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Using Personal Health Records to Promote Patient Activation in the Homebound Older Adult Population

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Abstract

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Patient activation, or an individual's willingness and ability to take actions to maintain their health and wellness, is a primary component of the patient-centered health system. Activated patients are more likely to report positive experiences with their medical providers, have better health outcomes, and spend less on healthcare services. Homebound older adults face more barriers to patient activation than their non-homebound peers. Because people who are homebound are unable to leave their homes without significant assistance, regularly accessing clinic-based medical services is difficult. In addition, as a population, homebound older adults have more chronic diseases, physical and cognitive impairments, and challenges with activities of daily living than non-homebound older adults. The number of older adults who are homebound is on the rise, and they are a growing proportion of the older adult patient population. Therefore, more research is needed to understand how consumer health information tools can be used with this population to support activation and improve health outcomes. This dissertation explores the usability, feasibility, and preliminary effectiveness of personal health records with the homebound older adult patient population. In a series of studies, I outline the benefits of using personal health records with this population, assess how current personal health records meet the needs of homebound older adult users, and describe considerations for health systems and researchers who are interested in exploring personal health records for the homebound older adult population.

This work furthers our understanding of the application of personal health records in homebound older adult patient populations. In addition, I provide design recommendations on how future systems can better meet needs of homebound older adult users. Finally, I offer suggestions to help future researchers maximize the effectiveness of homebound older adult personal health record evaluations.

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CHAPTER 1: INTRODUCTION

1.1 CONTEXT AND MOTIVATION

Engaging patients in their own health and wellness has been shown to affect all three aspects of the Institute for Healthcare Improvement's triple aim- patient experience, population health, and healthcare costs (Dentzer, 2013). 'Patient activation' is one method to measure the level of engagement that an individual has in their health and wellness routines. Patient activation "emphasizes patients' willingness and ability to take independent actions to manage their health and care" (Hibbard & Greene, 2013, pg. 204). Activated individuals have been shown to be more knowledgeable and willing to adhere to their self-care routines, and engage in health-promotion activities such as exercise (Dentzer, 2013; Hibbard, Mahoney, Stockard, & Tusler, 2005). Activated patients, as a population, have lower overall healthcare expenditures and are less likely to suffer from medical errors than non-activated patients (Greene, Hibbard, Sacks, Overton, & Parrotta, 2015; Hibbard & Greene, 2013).

One widely used tool to measure an individual's patient activation level is a standardized assessment developed by Hibbard et al., the Patient Activation Measure (PAM) (Hibbard, Stockard, Mahoney, & Tusler, 2004). Work with Hibbard's PAM has shown that there are many attributes that can influence an individual's patient activation including individual characteristics (e.g. age, health literacy, medical condition) (Ryvicker, Feldman, Chiu, & Gerber, 2013), healthcare organization characteristics (e.g. access to a patient portal) (Solomon, Wagner, & Goes, 2012), and societal characteristics (e.g. social norms) (Hibbard & Greene, 2013). Previous work with the tool also suggests that an individual's PAM score can be increased by targeting one or more of these characteristics with health services interventions (Hibbard & Greene, 2013).

1.2 HOMEBOUND OLDER ADULTS

My dissertation discusses one patient population that could greatly benefit from increased patient activation- homebound older adults. Older adults, typically defined as people aged 65 and older, are an increasing large proportion of patients in the United States healthcare system. Unlike previous generations, more of today's older adults are staying independent in their homes as they age (Administration on Aging, Administration for Community Living, 2014). A subset of older adults who age in their homes, people classified as a 'homebound older adults, are a particularly high-risk older adult population. Homebound older adults are people, typically aged 65 and older, who are unable to leave their home without the assistance of others. Homebound older adults have the highest amount of healthcare expenditures out of all patient populations (Leff, Carlson, Saliba, & Ritchie, 2015), and have been found to perform fewer self-care routines than non-homebound older adults (Musich, Wang, Hawkins, & Yeh, 2015). Previous research also suggests that homebound older adults face many significant individual, organizational, and societal barriers to fostering patient activation (described below). Because these barriers are unique within the homebound older adult population, more research is needed to understand the extent of the impact of these barriers on patient engagement in this population, and how health services interventions can support increased activation among homebound older adults.

