagnosis)
  - Information and recordings from your initial and final interviews with the researcher
  - A log of the dates, times, and sections of My Chart you use during the study.
  - The dates of any cardiology office visits and telephone calls to and from your heart failure nurse.

2. Who within each Covered Entity may use or disclose your PHI?

The following persons or classes of persons within each Covered Entity are authorized to use or disclose your PHI for this research study:

- The Principal Investigator (the individual with primary responsibility for the research project) and the Principal Investigator’s study team, to the extent such persons are employees of a Covered Entity, for the purpose of conducting the study;
- Employees of a Covered Entity’s Health Information Management Department (or other holder of health records), for the purpose of managing the proper release of your PHI for this research study;
- Health care providers employed by a Covered Entity, for the purpose of (1) fulfilling orders made by the investigators for health care services (e.g., laboratory tests and diagnostic procedures) associated with the research study; (2) addressing correct payment for tests and procedures ordered by the investigators; and (3) for internal operations (e.g., quality assurance);
- Other employees of a Covered Entity who may reasonably need to access your PHI, for the purpose of performing their jobs (e.g., to ensure the integrity of the research, to ensure proper billing for treatment associated with the research, to ensure appropriate grant accounting, for billing and auditing, to maintain records resulting from the research, and for other similar and related matters);
- Other employees of a Covered Entity who may need to access your PHI, for the purpose of treatment, payment and health care operations, as such terms are explained in a Notice of Privacy Practices previously provided by each Covered Entity to you;
3. **To whom may a Covered Entity disclose your PHI?**

As part of this study, a Covered Entity may disclose your PHI (including the results of study tests and procedures), to the following persons or classes of persons:

- The Principal Investigator and the Investigator’s study team, to the extent such persons are not employees of a Covered Entity, for the purpose of conducting the study;
- The University of Vermont (“UVM”) Institutional Review Boards (or other institutional review boards), for the purpose of overseeing the protection of human subjects;
- Health care providers who are not employed by a Covered Entity, for the purpose of (1) fulfilling orders made by the investigators for health care services (e.g., laboratory tests and diagnostic procedures) associated with the research study; (2) addressing correct payment for tests and procedures ordered by the investigators; and (3) for internal operations (e.g., quality assurance);
- Authorized representatives of other medical centers or institutions participating in the research study, including members of any data safety monitoring board established for this study, for the purpose of enabling their full and active involvement in the research study;
- Authorized representatives of regulatory agencies, for the purpose of monitoring the research;
- UVM employees who may reasonably need to access your PHI, for the purpose of performing their jobs (e.g., to ensure the integrity of the research, to ensure proper billing for treatment associated with the research, to ensure appropriate grant accounting, for billing and auditing, to maintain records resulting from the research, and for other similar and related matters);

4. **How long will a Covered Entity be able to use or disclose your PHI?**

This Authorization for this specific study does not expire. Your PHI may be maintained in a research repository (i.e., a database) by a Covered Entity for this specific study. However, a Covered Entity may not re-use or re-disclose your PHI collected in this study for another purpose other than the research described in this document unless you have given written permission for the Covered Entity to do so or the Covered Entity has obtained permission to do so from an Institutional Review Board in accordance with applicable laws. An Institutional Review Board is a committee whose job it is to protect the safety and privacy of research subjects.

5. **Will you be able to access your PHI associated with this study?**

You will be able to have access to your PHI that is created or obtained by a Covered Entity in the course of this research study, to the extent such access is otherwise permitted by applicable laws, but only after this study has concluded. You will not be able to access the PHI during your participation in the study, to prevent the knowledge of
study results from affecting the reliability of the study. Nevertheless, your PHI will be available to your treating doctors should an emergency arise that would require those doctors to know this information to best treat you.

6. **What happens if you decide not to sign this Authorization?**

You are not obligated to sign this Authorization. However, if you decide not to sign the Authorization, you will not be allowed to participate or continue to participate in the research study, which means you will not be entitled to receive any treatment related to the research. A decision to not sign this Authorization will otherwise have no effect on your current or future medical care from a Covered Entity or payment for that medical care, nor will it cause any penalty or loss of benefits to which you are otherwise entitled or eligible.

7. **Can you change your mind and revoke this Authorization?**

You may withdraw your permission for the use and disclosure of any of your PHI for this research study, but you must do so in writing to the Principal Investigator at the address set forth above. Even if you withdraw your permission, the Principal Investigator for the research study may still use and disclose your PHI that was collected before your written request, to the extent necessary to preserve the integrity of the study. If you so withdraw, you may no longer participate in the research study.

8. **What happens once your PHI has been disclosed by a Covered Entity?**

We believe that most institutions involved with research understand the importance of preserving the confidentiality of participant health information. However, once a Covered Entity discloses your PHI, in a manner permitted by this Authorization, a re-disclosure of your PHI by the recipient will not be covered by this Authorization, and may not be subject to the HIPAA Privacy Regulations or other privacy laws. Of course, each Covered Entity and UVM agree to protect your PHI by using and disclosing it only as permitted in this Authorization and as directed by state and federal law.

9. **Will the results of the study be presented in publications?**

The results of the research study may be presented in publications, however names and other personally identifying information about you and other research participants will not be revealed in such publications.
10. Who should you contact with any questions or concerns regarding your privacy rights?

If you have any questions or concerns about your privacy rights, you should contact the Principal Investigator at 802-847-7763 or the Privacy Officer at the appropriate Covered Entity. For FAHC, the Privacy Officer is Michael Hawkins and he can be reached at (802) 847-3532.

All of the above has been explained to me and all of my current questions have been answered. I understand that, throughout my participation in the research study, I am encouraged to ask any additional questions I may have about the research use and disclosure of my PHI. Such future questions may be answered by the Principal Investigator or the Investigator’s study team.

I have read this Authorization, and acknowledge that I am the research subject or authorized to act on behalf of the research subject. By signing this Authorization, I agree to allow the use and disclosure of my PHI for the purposes described above, and I agree to the other terms identified above. A copy of this Authorization (as signed below) will be given to me.

_______________________________  ___________________________  _________________
Subject’s Name [print]               [Signature]  Date

_______________________________  ___________________________  _________________
Person obtaining authorization [print]  [Signature]  Date
Fifteen Fletcher Allen patients with a heart failure diagnosis and basic computer skills were completed a MyHealth usability study, conducted from December 2011 – April 2012. The study took approximately 25 minutes of the participant’s initial one-hour interview. Eight MyHealth topics were explored: Health Summary (including health issues, medications, allergies, and immunizations), results, the heart failure daily journal, messaging, questionnaires, appointments, heart failure prevention education resources, and prescription refills.

Testing was done in a quiet, private space – usually at Fletcher Allen, although two were conducted in the participant’s home. Testing was done on a Dell Inspiron laptop with a 14 in (35.6 cm) display, a screen resolution of 1366 x 768 pixels, and an external keyboard and mouse. The website was accessed via Internet Explorer 8. To maximize the viewing area, all toolbars that could be closed were, and the taskbar at the bottom of the screen was hidden.

For each topic participants were asked to complete a set of tasks in a sample chart. Participants began with the Health Summary topic after which they completed as many of the remaining tasks as they could in the allotted 25 minutes – on a rotating basis. Subject 1 started with results, Subject 2 with the daily journal, and so on. No one completed all eight tasks. Andrew MyHealth, the study patient, was developed in conjunction with the cardiology heart failure nurse. He had a "robust" problem list and medication list. His
results included an echocardiogram stress test, and BUN and potassium labs. He was
designed to have a health profile similar to those of the participants. Participants
completed the usability tasks in Andrew MyHealth’s MyHealth account on the test
MyHealth website.

After completing the tasks participants answered a series of questions about their
satisfaction on a Likert scale ranging from 1 (agree) to 7 (disagree). The question
included the three items in the standard usability After Scenario Questionnaire and other
questions specific to MyHealth in the same format. Usability findings and
recommendations are described below, beginning with general recommendations for
screen layout, site conventions, and instruction clarity. These are followed by a detailed
examination of the Healthwise feature and each of the eight tasks and their outcomes.

**General Recommendations**

Most usability problems arose due to issues of screen layout, lack of clear and
consistent site conventions, and instruction clarity, as described in Chapter 4.

Recommendations for these areas are provided.

*Screen Layout*

- Reduce the need for scrolling by reducing header height and removing white space
- Rework left-column options on the home page

*Site Conventions*

- Display buttons with a three-dimensional look
- Display links with a consistent color and underlined text
- Use standard terminology in labels and links
Instruction Clarity

- Rewrite instructions to provide shorter, clearer prose
- Include specific details of MyHealth rules in the FAQ section
- Create a clear visual hierarchy through text size and placement to make necessary instructions clearer to the user
- Display what-will-happen-next details on final communication screens. Include the name of the provider or clinic to whom the message was sent
- Provide warning pop-ups when users leave communication screens without completing the task

Healthwise

Patient education material supplied by Healthwise is available through MyHealth. Users can use the Health Library to look up information. Additionally, information on medical problems, medications, and tests are available through links attached to their names.

Participants found this information accessible, understandable, informative, and complete. For example, one participant commented "Boy, it really goes very extensively through the uses of beta blockers," during her examination of Andrew MyHealth’s medications.

The Healthwise information opens in a new window that’s smaller than the MyHealth window. Participants needed to enlarge the window to easily view the information. The larger size did not "stick," causing participants to have to enlarge or
maximize it every time it was opened. MyHealth links were not displayed in a consistent manner.

**Recommendations:**

- Enlarge the default size of the Healthwise window
- When the user changes the window size, store this as the default for when it next opens
- Underline all links

**Medical Information - Health Summary**

**The Task**

MyHealth allows patients to access their medical information and manage their billing and insurance information. I’d like you to access the patient’s medical information and view their health summary.

1. Access Andrew’s Medical Information
2. Access his health summary
3. Examine his
   a. Health Issues
   b. Medications
   c. Allergies
   d. Immunization
Results

Table 3. Medical Information Task Summary Statistics

<table>
<thead>
<tr>
<th>Summary Statistics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>15</td>
</tr>
<tr>
<td>Minutes to complete task</td>
<td>1-8 (M 3.6, SD 2.1)</td>
</tr>
<tr>
<td>Completed task with no problem or self-correction</td>
<td>87% (13)</td>
</tr>
<tr>
<td>Needing prompting</td>
<td>13% (2)</td>
</tr>
<tr>
<td>Understood information (investigator evaluation)</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 4. Medical Information Task Satisfaction Question Means

<table>
<thead>
<tr>
<th>Question</th>
<th>Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was able to understand the information</td>
<td>1.2 (SD 0.5)</td>
</tr>
<tr>
<td>I was able to identify the patient’s medication from the generic names supplied.</td>
<td>1.7 (SD 1.5)</td>
</tr>
<tr>
<td>I think this information will be useful to me</td>
<td>1.4 (SD 0.8)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the ease of completing this task.</td>
<td>1.1 (SD 0.3)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the amount of time it took to complete this task.</td>
<td>1.2 (SD 0.5)</td>
</tr>
<tr>
<td>Overall Mean</td>
<td>1.3 (SD 0.5)</td>
</tr>
</tbody>
</table>

* Likert Scale from 1 (Agree) to 7 (Disagree)

Discussion

Participants began this task from the MyHealth Home. There are three ways to access the Medical Information: the tab at the top, the icon beside the Medical Information title, and the button at the bottom of the screen (see Figure 7).

Due to the screen size, the bottom button was not visible. People tried a number of things to open the Medical Record section: clicking the bullet points; clicking the Medical Record title, which is a dark blue, the common color of links; and hovering over, considering, and then rejecting the links on the far left. Everyone eventually opened the section via the icon. No one used the upper page tab.
On the medical information page, "View your health summary" is a prominent link. The same information is available through the Medical Record section on the left, either through the Health Summary section or by accessing Health Issues, Medications, Allergies, and Immunizations individually (see Figure 8).

All but one participant accessed the information via the "View your health summary" link or icon. The other participant used the individual Medical Record links to access the four topics.
Participants spent more or less time looking at the information. Many of the medications were familiar to them. Many participants clicked the medication name and were brought to the Healthwise information on the medication which participants found accessible and complete. They tended to be satisfied with accessing the information. As one commented, "Now that was pretty easy, and I don’t have a lot of patience."

Recommendation:

- Make the Medical Information and Billing and Insurance titles on the home page links to those areas

Results

The Task

Patients have access to their test results.
1. Access Andrew’s Test Results
2. Examine the results listed below – Find them and try to understand them
   a. Echo Results
   b. BUN results
   c. Potassium Results
Results

Table 5. Results Task Summary Statistics

<table>
<thead>
<tr>
<th>Summary Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
</tr>
<tr>
<td>Minutes to complete task</td>
</tr>
<tr>
<td>Completed task with no problem or self-correction</td>
</tr>
<tr>
<td>Needing prompting</td>
</tr>
<tr>
<td>Needed specific instruction</td>
</tr>
<tr>
<td>Understood information (investigator evaluation)</td>
</tr>
</tbody>
</table>

Table 6. Results Task Satisfaction Question Means

<table>
<thead>
<tr>
<th>Question</th>
<th>Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was able to find the test results easily</td>
<td>1.3 (SD 0.5)</td>
</tr>
<tr>
<td>I was able to understand the information in the reports</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>I think this information will be useful to me</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the ease of completing this task.</td>
<td>1.2 (SD 0.4)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the amount of time it took to complete</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>this task.</td>
<td></td>
</tr>
<tr>
<td>Overall Mean</td>
<td>1.1 (SD 0.1)</td>
</tr>
</tbody>
</table>

* Likert Scale from 1 (Agree) to 7 (Disagree)

Discussion

Test results are not on the main page when opening medical information. They are in the Medical Record section of MyHealth (see Figure 9.) The Medical Record section was open for participants as they started this task because completing the first task, accessing the Health Summary, caused it to open. All participants were able to open the Test Results section. Although not underlined, test names, displayed in blue, were links to the result information. Text on the screen instructed the user to click a row to view test results. All but one participant opened the test and viewed their results independently. One participant needed specific instruction to complete this task, despite the instructions provided on the screen.
Time differences between participants were primarily due to time spent reading the results. Many participants used the link to Healthwise and read about the study. One participant commented that she would spend more time on her own results.