1.2.1 Barriers to patient activation

Homebound older adults are more medically complex than non-homebound older adults. For example, one recent study compared Medicare insurance data between older adults who are homebound and older adults who are not homebound. Homebound older adults reported having more chronic conditions, with 33.4% reporting 2 or more conditions (compared to 12.2% of non-homebound individuals), taking more prescription drugs with 25.7% of homebound older adults

taking 7 or more medications (compared to 12.0% of non-homebound older adults), and experiencing more cognitive impairments than non-homebound older adults (17.1% of homebound older adults, 4.7% of non-homebound older adults) (Musich et al., 2015). Another study found that 98% of homebound older adults reported having at least one impairment with an instrumental activity of daily living (mean: 5.2), and 71% had at least one impairment with an activity of daily living (mean: 2.6) (Beck, Arizmendi, Purnell, Fultz, & Callahan, 2009). In addition, homebound older adults are more likely to be part of groups that already experience health disparities. Homebound older adults report less educational attainment, have less income, and are more likely to identify with racial and ethnic minorities than non-homebound older adults (Ornstein et al., 2015). These characteristics (income, education, and minority identification) are known as social determinants of health in the United States (Centers for Disease Control and Prevention, 2013). These individual factors may contribute to lower patient engagement among homebound older adults, and inhibit the effectiveness of traditional healthcare interventions designed to increase individual patient activation.

Homebound older adults also experience organizational barriers to patient activation. Most of the services that are available to homebound older adults focus on the physical needs of a homebound older adults' care, and these services fail to specifically address individual barriers to patient activation, such as behavioral health issues and/or health literacy (Musich et al., 2015). In addition, people who are more medically complex are also at a higher risk for medical errors, and are more vulnerable to complications with care coordination (Bodenheimer, 2008; Wagner, Austin, & Von Korff, 1996). This lack of care coordination could also lead to unmet needs and misalignments between the needs of homebound older adults and the available healthcare services.

Finally, homebound older adults also experience societal barriers to patient activation. Although the US has increased focus on the healthcare of older adults, homebound older adults receive relatively little attention in the public space (Musich et al., 2015). This lack of attention is evident in the lack of screening for homebound status that medical professionals perform during healthcare encounters, and the reduced awareness of signs that individuals could become homebound among an individual's family and friends (Leff et al., 2015). In addition, access to Medicare and Medicaid home-based services has declined over the past several decades in efforts to cut governmental healthcare expenditures. This lack of availability of services reduces the chances that a homebound older adult has access to the home-based services that they need (Musich et al., 2015). Finally, the dynamics of family and informal caregiving have changed in recent years. More older adults are living alone than in previous generations, and are living farther from their main family caregivers (Vespa, Lewis, & Kreider, 2013). This shift in living arrangements has caused remote family caregiving to become more common. Remote caregiving may reduce the ability for family caregivers to recognize and meet all of the homebound older adults' needs. The combination of these society factors implies that homebound older adults may have limited access to resources. Homebound older adults are often not recognized as "homebound." If the older adult is properly assessed as homebound, access to formal and informal home-based services have become more limited over the last several decades.

In conclusion, homebound older adults face many individual, organizational, and societal barriers to patient activation. Older adults who are homebound have complex medical conditions, poly-pharmacy routines, and report higher levels of cognitive and functional impairments. Unfortunately, a lack of healthcare organizational and societal support to manage these

individual barriers may be further contributing to the effect that these characteristics have on a homebound older adult's patient activation.

1.2.2 Promoting patient activation with personal health records

The United States, under the direction of the Office of National Coordinator for Health Information Technology (ONC), has developed a plan to use consumer health information technology (CHIT) to support patient activation throughout our healthcare delivery system. ONC defines consumer e-health tools as "a broad category of electronic tools and services that are primarily consumer oriented but that overlap with health information technology, a term more conventionally used in the context of technology for health care providers" (Ricciardi, Mostashari, Murphy, Daniel, & Siminerio, 2013). CHIT allows individuals' increased access to, and sharing of, important medical information including medical records, patient reported outcomes, and patient health tracking. The ONC suggests that by providing these tools, patients will be better positioned to engage with the healthcare system (Ricciardi et al., 2013).

An electronic personal health record (PHR) is one CHIT tool that has been promoted by ONC to increase patient activation ("PHR Ignite", 2013). PHRs provide the opportunity for individuals to access, manage, and share their personal health information (Detmer, Bloomrosen, Raymond, & Tang, 2008; 2003). There are two types of personal health records: tethered (i.e. "connected") and untethered (i.e. "standalone"). Tethered systems are only available to individuals' who are associated with a particular healthcare organization. In these systems, patients can typically view laboratory results, see provider notes from medical encounters, and perform administrative functions (paying medical bills, scheduling appointments, messaging providers, etc.). Standalone PHRs are not associated with any healthcare provider. These systems are available to anyone who wishes to create an account, and are typically populated with health

information directly by the patient. Standalone systems allow patients to directly manage their personal health information, and control the sharing of this information with others ("Personal health records: what providers need to know," n.d.).