The provider added a comment for the Echo and BUN results (see Figure 10). Half the users did not notice either comment. The other half only noticed one or the other. When asked about this, one user replied

I’ll tell you what, I read almost everything on that page, and I’ll tell you and I’ll be honest with you, I don’t think I did [see the comment]. I just think I skipped over it. … And it’s in red compared to the black... And that’s really what you want. You read all that technical stuff. But you really want to know, "What did the doctor think?"

The rules for releasing results to MyHealth are complex. The rules are not available to patients in MyHealth. One patient who was using MyHealth before the study described his experience as frustration:

It’s frustrating that they don’t always release information, [or] I’ll ask for a release but it takes a while, or they’ll release my stress test and only add a little blurb. Sometimes they don’t release all the results which is frustrating. I asked somebody at my cardiologist appointment, and they said, "Well the cardiologist doesn’t know how to do that," or something.
Figure 10. MyHealth Results Screen with Comments from the Provider

![Image]

© 2012 Epic Systems Corporation. Used with permission.

**Recommendations**

- Provide a link to the results rules from the results page
- Underline the test name links
- Redesign the provider comments section to make it more visible

**The Heart Failure Daily Journal**

**The Task**

You can record the information in your daily heart failure journal in MyHealth.

The information will be sent to your Cardiology nurse, and included in your Fletcher Allen electronic health record.

1. Access Andrew’s Heart Failure Journal
2. Examine his 5 most recent entries in the active Heart Failure Daily Journal
3. Make a new entry – enter this data:
   - Date: Today
   - Weight: 155 lbs.
   - Blood pressure: 124/82
• Pulse: 72
• Energy: Good
• Breathing: Slightly winded
• Swelling: Scant

4. View all of the data
5. Change today’s energy level to Great

Results

Table 7. Daily Journal Task Summary Statistics

<table>
<thead>
<tr>
<th>Summary Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
</tr>
<tr>
<td>Minutes to complete task</td>
</tr>
<tr>
<td>Completed task with no problem or self-correction</td>
</tr>
<tr>
<td>Needing prompting</td>
</tr>
<tr>
<td>Needed specific instruction</td>
</tr>
<tr>
<td>Understood information (investigator evaluation)</td>
</tr>
</tbody>
</table>

Table 8. Daily Journal Task Satisfaction Question Means

<table>
<thead>
<tr>
<th>Question</th>
<th>Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was able to find the Heart Failure Journal easily</td>
<td>2.8 (SD 1.2)</td>
</tr>
<tr>
<td>I was able to understand the information in the display</td>
<td>1.4 (SD 1.0 )</td>
</tr>
<tr>
<td>It was clear to me that my doctor and nurse will be able to see this</td>
<td>1.7 (SD 1.2 )</td>
</tr>
<tr>
<td>information in PRISM</td>
<td></td>
</tr>
<tr>
<td>I think this feature will be useful to me</td>
<td>1.6 (SD 1.1 )</td>
</tr>
<tr>
<td>Overall, I was satisfied with the ease of completing this task.</td>
<td>1.7 (SD 1.1)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the amount of time it took to complete this</td>
<td>1.6 (SD 0.8)</td>
</tr>
<tr>
<td>task.</td>
<td></td>
</tr>
<tr>
<td>Overall Mean</td>
<td>1.8 (SD 0.8 )</td>
</tr>
</tbody>
</table>

* Likert Scale from 1 (Agree) to 7 (Disagree)

Discussion

Patients receive notice of their enrollment in the daily journal through their In Box. The message contains a link to the journal. The journal is also accessed through the Health Tracker in the Medical Record section. In the study patient, the In Box message was no longer available, and participants had to find the journal in the Medical Record.
section. This proved difficult for most participants. It was unclear conceptually where this activity belonged, and what it should have been called. As one said "I’m not sure it was intuitive for everyone to find it that way." Possible titles suggested included My Health Journal, My Vitals, and Tool Box.

The layout of the daily journal made completing this task challenging. Both horizontal and vertical scrolling were required. Placement of buttons made them hard to find. The buttons to review data, add new data, and edit data were hard to find.

Recommendations

• Reconsider the name and location of the task
• Reverse the display order so that the most current data is visible without scrolling
• Remove white space to increase the data available on the page
• Rename the Apply button to View Data
• Store and reuse the data selection values
• Reduce the default data selection value to 5
• Relocate the Add New Data and View Data buttons
• Change the focus to the relevant view data radio button when the fields are changed
• Work with providers to limit long responses that increase scrolling
• Move the Edit and Delete buttons to the top/left to make them visible
Messages

The Task

1. Read your message from [Your nurse] about your glasses
2. Answer her message with this answer:
   - Yes, they are! I’ll pick them up this afternoon
3. Send a new message to [Your doctor] that says:
   - I’m learning how to use MyHealth!

Results

Table 9. Massage Task Summary Statistics

<table>
<thead>
<tr>
<th>Summary Statistics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>6</td>
</tr>
<tr>
<td>Minutes to complete task</td>
<td>2-9 (M 4.7, SD 2.2)</td>
</tr>
<tr>
<td>Completed task with no problem or self-correction</td>
<td>33% (2)</td>
</tr>
<tr>
<td>Needing prompting</td>
<td>17% (1)</td>
</tr>
<tr>
<td>Needed specific instruction</td>
<td>17% (1)</td>
</tr>
<tr>
<td>Unable to complete task successfully</td>
<td>33% (2)</td>
</tr>
<tr>
<td>Understood information (investigator evaluation)</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 10. Task Satisfaction Question Means

<table>
<thead>
<tr>
<th>Question</th>
<th>Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was able to understand how to read a message</td>
<td>1.2 (SD 0.4)</td>
</tr>
<tr>
<td>I was able to understand how to answer a message</td>
<td>1.3 (SD 0.5)</td>
</tr>
<tr>
<td>I was able to understand how to send a new message</td>
<td>2.2 (SD 2.2)</td>
</tr>
<tr>
<td>It was clear when my message was sent</td>
<td>1.2 (SD 2.2)</td>
</tr>
<tr>
<td>It was clear what kind of messages I could send and to whom</td>
<td>2.7 (SD 2.1)</td>
</tr>
<tr>
<td>It was clear that I should not send urgent messages in MyHealth – instead, I should call the office, visit the Emergency Department or call 9-1-1</td>
<td>3.3 (SD 2.7)</td>
</tr>
<tr>
<td>I think this feature will be useful to me</td>
<td>1.5 (SD 0.5)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the ease of completing this task</td>
<td>2.3 (SD 1.7)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the amount of time it took to complete this task.</td>
<td>2.0 (SD 1.8)</td>
</tr>
<tr>
<td>Overall Mean</td>
<td>2.1 (SD 1.3)</td>
</tr>
</tbody>
</table>

* Likert Scale from 1 (Agree) to 7 (Disagree)
Discussion

Users are notified by email that they have a message in MyHealth. Upon opening the Medical Information section they'll receive a linked message about the mail (see Figure 11).

Figure 11. New Message Announcement

Clicking the link brings the user into the message. Users can also access their Inbox from the Medical Message Center. Once in the Inbox, messages are accessed by clicking their subjects (See Figure 12).

Participants were able to answer the message from Nurse Cindy without difficulty, although many chose to type a different answer. Sending a new message proved more difficult. One participant did not understand that Contact Doctor’s Office was the correct link for sending a message (see Figure 12).
Users can send messages to providers they've had appointments with in the past year. Several sent the message to the doctor that was first on the list, rather than using the dropdown list to choose the doctor specified in the task (see Figure 13). This may be less of an issue when users are sending their own message than it was for the study.

When sending a message, MyHealth has a preset drop down list of subject line choices (see Figure 13). The task asked participants to send a message saying “I'm learning how to use MyHealth!” This did not fit any of the choices, and participants had difficulty deciding what category to use. In the study the message was contrived. However, in actuality, as one patient pointed out, “I may want to send a message that’s not a question, but a statement.” In the final interview participants reported sending the heart failure nurse messages about medication changes and incidents with their implanted devices that were informational, not questions. Although the activity states that the
message is going to the Doctor's office (see Figure 13), this was not clear to everyone. One participant described a message he sent to his doctor upon enrolling in the study, to let the doctor know that he was using MyHealth. He received an answer from the nurse letting him know that the doctor did not get the messages, the nurse did. Finally, due to the screen size, participants had to scroll to send the message. One participant did not send the message – and rather went back to the home page thinking he’d sent the message.

Figure 13. Contact Doctor's Office Screen
Recommendations:

- Revise the names of the Medical Message Center choices to make them consistent (Inbox vs. sent messages) and clearer

- Add an Other in the Subject dropdown – for things like: “I was diagnosed with shingles when I was in Florida.”

- Give the user a reminder if they leave the page without sending or cancelling their message

- Consider alternate terminology to make it clearer that it is office staff, not the doctor who will receive the message

Questionnaire

The Task

You may be sent questionnaires from the doctor’s office.

1. Andrew has been sent a questionnaire – find it in his InBox
2. Complete it and return it to the sender.

Results

Table 11. Questionnaire Task Summary Statistics

<table>
<thead>
<tr>
<th>Summary Statistics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>6</td>
</tr>
<tr>
<td>Minutes to complete task</td>
<td>3-13</td>
</tr>
<tr>
<td>(M 6.3, SD 3.4)</td>
<td></td>
</tr>
<tr>
<td>Completed task with no problem or self-correction</td>
<td>17% (1)</td>
</tr>
<tr>
<td>Needing prompting</td>
<td>17% (1)</td>
</tr>
<tr>
<td>Needed specific instruction</td>
<td>67% (4)</td>
</tr>
<tr>
<td>Understood information (investigator evaluation)</td>
<td>100%</td>
</tr>
</tbody>
</table>
Table 12. Questionnaire Task Satisfaction Question Means

<table>
<thead>
<tr>
<th>Question</th>
<th>Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>The questionnaire was easy to find</td>
<td>2.3 (SD 1.4)</td>
</tr>
<tr>
<td>The questionnaire was easy to complete</td>
<td>1.5 (SD 0.8)</td>
</tr>
<tr>
<td>It was clear that my answers would be stored in PRISM for my health care team to see</td>
<td>2.2 (SD 1.9)</td>
</tr>
<tr>
<td>I think answering questions in this way will be useful to me</td>
<td>1.7 (SD 1.5)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the ease of completing this task.</td>
<td>1.5 (SD 0.8)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the amount of time it took to complete this task.</td>
<td>1.2 (SD 0.4)</td>
</tr>
<tr>
<td>Overall Mean</td>
<td>1.7 (SD 0.7)</td>
</tr>
</tbody>
</table>

* Likert Scale from 1 (Agree) to 7 (Disagree)

Discussion

Although the task instructions stated *Andrew has been sent a questionnaire – find it in his InBox*, participants had difficulty finding the questionnaire. The questionnaire had 21 Likert scale questions. Epic did not allow horizontal formatting the questions with the text on the left, and the choices on the right. Rather, the questions were presented vertically – leading to a very long page which required scrolling. The number of questions per page was controlled by PRISM. In this case, the questions were asked over five screens, each of which required scrolling to complete. There were four questions on the first four screens, and five on the final screen. There was no indication of progress through the questionnaire. The display size forced scrolling on every page. One participant at the start of the fourth screen commented "This is a long one" in reference to the questionnaire.

Once all the questions were answered, a preview screen to confirm the answers was displayed. Clicking an edit icon (pencil) returned the user to the screen where that question was answered. One respondent suggested adding this to the instructions.
When returning to the questionnaire for editing, all the questions on that screen were visible. The user was not brought to the specific question requested. The button to return to the preview page was labeled *Jump to Preview*, a label that surprised one participant.

It was only from the preview page that the questionnaire is submitted. One participant clicked "Save and Quit" at the bottom of the first screen. He did not complete and send the questionnaire, although he thought he had.

Once the user clicked "Submit Questionnaire" a confirmation page was displayed. One participant felt the instructions on the preview page should be modified to *Please Submit* your responses rather than *Please Confirm* your responses to make this clearer.

There was no text indicating that the submitted questionnaire would be stored in the patient’s EHR. The mean Likert score of 2.4 to the question: *It was clear that my answers would be stored in PRISM for my health care team to see*, indicates some unease about this. As one participant stated "I assume that if it has been submitted that it’s been returned to the center."

Unlike the daily journal, once the questionnaire had been submitted it was not retrievable by the patient. The message asking the patient to complete the message remained in the Inbox until the user deleted it, but the user could no longer access the link to the questionnaire itself.

The questionnaire results and a tabulated score are sent to the provider. The user did not see the computed score. One participant felt the questionnaire would only be useful if he received information on his results –his score and its interpretation.