Intervention studies have shown that PHRs have the potential to increase patient activation (Solomon et al., 2012), promote health behaviors (Chrischilles et al., 2014), and improve the patient-clinician relationship (Heyworth et al., 2014; Nagykaldi, Aspy, Chou, & Mold, 2012); however, larger randomized control trials have not replicated these gains (P. J. Wagner et al., 2012). Even though evidence to support PHR use among patients is mixed, more US healthcare organizations are offering these tools to their patients. This has led to a significant increase in the number of PHR users over the past decade. For example, between 2008 and 2013 the number of PHR users in the United States increased by over 23 million people (to a total of 31 million users) (Ford, Hesse, & Huerta, 2016). In addition, models show that PHR adoption could reach rates as high as 75% of the US patient population by 2020 (Ford et al., 2016).

One reason for this disconnect between success seen in intervention studies, and largescale randomized control trials may be the inconsistent adoption and use of PHRs even among the intervention groups in controlled trials (P. J. Wagner et al., 2012). Over the last several years, several studies have found that many patient populations, including older adults, are not adopting PHRs at the same rates as the general population (Goel et al., 2011; Gordon & Hornbrook, 2016; Graetz, Gordon, Fung, Hamity, & Reed, 2016; Karter et al., 2011; A. Smith, 2014; S. G. Smith et al., 2015). Older adults, particularly older adults who report low levels of healthcare literacy, educational attainment, and report identifying as racial and ethnic minorities have not adopted PHRs at the same rates as other patient populations. Many of these characteristics overlap with the characteristics of the homebound older adult population.

1.2.3 Systematic review of PHR evaluations with older adult users¹

To better understand why differences in adoption are seen among older adult subgroups, I conducted a systematic literature review to better understand the perceptions of PHRs among older adult users. This review assessed the literature that describes older adult user perspectives from PHR evaluation studies. Below is a summary of my review. A full description on the methods and results can be found in a published manuscript (Kneale & Demiris, 2017).

1.2.3.1 Methods

I performed a systematic search of Medline (via PubMed), CINAHL (via EBSCO), PsycINFO (via EBSCO), and Embase (via Ovid). For the search strategy, I used combinations of key words for 'personal health records' and 'older adults' to gather a broad sweep of the literature. The following key words were used for personal health record: 'personal health record,' 'personal medical record,' 'personal electronic health record,' 'patient health record,' 'patient medical record,' 'patient web portal,' 'shared electronic health record,' 'shared electronic medical record,' 'patient internet portal,' and 'personally controlled health record.' The following key word terms were used for older adults: 'older adult,' 'elder,' 'older people,' 'aged,' 'aging,' 'geriatric,' and 'senior.' Indexing terms unique to the databases searched, including MeSH and Emtree controlled terminologies, were used where appropriate. All searches were conducted on July 1, 2015. No date restrictions were placed on the search.

Two rounds of publication selection were conducted. The first round evaluated potential manuscript abstracts, and the second round reviewed the full-text publication. Publications were included if 1) there was a full-text, English version available, and 2) if the publication described

¹ This section was adopted from Kneale & Demiris, 2017

a primary data study where participants', aged 60 and older, used a PHR and were asked to describe their perceptions of the tool. Studies were excluded if the publication only described perceptions of clinicians, only reported quantitative PHR data (e.g. number of logins attempted), or older adult opinions were only generated from a laboratory setting. My co-author, Dr. George Demiris, reviewed ten percent of the excluded manuscript in each round and all of the included manuscripts to ensure that articles were being included and excluded appropriately.

In addition to the publication abstraction, we performed a quality review on the included manuscripts. For this measure, both Dr. Demiris and I assessed each manuscript for three most important items from the condensed version of the Statement on Reporting of Evaluation Studies in Health Informatics ("mini-STARE-HI") (de Keizer et al., 2010), and two additional criteria: 'provides a description of the PHR functionality under investigation' and 'describes how participants used the PHR functionality under investigation'. These additional elements were added to help readers better understand how the context of the evaluation study. Dr. Demiris and I reviewed each publication separately, and compared our results. Disagreements were resolved through consensus.

1.2.3.2 Results

Figure 1 displays the results from my systematic literature search on PHR evaluation studies. Seven hundred and ninety-six publications were screened, and ten publications (5.59%) were included in the final review.



Figure 1. Results from the Systematic Literature Search on PHR Evaluation Studies There were no date restrictions placed on the search, but all manuscripts were published between 2009 and 2014. Seven studies were conducted in the United States (Boland et al., 2014; Heyworth et al., 2014; Kim et al., 2009; Kogut, Goldstein, Charbonneau, Jackson, & Patry, 2014; Nazi, Hogan, McInnes, Woods, & Graham, 2013; C. Turvey et al., 2014; C. L. Turvey et al., 2012), two studies were conducted in Canada (Pai, Lau, Barnett, & Jones, 2013; Spencer, Alexander, & Kaufman, 2011), and one study was conducted in New Zealand (Gu & Day, 2013). These manuscripts included ten studies on seven unique PHRs, with the United States Veteran's Administration system ("My HealtheVet", n.d.) being the subject of four separate evaluations

(Heyworth et al., 2014; Nazi et al., 2013; C. Turvey et al., 2014; C. L. Turvey et al., 2012). Table

1 shows a summary of the included articles.

First Author	Year	PHR	Participant Demographics	Outcome Measures	Total Quality Rating (max = 5)
Boland	2014	Microsoft Health Vault	% Female: 55% Average age: 69.6 % European descent: 37% % college educated or higher: 29% % good/excellent health: 76% Average income (by zip code): \$49,000	Participant satisfaction (survey) Adherence to prescribed mediation regimen (electronic pill bottle)	3
Gu	2013	PHR*	% Female: 30% Average age: 63.5 % computer skill intermediate/advanced: 60% Average # of diagnoses: 2.8	Participant satisfaction (interview) Participant usage (interview)	4
Heyworth	2014	My HealtheVet	% Female: 9% Average age: 61 % patients 1+ chronic conditions: 100% % 5+ medications: 78% % private insurance or Medicare: 70%	Participant satisfaction (interview) # of potential adverse drug events # of medication discrepancies	5
Kim	2009	Personal Health Information Management System*	% Female: 71.4% Average age: 63	Participant satisfaction (survey) Participant usage (survey, PHR log)	4
Kogut	2014	ER-Card	% Female: 46.7% % 65+: 76.7% % with cardiovascular, respiratory or diabetes diagnosis: 100%	Participant usage (interview)	3

Table 1. Systematic Literature Review: Summary of Results

Nazi	2013	My HealtheVet	% Female: 8% % aged 61-70 years old: 45% % college graduate or higher: 23% % computer skills intermediate/advance: 97%	Participant satisfaction (survey) Participant usage (survey)	5
Pai	2013	PROVIDER*	% Female: 0% Average age: 64 % Caucasian: 95.46% % completed post- secondary education: 75% % computer usage 5+ hours per week: 55% % with prostate cancer: 100% % married: 71%	Participant satisfaction (survey) Participant usage (survey, PHR log) Future PHR cost preferences (survey)	5
Spencer	2011	Geriatric MyHealth Passport*	Average age: 92.1	Participant satisfaction (interview) Participant usage (interview)	5
Turvey	2014	My HealtheVet	% Female: 8.3% % aged 60-69: 51.0% % computer skills intermediate/advanced: 97% Average # of illnesses: 2.3	Participant satisfaction (survey) Participant usage (survey)	5
Turvey	2012	My HealtheVet	% Female: 9% (wave 1) 8% (wave 2) % aged 60-69: 47% (wave 1), 48% (wave 2) % who visit PHR monthly/weekly/daily: 79% (wave one), 77% (wave two) % health "good" or better: 61% (wave one/two)	Participant usage (survey)	5

* Denotes a proprietary PHR system

All studies reported participant age, but one study did not provide specifics on the age range of the older adults, only stating that 76.7% of participants were aged 65 or older (Kogut et al., 2014). Of the remaining nine studies that did provide more information, five publications

(62.5%) reported an average age between 60 and 70 (Boland et al., 2014; Gu & Day, 2013; Heyworth et al., 2014; Kim et al., 2009; Pai et al., 2013), and three (37.5%) reported that the ages of 45% or more of the older adult participants fell between age 60 and 69 (Nazi et al., 2013; C. Turvey et al., 2014; C. L. Turvey et al., 2012). Two studies (20%) reported the race and/or ethnicity of the participants. One study reported that 37% of their participants identify as "European descent" (Boland et al., 2014). Almost all (95.46%) of the other study participants identified as "Caucasian" (Pai et al., 2013). Four studies (40%) had participants who reported computer literacy at or above an intermediate level (Gu & Day, 2013; Nazi et al., 2013; Pai et al., 2013; C. Turvey et al., 2014), and one study (10%) reported that 79% of study participants visited the PHR at least once a month (C. L. Turvey et al., 2012).