*Recommendations*

- Allow different formats for presenting questions such as Likert scales in one row
• Provide information on the questionnaire size, and number of questions remaining as the user completes the questionnaire
• Provide patients access to their completed questionnaires
• Allow set up of standard messaging so users always receive questionnaire instructions
• Rename the Jump to Preview button to “Return to Preview and Submit”
• Modify the Confirm screen instructions
• Explain the pencil icon

Appointments

The Task

You can request an appointment through MyHealth.

1. Examine the patient’s future and past appointments.
2. Send the office a request for an appointment with Dr. Tischler about a new problem. Let them know you’re available on Tuesday, Wednesday or Thursday mornings. Include this message:
   “I’m concerned about my energy levels. Can we meet?”

Results

Table 13. Appointment Task Summary Statistics

<table>
<thead>
<tr>
<th>Summary Statistics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>5</td>
</tr>
<tr>
<td>Minutes to complete task</td>
<td>2-3 (M 2.2, SD 0.4)</td>
</tr>
<tr>
<td>Completed task with no problem or self-correction</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Needing prompting</td>
<td>0</td>
</tr>
<tr>
<td>Needed specific instruction</td>
<td>0</td>
</tr>
<tr>
<td>Did not complete the task correctly</td>
<td>60% (3)</td>
</tr>
<tr>
<td>Understood information (investigator evaluation)</td>
<td>100%</td>
</tr>
</tbody>
</table>
### Table 14. Task Satisfaction Question Means

<table>
<thead>
<tr>
<th>Question</th>
<th>Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was able to understand how to view my appointments</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>The appointment information was clear and easy to understand</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>I was able to understand how to request an appointment</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>It was clear that my request was sent</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>It is clear what will happen next</td>
<td>3.8 (SD 2.7)</td>
</tr>
<tr>
<td>I think this feature will be useful to me</td>
<td>2.2 (SD 2.4)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the ease of completing this task.</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the amount of time it took to complete this task.</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>Overall Mean</td>
<td>1.5 (SD 0.4)</td>
</tr>
</tbody>
</table>

* Likert Scale from 1 (Agree) to 7 (Disagree)

### Discussion

Participants were able to view past and future appointments without difficulty.

The biggest challenge was sending the appointment request to the correct doctor. Three of the five participants sent the request to the default doctor, not the doctor specified in the instructions.

It was also not clear what would happen when the message was sent. One participant stated, "There was no email notification or anything else." Another described it this way: "It’s like email; you assume they’ll get it." One participant did not use the appointment functionality, and sent the request from the Medical Message center as a non-urgent medical question in the **Contact Doctor’s Office** section.

### Recommendations

- Include the details of what will happen once the request has been submitted on the final screen
- Include which provider’s office was requested on the final screen
Heart Failure Prevention Resources

The Task

Examine the heart failure prevention resources

Results

Table 15. Heart Failure Prevention Resources Task Summary Statistics

<table>
<thead>
<tr>
<th>Summary Statistics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>6</td>
</tr>
<tr>
<td>Minutes to complete task</td>
<td>1-5 (M 3.0, SD 1.4)</td>
</tr>
<tr>
<td>Completed task with no problem or self-correction</td>
<td>33% (2)</td>
</tr>
<tr>
<td>Needing prompting</td>
<td>0</td>
</tr>
<tr>
<td>Needed specific instruction</td>
<td>66% (4)</td>
</tr>
<tr>
<td>Understood information (investigator evaluation)</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 16. Heart Failure Prevention Resources Task Satisfaction Question Means

<table>
<thead>
<tr>
<th>Question</th>
<th>Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was able to find the Heart Failure Prevention resources easily</td>
<td>3.7 (SD 2.0)</td>
</tr>
<tr>
<td>I think this feature will be useful to me</td>
<td>1.7 (SD 1.1)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the ease of completing this task.</td>
<td>2.0 (SD 1.8)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the amount of time it took to complete</td>
<td>2.2 (SD 2.2)</td>
</tr>
<tr>
<td>this task.</td>
<td></td>
</tr>
<tr>
<td>Overall Mean</td>
<td>2.4 (SD 1.7)</td>
</tr>
</tbody>
</table>

*Likert Scale from 1 (Agree) to 7 (Disagree)

Discussion

My Health provides Healthwise patient information through the Health Library. Five of the six participants started their search for heart prevention resources in the Health Library. For the study, a selection of Fletcher Allen Cardiology heart failure resource documents was also made available. They were placed in the Medical Record section. This was not an intuitive place to look for them. To keep the label short they were named "HF Prevention Resources." The participants did not recognize the initials
HF, and therefore, even when looking in the Medical Record section, they had difficulty identifying the resources. Once they found the correct link, they had little difficulty accessing and understanding the information.

**Recommendation:**

- Consider an alternative location for this material

**Request Rx Refill**

**The Task**

You can order prescription refills online.

1. Request a refill of Andrew’s Furosemide
2. Specify that you’ll pick it up at Kinney Drugs in Milton

**Results**

**Table 17. Prescription Refill Task Summary Statistics**

<table>
<thead>
<tr>
<th>Summary Statistics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>7</td>
</tr>
<tr>
<td>Minutes to complete task</td>
<td>1-2 (M 1.8, SD 3.7)</td>
</tr>
<tr>
<td>Completed task with no problem or self-correction</td>
<td>86% (6)</td>
</tr>
<tr>
<td>Needing prompting</td>
<td>0</td>
</tr>
<tr>
<td>Needed specific instruction</td>
<td>14% (1)</td>
</tr>
<tr>
<td>Understood information (investigator evaluation)</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Table 18. Prescription Refill Task Satisfaction Question Means**

<table>
<thead>
<tr>
<th>Question</th>
<th>Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was able to find the refill request section easily</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>I think this feature will be useful to me</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the ease of completing this task.</td>
<td>1.0 (SD 0.0)</td>
</tr>
<tr>
<td>Overall, I was satisfied with the amount of time it took to complete this task.</td>
<td>1.1 (SD 0.3)</td>
</tr>
<tr>
<td>Overall Mean</td>
<td>1.0 (SD 0.1)</td>
</tr>
</tbody>
</table>

* Likert Scale from 1 (Agree) to 7 (Disagree)
Discussion

Refilling prescription functionality was accessible from several areas – My Health Summary, Medications, and the Message Center. Participants were able to complete this task and thought it will be useful.

The functionality was split into two screens, which posed a hurdle for all participants. The first screen allowed the user to choose the medication to refill, and had a field for comments. On the second screen the patient specified their pharmacy and submitted the request. Every participant entered their pharmacy in the comment field on the first screen before proceeding to the next screen. This may have been an artifact of the way the task was presented:

1. Request a refill of Andrew’s Furosemide
2. Specify that you’ll pick it up at Kinney Drugs in Milton

One participant who had been using MyHealth before enrolling in the study had not used MyHealth to renew his prescriptions. His explanation that "they don’t have a pharmacy [selection] as far as I can tell; I can’t tell where the refills will go," indicates that this may be a larger issue than just the wording of the task. Another participant noted that the pharmacy selection and comments field should be on the same screen.