Seven studies (70%) described the health of the participants. Two studies (20%) had participants who reported their health as "good" or better (e.g. "very good," "excellent," etc.) (Boland et al., 2014; C. L. Turvey et al., 2012). Two studies (20%) reported the average of diagnoses per patient as 2.8 (Gu & Day, 2013) and 2.3 (C. Turvey et al., 2014). Two studies (20%) recruited participants with specific primary diagnoses: prostate cancer (Pai et al., 2013) and participants who had a primary hospital diagnosis with a cardiovascular or respiratory illness or diabetes (Kogut et al., 2014). The study with prostate cancer patients provided specifics on the cancer diagnosis but not on other health conditions (Pai et al., 2013). The study that recruited patients with primary diagnoses did not provide further details on the health conditions (Kogut et al., 2014). One study (10%) reported that 100% of their participants had at least one chronic condition (but did not elaborate), and 78% were prescribed five or more medications (Heyworth et al., 2014).

Eight studies (80%) reported participant satisfaction as a main outcome of the study (Boland et al., 2014; Gu & Day, 2013; Heyworth et al., 2014; Kim et al., 2009; Nazi et al., 2013; Pai et al., 2013; Spencer et al., 2011; C. Turvey et al., 2014). Participants expressed their satisfaction through surveys (Boland et al., 2014; Kim et al., 2009; Nazi et al., 2013; Pai et al., 2013; C. Turvey et al., 2014) and interviews (Gu & Day, 2013; Heyworth et al., 2014; Spencer et al., 2011). In these studies, the majority of participants were satisfied or highly satisfied with the PHR. Satisfaction from the system came from a reported improvement in the individual's ability to manage and understand their health information, improvement in their confidence of their self-management routines, and perception that their providers were better equipped to make clinical recommendations based on the PHR information (Kim et al., 2009; Nazi et al., 2013; Spencer et al., 2011; C. Turvey et al., 2014). Participants in three publications specifically mentioned that PHR use was thought to improve their relationship with their medical providers (Gu & Day, 2013; Nazi et al., 2013; Spencer et al., 2011).

Reported dissatisfaction from PHRs mostly involved usability including difficulties with using the information from PHRs, including printing summary sheets (Gu & Day, 2013; Heyworth et al., 2014; Pai et al., 2013; C. Turvey et al., 2014). Despite reporting usability problems, older adult participants found value in the PHR and most were planning on continuing to use the system after the study ended. This is exemplified by one study reporting 50% of participants had difficulty navigating the PHR, but 59% of the same participants stated they would use the system again (Heyworth et al., 2014).

A different set of eight publications (80%) described how participants reported using the PHR during the study period (Gu & Day, 2013; Kim et al., 2009; Kogut et al., 2014; Nazi et al., 2013; Pai et al., 2013; Spencer et al., 2011; C. Turvey et al., 2014; C. L. Turvey et al., 2012).

Five of these publications collected this measure through surveys (Kim et al., 2009; Nazi et al., 2013; Pai et al., 2013; C. Turvey et al., 2014; C. L. Turvey et al., 2012), and three studies collected this information through interviews (Gu & Day, 2013; Kogut et al., 2014; Spencer et al., 2011). Two cross-sectional studies that evaluated the My HealtheVet PHR reported that 75% of the study participants were regular, long-term users of the system (Nazi et al., 2013; C. L. Turvey et al., 2012). However, two studies that introduced new PHRs into a population reported low levels of use over the study period, with one study finding that participants only used the system, on average, three times in six months (Kim et al., 2009), and one study reporting only 35.4% of participants remembered that they had created a PHR account at the follow-up interview (average 257 days after account creation) (Spencer et al., 2011). When older adults used PHRs that were connected to a health system, the participants in three studies (30%) reported viewing medical records and administrative functions (such as re-ordering medications) as the most commonly used features (Gu & Day, 2013; Nazi et al., 2013; Pai et al., 2013). Two studies (20%) that used PHRs that were not connected to any existing health data reported that participants were willing to enter data into the system at least once during the study period (Kim et al., 2009; Spencer et al., 2011).