Recommendation:

- Move the comment field to the second screen below the pharmacy selection field
Appendix G

Rural - Urban Mix of Participants

The US census defines areas with a population density of at least 1,000 people per square mile as urban. The Vermont Department of Health uses a three-category grouping when defining towns: urban, rural, or mixed. Towns whose census areas are more than 90% urban are urban, those whose areas are more than 90% non-urban are rural, and those whose areas fall between 10 and 90% urban and rural are classified as mixed.

ZIP codes of patients were obtained. Although ZIP code and census areas do not have a perfect one-to-one correspondence, they were considered adequate for the level of detail needed. Participants were assigned based on the urban, mixed, or rural definition assigned to the major town in their ZIP code area. To validate the data, participants were asked if they lived in an urban, suburban, small town, village, or rural area. Those answering suburban or small town were classified as living in a mixed area, and those answering village or rural were classified as rural. ZIP codes of patients seen in the Cardiology clinic between April 2010 and March 2011 with heart failure were also obtained and classified. The results are shown in Table 19.

<table>
<thead>
<tr>
<th>Table 19. Urban-Rural Mix of Participants and Cardiology Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Cardiology Patients</td>
</tr>
<tr>
<td>------------------------</td>
</tr>
<tr>
<td>Count</td>
</tr>
<tr>
<td>Rural</td>
</tr>
<tr>
<td>Mixed</td>
</tr>
<tr>
<td>Urban</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>
Computer Expertise Questions and Results

Computer expertise was measured on four scales: 1) a general confidence score, 2) a scale of overall use and confidence, 3) a more detailed scale that measured use and confidence on four frequently used computer application, and 4) the investigator's subjective rating based on facility with the mouse, accessing links, and general ease with webpage navigation (see Table 20).

### Table 20. Computer Expertise Scales

<table>
<thead>
<tr>
<th>Scales</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scale 1: Overall Confidence.</strong> Expert: score of 2</td>
</tr>
<tr>
<td>Overall, how confident are you when using a computer?</td>
</tr>
<tr>
<td>Very (2)                 Somewhat (1)                 Not confident (0)</td>
</tr>
<tr>
<td><strong>Scale 2: Overall Use and Confidence.</strong> Expert: combined score of 4 or more</td>
</tr>
<tr>
<td>How often do you use the computer?</td>
</tr>
<tr>
<td>Daily (3)    Once a week or more but not daily (2)    Once a month or more but not weekly (1)</td>
</tr>
<tr>
<td>Overall, how confident are you when using a computer?</td>
</tr>
<tr>
<td>Very (2)                 Somewhat (1)                 Not confident (0)</td>
</tr>
<tr>
<td><strong>Scale 3: Detailed Use and Confidence.</strong> Expert: combined score of 16 or more</td>
</tr>
<tr>
<td>Think about the 4 things you use your computer for the most. For each, tell me what you do, how often, and how comfortable you are doing it.</td>
</tr>
<tr>
<td>For each activity:</td>
</tr>
<tr>
<td>Frequency</td>
</tr>
<tr>
<td>Daily or more (3)    Weekly or more (2)    Monthly or more (1)</td>
</tr>
<tr>
<td>Confidence</td>
</tr>
<tr>
<td>Very (2)                 Somewhat (1)                 Not confident (0)</td>
</tr>
<tr>
<td><strong>Scale 4: Interviewer's subjective rating.</strong></td>
</tr>
</tbody>
</table>
Results

Frequently used computer applications and functions included email, spreadsheets and accounting software, reading newspapers and books, online banking, research, word processing, selling on Esty, genealogy, shopping, ordering medications, checking stock values, Facebook, listening to music, checking the weather, searching for jobs, recording CDs and DVDs, following sports, and playing games. Ratings on each scale by participant are shown in Table 21.

<table>
<thead>
<tr>
<th>Scale 1: Confidence</th>
<th>Scale 2: Use and Confidence</th>
<th>Scale 3: Detailed Use and Confidence</th>
<th>Scale 4: Investigator Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>expert</td>
<td>expert</td>
<td>expert</td>
<td>expert</td>
</tr>
<tr>
<td>expert</td>
<td>expert</td>
<td>expert</td>
<td>expert</td>
</tr>
<tr>
<td>expert</td>
<td>expert</td>
<td>expert</td>
<td>expert</td>
</tr>
<tr>
<td>expert</td>
<td>expert</td>
<td>expert</td>
<td>expert</td>
</tr>
<tr>
<td>expert</td>
<td>expert</td>
<td>expert</td>
<td>expert</td>
</tr>
<tr>
<td>intermediate</td>
<td>expert</td>
<td>expert</td>
<td>expert</td>
</tr>
<tr>
<td>expert</td>
<td>expert</td>
<td>intermediate</td>
<td>expert</td>
</tr>
<tr>
<td>expert</td>
<td>expert</td>
<td>intermediate</td>
<td>expert</td>
</tr>
<tr>
<td>intermediate</td>
<td>expert</td>
<td>intermediate</td>
<td>expert</td>
</tr>
<tr>
<td>intermediate</td>
<td>intermediate</td>
<td>intermediate</td>
<td>intermediate</td>
</tr>
<tr>
<td>expert</td>
<td>intermediate</td>
<td>intermediate</td>
<td>intermediate</td>
</tr>
<tr>
<td>expert</td>
<td>expert</td>
<td>expert</td>
<td>intermediate</td>
</tr>
<tr>
<td>intermediate</td>
<td>expert</td>
<td>expert</td>
<td>intermediate</td>
</tr>
<tr>
<td>expert</td>
<td>expert</td>
<td>expert</td>
<td>intermediate</td>
</tr>
<tr>
<td>expert</td>
<td>expert</td>
<td>expert</td>
<td>intermediate</td>
</tr>
<tr>
<td>expert</td>
<td>expert</td>
<td>expert</td>
<td>intermediate</td>
</tr>
</tbody>
</table>
Appendix I

Usability Patient Details

The usability patient was a fictitious patient created to have a medical profile typical of those with heart failure. His record included the following details shown in Table 22.