One study specifically asked participants if they shared PHR data with anyone in their care team. This study found that only 11.8% of the participants shared data with a family member, 9.7% shared data with an out-of-network provider, and 5.7% shared data with innetwork providers. When information was shared, laboratory results were the most common data element (C. Turvey et al., 2014).

Finally, one publication asked participants to describe the ideal situation for paying for a PHR tool. This study was conducted in the centralized health system in Canada. In this setting,

47% of participants agreed to the statement "would be willing to pay user fee for the use of personal health record system." When asked who should pay for the system, all participants expressed that the government health system should help fund PHRs, but some participants thought healthcare institutions and private industry may also play a role in the cost (Pai et al., 2013).

1.2.3.3 Discussion

From analyzing the PHR evaluation studies in this review, there appears to be a lack of diversity in the demographics of the older adult participants. Overall, study participants were younger older adults (aged 60 to 70 years old), reported to be in good health, and had high levels of computer literacy and/or educational attainment. In addition, only two studies (20%) enrolled participants with somewhat equal representation between sex or gender (Boland et al., 2014; Kogut et al., 2014). Only one study reported recruited racially or ethnically diverse participants (Boland et al., 2014).

In addition to the lack of diversity in the reported demographics, many studies did not report comprehensive demographics on their participants. Besides age, the next most common demographics that were reported were percent of male/female participants (n=9, 90%), health status (n=7, 70%), and computer literacy/usage (n=4, 40%). Even when reported, these studies used different measures and levels of specificity. For example, health status information was collected by using a Likert scale (n=2, 20%) (Boland et al., 2014; C. L. Turvey et al., 2012), reporting an average number of diagnoses per participant (Gu & Day, 2013; C. Turvey et al., 2014), reporting categories of the primary diagnosis of the participants last hospital stay (e.g. "cardiovascular disease" or "diabetes") (Kogut et al., 2014), including detailed information about

only one diagnosis (prostate cancer) with no comorbidity information (Pai et al., 2013), and reporting that 100% of participants had at least one chronic disease (Heyworth et al., 2014).

It should be noted that some of the demographics in study participants could be explained from the study recruiting samples. Four studies (40%) were conducted with United States veterans (Heyworth et al., 2014; Nazi et al., 2013; C. Turvey et al., 2014; C. L. Turvey et al., 2012), and one study recruited men with prostate cancer (Pai et al., 2013). Although this explains why some studies have biased samples, it does not make the challenge of how to interpret these results any easier. For example, the United States Veteran's Administration (VA) reports that there are over 180,000 homebound veterans receiving benefits from the VA (Office of the Inspector General, 2016). From the information presented in the four VA studies, it is unclear if homebound individuals were part of the sample population based on the demographics reported.

The demographics reported in these studies make it difficult to generalize the study results to homebound older adults. Homebound status of the older adult participants was not collected in any study, and the demographics that were reported do not align with the homebound older adult population. As noted in section 1.2, homebound older adults are older, more medically complex, and are more likely to be in sub-populations who face health disparities than non-homebound older adults (Musich et al., 2015; Ornstein et al., 2015).

In addition, the ways that these studies reported participant satisfaction leave many open questions. Most of the satisfaction information was collected through surveys (Kim et al., 2009; Nazi et al., 2013; Pai et al., 2013; C. Turvey et al., 2014; C. L. Turvey et al., 2012). Using surveys for reporting user satisfaction is useful for quantifying study outcomes; however, qualitative methods offer a chance to better understand the context for the health information technology evaluation and the nuances of patient satisfaction (Sockolow, Dowding, Randell, &

Favela, 2016). There were three studies that used interviews to determine patient satisfaction. However, these studies only reported an overview of the participant satisfaction discussions (Gu & Day, 2013; Heyworth et al., 2014; Spencer et al., 2011).

1.2.3.4 Conclusions

The studies analyzed in this literature review provide opportunities for future research. Overall the older adults in these studies are satisfied with the PHRs that they were asked to evaluate. The homogeneity of the demographics of these participants, however, means that these results may not be generalizable to all older adult groups. Homebound older adults are a sub-group of older adults who are medically complex, and face many barriers to patient activation. These characteristics may change the way that homebound older adults view PHRs.

In addition, the specific facilitators and barriers to user satisfaction were not fully explored in these studies. Usability challenges were reported, but these challenges were not translated into design recommendations for future systems (Gu & Day, 2013; Heyworth et al., 2014; Pai et al., 2013; C. Turvey et al., 2014). In addition, it is unclear how the usability challenges described in these studies affect PHR adoption. In one study, older adults were bothered by the usability challenges, but stated that they would continue to use the system because of the perceived benefits (Heyworth et al., 2014).

Finally, none of these studies evaluated PHRs from multiple perspectives, such as provider and patient. Several of these studies connected the PHR to at least one of the participant's medical providers (Boland et al., 2014; Gu & Day, 2013; Heyworth et al., 2014; Nazi et al., 2013; Pai et al., 2013; C. Turvey et al., 2014; C. L. Turvey et al., 2012). In order for these systems to support care coordination between the older adult and their care providers, the entire care team must be able and willing to use the system. Therefore, future studies could

highlight differences in satisfaction or experience between older adult participants and their care team to better understand how PHRs can facilitate care coordination.

1.3 CONTRIBUTION AND AIMS

This dissertation investigates the benefits and barriers of PHR adoption among homebound older adults. Specifically, my dissertation aims are to: 1) understand whether existing personal health records meet the needs of homebound older adults, 2) determine the feasibility of conducting a personal health record intervention study with homebound older adults, and 3) conduct a preliminary examination of the potential effectiveness of personal health records on homebound individuals.

The main findings from this work can be used to better understand how to build PHR systems and promote PHR use among homebound older adults. By specifically focusing on adoption of PHRs among homebound older adults, we can support these individuals who may not currently be following the same adoption trends as the general US population. In addition, these findings can be used to help future CHIT designs better understand and meet the unique needs of homebound older adults to reduce the likelihood that future CHIT unintentionally creates barriers for adoption among homebound older adults. Finally, this work can be used to help promote awareness of general homebound older adults' healthcare information needs. Not all homebound older adults will want to adopt CHIT tools, but many homebound older adults will need to manage their healthcare information. Understanding the general information needs of this population can help current home-based services better meet and understand their client's needs.

1.4 GUIDE FOR THE READER

This dissertation discusses how personal health records may contribute to improving patient activation among homebound older adults. Below is an outline of the content of each chapter. **Chapter 2:** Paper 1 examines the homebound older adult literature to define six PHR features that would be particularly beneficial for this population. After the criteria were defined, I evaluated existing PHRs against these criteria. The results from this study imply that commercially available PHRs may not have the features required to be useful for homebound older adult users. This lack of available features may limit the perceived usefulness, and ultimately the adoption, of PHRs with homebound older adult users.

Chapter 3: Paper 2 describes a heuristic usability evaluation that was conducted with two personal health records that had a high number of features that are considered desirable for homebound older adults. This review assesses each system from three perspectives: a homebound older adult, an informal caregiver, and a home health nurse. This paper provides design recommendations that could improve the effectiveness of PHRs for homebound older adult users.

Chapter 4: Paper 3 discusses the feasibility of performing an intervention study evaluating a commercially available personal health record with homebound older adult participants. Results are presented from a study to examine the recruitment and retention of homebound older adults receiving home-based services following a hospitalization. In addition, I outline lessons learned for others who wish to involve homebound older adults in technology-based healthcare systems research studies.

Chapter 5: Paper 4 examines my findings from a pilot study to evaluate personal health records with homebound older adults and their caregivers. I discuss the conceptual model used to gather

study data, describe the qualitative and quantitative results from the participant interviews and participant questionnaires, and examine the feasibility of these methods.

Chapter 6: This final chapter summarizes my dissertation findings and conclusions. I evaluate my dissertation study methodologies and findings, and discuss implications and the broader themes that emerged from this work. In addition, I outline areas for future work and how my findings can be used to inform different aspects of homebound older adults' care.

CHAPTER 2: PAPER 1: DEFINITION AND PREVALENCE OF PERSONAL HEALTH RECORD FEATURES FOR HOMEBOUND OLDER ADULTS

2.1 Abstract

2.1.1 Objective

Personal health records (PHRs) are tools that help people access, manage, and share their personal health information. Homebound older adults, because of their mobility restrictions and increased medical complexity, are one population that could benefit from increased adoption of these tools. This study evaluates literature on homebound older adults to define six PHR features that would be helpful for this population. These features were then used to understand to what extent existing PHR systems would meet the needs of the homebound older adult population.