Table 22. Usability Patient Details

<table>
<thead>
<tr>
<th>Topic</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Andrew MyHealth</td>
</tr>
<tr>
<td>Age and Gender</td>
<td>69 year old male</td>
</tr>
<tr>
<td>Problem List</td>
<td>Congestive Heart Failure, Coronary Artery Disease, Hypertension, Chronic Kidney Disease, Hypercholesterolemia, Atrial Fibrillation, Osteoarthritis of the Knee</td>
</tr>
<tr>
<td>Allergies</td>
<td>Ibuprofen (causes hives)</td>
</tr>
<tr>
<td>Medications</td>
<td>Aspirin chewable 80 mg tablet; daily</td>
</tr>
<tr>
<td></td>
<td>Acetaminophen (Tylenol) 1000 mg two times per day</td>
</tr>
<tr>
<td></td>
<td>Metoprolol (Lopressor) 50 mg tablet daily</td>
</tr>
<tr>
<td></td>
<td>Furosemide (Lasix) 80 mg daily</td>
</tr>
<tr>
<td></td>
<td>Hydrochlorothiazide (Microzide) 12.5 mg daily</td>
</tr>
<tr>
<td></td>
<td>Warfarin (Coumadin) 4 mg daily</td>
</tr>
<tr>
<td></td>
<td>Atorvastatin (Lipitor) 40 mg daily</td>
</tr>
<tr>
<td></td>
<td>Valsartan (Diovan) 320 mg daily</td>
</tr>
<tr>
<td></td>
<td>Nifedipine (Procardia-xl) 60 mg two times per day</td>
</tr>
<tr>
<td></td>
<td>Ezetimibe (Zetia) 10 mg at bedtime</td>
</tr>
<tr>
<td></td>
<td>Epoetin alfa (Epogen, Procrit) 2,000 unit/ml injection every 14 days</td>
</tr>
<tr>
<td></td>
<td>Hydrocortisone (Anusol-HC) 2.5% rectal cream as needed</td>
</tr>
<tr>
<td>Immunizations</td>
<td>Influenza: 2010, 2011</td>
</tr>
<tr>
<td></td>
<td>Tetanus: 2005</td>
</tr>
<tr>
<td>Past Medical</td>
<td>Arthritis</td>
</tr>
<tr>
<td>History</td>
<td>Eye surgery for cataracts: 2003, 2004</td>
</tr>
<tr>
<td></td>
<td>Left Hip Replacement: 2005</td>
</tr>
<tr>
<td></td>
<td>Former smoker, quit in 1972</td>
</tr>
</tbody>
</table>
**Echocardiogram Results**

**Summary:**
1. **Left ventricle:** The cavity size was normal. Wall thickness was normal. Systolic function was normal. The estimated ejection fraction was 60-65%. Wall motion was normal; there were no regional wall motion abnormalities.
2. **Aortic valve:** Mild regurgitation.
3. **Left atrium:** The atrium was severely dilated.
4. **Right ventricle:** The cavity size was mildly dilated.
5. **Right atrium:** The atrium was mildly dilated.
6. **Tricuspid valve:** Moderate-severe regurgitation.
7. **Summary - Overall left ventricular systolic function was normal.**

   Left ventricular ejection fraction was estimated to be 65%. There were no left ventricular regional wall motion abnormalities. Aortic valve thickness was mildly increased. There was mild aortic valvular regurgitation by color Doppler. There was moderate mitral annular calcification. There was moderate mitral valvular regurgitation by color Doppler. Left atrium dilation: moderate to severe. Right ventricle dilation: mild. Estimated peak pulmonary artery systolic pressure: 55 mmHg to 60 mmHg. There was moderate to severe tricuspid valvular regurgitation by color Doppler. The right atrium dilation: mild to moderate. Inferior vena cava dilation: mild.

**Procedure Data**
Transthoracic echocardiography. M-mode, complete 2D, complete spectral Doppler, and color Doppler. A Transthoracic Echocardiogram was performed. Scanning was performed from the parasternal, apical, subcostal, and suprasternal notch acoustic windows. The patient tolerated the procedure well.

**Cardiac Anatomy**
- **Left ventricle:** The cavity size was normal. Wall thickness was normal. Systolic function was normal. The estimated ejection fraction was 60-65%. Wall motion was normal; there were no regional wall motion abnormalities. Wall motion score: 1.00.
- **Aortic valve:** Mildly thickened leaflets. Doppler: Mild regurgitation.
- **Left atrium:** The atrium was severely dilated.
- **Right ventricle:** The cavity size was mildly dilated. Tricuspid valve: Doppler: Moderate-severe regurgitation.
- **Pulmonary artery:** Pulmonary systolic pressure was estimated to be 55 mm Hg. = 60 mm Hg.
- **Right atrium:** The atrium was mildly dilated.

**MyHealth Comment:**
The results of your echocardiogram are similar to your previous test. It shows that your heart function is stable and the extent of your valve disease is unchanged.
<table>
<thead>
<tr>
<th>Topic</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lab Results</td>
<td>BUN 34 mg/dl (Reference range: 10-26 mg/dl). MyHealth comment: This is a kidney function test. The results are a little high, but stable for you. Potassium 3.2 mEq/L (Reference range: 3.5-5.0 mEq/L)</td>
</tr>
</tbody>
</table>

### Daily Journal

<table>
<thead>
<tr>
<th>Date</th>
<th>Weight</th>
<th>Blood Pressure</th>
<th>Pulse</th>
<th>Energy</th>
<th>Breathing</th>
<th>Swelling</th>
</tr>
</thead>
<tbody>
<tr>
<td>12/12</td>
<td>152.8</td>
<td>106/72</td>
<td>76</td>
<td>Good</td>
<td>Slightly winded</td>
<td>None</td>
</tr>
<tr>
<td>12/13</td>
<td>153.6</td>
<td>110/76</td>
<td>78</td>
<td>Good</td>
<td>Slightly winded</td>
<td>None</td>
</tr>
<tr>
<td>12/14</td>
<td>155.2</td>
<td>120/84</td>
<td>80</td>
<td>Not so good</td>
<td>Winded</td>
<td>Scant</td>
</tr>
<tr>
<td>12/15</td>
<td>156.5</td>
<td>136/88</td>
<td>82</td>
<td>Not so good</td>
<td>Winded</td>
<td>Scant</td>
</tr>
<tr>
<td>12/16</td>
<td>154.8</td>
<td>124/82</td>
<td>78</td>
<td>Not so good</td>
<td>Slightly winded</td>
<td>Scant</td>
</tr>
</tbody>
</table>
Appendix J

System Usability Scale Questions and Results

The System Usability Scale is a short ten-item survey whose aggregate score provides a general measure of usability satisfaction. Participants completed the survey after their initial usability study and again at the start of their final interview. The wording of some questions was modified slightly between the surveys to fit the circumstances. The survey questions are shown in Table 23.

Table 23. MyHealth System Usability Scale Survey

<table>
<thead>
<tr>
<th>Rank each on a scale of 1 (Strongly Agree) to 5 (Strongly Disagree)</th>
<th>Initial Survey Completed Following the Usability Study</th>
<th>Final Survey Completed at the Start of the Final Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think that I will use MyHealth frequently</td>
<td>I use MyHealth frequently</td>
<td></td>
</tr>
<tr>
<td>I found MyHealth unnecessarily complex</td>
<td>I find MyHealth unnecessarily complex</td>
<td></td>
</tr>
<tr>
<td>I thought MyHealth was easy to use</td>
<td>I think MyHealth is easy to use</td>
<td></td>
</tr>
<tr>
<td>I think that I would need help to be able to use MyHealth</td>
<td>I needed help to be able to use MyHealth</td>
<td></td>
</tr>
<tr>
<td>I found that the various functions in MyHealth were worked well together</td>
<td>I find that the various functions in MyHealth worked well together</td>
<td></td>
</tr>
<tr>
<td>I thought there was too much inconsistency in MyHealth</td>
<td>I think there is too much inconsistency in MyHealth</td>
<td></td>
</tr>
<tr>
<td>I would imagine that most people would learn to use MyHealth very quickly</td>
<td>I would imagine that most people will learn to use MyHealth very quickly</td>
<td></td>
</tr>
<tr>
<td>I found MyHealth very cumbersome to use</td>
<td>I find MyHealth very cumbersome to use</td>
<td></td>
</tr>
<tr>
<td>I felt very confident using MyHealth</td>
<td>I feel very confident using MyHealth</td>
<td></td>
</tr>
<tr>
<td>I needed to learn a lot of things before I could get going with MyHealth</td>
<td>I needed to learn a lot of things before I could get going with MyHealth</td>
<td></td>
</tr>
</tbody>
</table>
The range, mean and standard deviation of each survey is shown in Table 24.

There was no significant difference between the two scores (p=0.88). Initial and Final scores for each participant are shown in Figure 14.

Table 24. Initial and Final System Usability Score Summary Statistics

<table>
<thead>
<tr>
<th>Summary Statistics</th>
<th>Initial System Usability Scale</th>
<th>Final System Usability Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range</td>
<td>50-100</td>
<td>40-94</td>
</tr>
<tr>
<td>Mean</td>
<td>78.3</td>
<td>80.4</td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>14.7</td>
<td>14.4</td>
</tr>
</tbody>
</table>

Figure 14. Initial and Final System Usability Scores by Participant
My Health Usage Data

Table 25 displays the MyHealth usage data during their 3-month study period for the 13 participants who completed the study. For each activity, the total number of accesses, the number of accesses made by the most frequent user, and the number of participants who accessed the activity were calculated. After login, the heart failure daily journal was the most frequently accessed activity, followed by reading messages, viewing health information in the snap shot, sending messages, viewing appointments, and viewing results.

Table 25. MyHealth Activity Usage Data

<table>
<thead>
<tr>
<th>MyHealth Activities Accessed</th>
<th>Number of Times Activity was Accessed</th>
<th>Number of Accesses by Most Frequent User</th>
<th>Number of Users who accessed the activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Login</td>
<td>294</td>
<td>88</td>
<td>13</td>
</tr>
<tr>
<td>Heart Failure Daily Journal Entry</td>
<td>241</td>
<td>88</td>
<td>11</td>
</tr>
<tr>
<td><strong>Message Center</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reading Messages</td>
<td>117</td>
<td>31</td>
<td>12</td>
</tr>
<tr>
<td>Sending Messages</td>
<td>66</td>
<td>32</td>
<td>11</td>
</tr>
<tr>
<td>Medication Renewal Request</td>
<td>19</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Schedule Appointment Request</td>
<td>5</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Cancel Appointment Request</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Health Snapshot (includes allergies, medications, health issues, and immunizations)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Allergy Access</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Other Health Issues Access</td>
<td>9</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Other Immunizations Access</td>
<td>6</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Other Medications Access</td>
<td>9</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>MyHealth Activities Accessed</td>
<td>Number of Times Activity was Accessed</td>
<td>Number of Accesses by Most Frequent User</td>
<td>Number of Users who accessed the activity</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------------------------------</td>
<td>-----------------------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td><strong>Appointments</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>View upcoming or past Appointment List</td>
<td>36</td>
<td>13</td>
<td>10</td>
</tr>
<tr>
<td>Link to Appointment Details for upcoming or past appointment</td>
<td>15</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td><strong>Results</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>View Results List</td>
<td>33</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>Link to Result Details</td>
<td>11</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td><strong>History</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>View Medical History List</td>
<td>8</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>View Inpatient Data</td>
<td>11</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td><strong>Other Activities</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Link to Provider Details</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Proxy Access (View Family Member's Accounts)</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Terms and Conditions</td>
<td>3</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Wallet Card</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Personal Preferences</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Download Your Medical Record</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>View Demographics (Name, Address, Phone number)</td>
<td>10</td>
<td>3</td>
<td>7</td>
</tr>
</tbody>
</table>
Appendix L

Fletcher Allen's Heart Failure Journal

Fletcher Allen's Heart Failure Journal that is given to new patients. Following introductory material it has pages in which to record 24 weeks of weight and symptoms. The journal's sample page, as shown in Figure 15, provided the basis for the MyHealth daily journal. Tips from the journal were included in the Heart Failure Resources Tips.

Figure 15. Fletcher Allen Heart Failure Journal Sample Page

<table>
<thead>
<tr>
<th>DATE</th>
<th>MON</th>
<th>TUES</th>
<th>WED</th>
<th>THURS</th>
<th>FRI</th>
<th>SAT</th>
<th>SUN</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9/4</td>
<td>9/5</td>
<td>9/6</td>
<td>9/7</td>
<td>9/8</td>
<td>9/9</td>
<td>9/10</td>
</tr>
<tr>
<td>WEIGHT</td>
<td>155 lbs.</td>
<td>154 lbs.</td>
<td>153 lbs.</td>
<td>154 lbs.</td>
<td>153 lbs.</td>
<td>154 lbs.</td>
<td>155 lbs.</td>
</tr>
<tr>
<td>BLOOD PRESSURE &amp; PULSE</td>
<td>140/90</td>
<td>140/90</td>
<td>140/90</td>
<td>140/90</td>
<td>140/90</td>
<td>140/90</td>
<td>140/90</td>
</tr>
<tr>
<td>ENERGY</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

**ENERGY SCALE**

1. Great
2. Good
3. Not so good
4. Lousy

Use numbers below to reflect your energy levels

| BREATHING | 2 | 2 | 2 | 3 | 3 | 3 | 3 |

**BREATHING SCALE**

1. Great
2. Slightly winded
3. Winded
4. Trouble breathing

Use numbers below to reflect your breathing levels

| SWELLING | 4 | 4 | 4 | 4 | 4 | 3 | 3 |

**SWELLING SCALE**

1. None
2. Scant
3. Moderate
4. Severe

Use numbers below to reflect your swelling levels

**Tip of the Week**

Weigh yourself every morning in your bedclothes (urinating first and before eating). A digital scale is best.
Reference List