2.1.2 Methods

First, we conducted a literature review using Medline (via PubMed), CINAHL (via EBSCO), and Embase (via Ovid) to identify studies that provided a description of the United States homebound population including demographics, health status, technology use, and care preferences. Secondly, we analyzed this literature to identify six PHR features that would support a homebound older adult's care needs. Finally, we evaluated PHRs that are being marketed to healthcare consumers against these features to understand how existing systems meet these criteria.

2.1.3 Results

Six PHR features were identified in the assessment: saves information regarding discontinued medications, able to customize patient outcome measures, accepts a portable document format (PDF) document, provides role-based proxy access, provides no-cost access for standard use, and offers access through a web browser. We identified 96 individual PHRs and included 12 in our evaluation. Many of the six features were not present in the systems evaluated. Only two PHRs (16%) had all the features, and half of the systems (n=6) had three features or less.

2.1.4 Conclusions

The results from this study imply that current PHRs may be missing features that would be beneficial for homebound older adult users. Without taking this population's needs into consideration when designing PHR systems, we are limiting the potential effectiveness of such systems. More effort is needed to better understand homebound older adult PHR requirements, and to develop systems that better fit these needs.

2.2 PAPER 1 FULL TEXT

2.2.1 Introduction

In 2014 the National Academy of Medicine (NAM), formally known as the Institute of Medicine, and the National Research Council (NRC) estimated that between ten and fifteen million people in the United States were receiving health and wellness services in their home (i.e. 'home care'). Many of these individuals received home care due to the dual challenges of managing complex medical conditions and an inability to regularly leave their place of residence without significant assistance (e.g. being 'homebound') (Weisfeld & Lustig, 2015). 'Older adults', defined as people aged 65 and older, make up a large portion of people receiving home care services. Medicare, a government insurance for older adults, is the largest payer of home care, and spent over \$18 billion in 2012 on these services. In addition, in 2015, forty-seven percent of non-paid family and friend caregivers were caring for someone aged 75 years or older, with the average age of the care recipient being 69.4 years old (AARP).

As the baby boomer generation ages, the number of people who need home care is increasing (Weisfeld & Lustig, 2015). Simultaneously, shortages in the home care workforce and changing family dynamics are reducing the number of available caregivers (Weisfeld & Lustig, 2015). This means that there is a growing gap between the number of individuals who need care, and the number of providers available to support home-based services. Because of this gap, there is a greater need to explore care support tools, and understand how home health technologies can assist homebound older adults between home care visits (Weisfeld & Lustig, 2015).

Personal health records (PHRs) are tools that have been developed to support patient engagement by allowing individuals to access, manage, and share their personal health information (Irizarry, DeVito Dabbs, & Curran, 2015). People who have chronic diseases (Archer, Fevrier-Thomas, Lokker, McKibbon, & Straus, 2011; Wells, Rozenblum, Park, Dunn, & Bates, 2014), older adults (Archer et al., 2011), and people who care for older adults (Archer et al., 2011) are seen as populations that could particularly benefit from increased PHR use. This is because each of these populations have higher care management demands than the general adult population (Archer et al., 2011; Wells et al., 2014). PHRs offer many benefits to people who manage complex care routines such as health and wellness reminders (Wells et al., 2014), increased access to care (Archer et al., 2011), and an improvement in patient health literacy (Archer et al., 2011; Wells et al., 2014). These attributes are consistent with increased patient engagement, and improved care outcomes (Greene et al., 2015).

Several recent studies report an increase in adoption of PHRs among older adults; however, not all older adult subgroups are adopting PHRs at the same rates (Gordon & Hornbrook, 2016; Graetz et al., 2016; S. G. Smith et al., 2015). Older adults who are over 70 years old (Gordon & Hornbrook, 2016; Graetz et al., 2016), report lower levels of educational attainment (Graetz et al., 2016; S. G. Smith et al., 2015), and identify with racial and ethnic minorities (Gordon & Hornbrook, 2016; Graetz et al., 2016; S. G. Smith et al., 2015) all are statistically less likely to use a PHR. The differences in PHR adoption among sub-groups has even been present when studies have attempted to adjust calculations for differences in Internet use and access to Internet-enabled devices (Graetz et al., 2016). People who have these characteristics are also more likely to be homebound (Ornstein et al., 2015), and therefore eligible for home care services (Weisfeld & Lustig, 2015). This means that a 75-year-old homebound older adult with multiple chronic conditions may benefit from using a PHR, but are less likely to use one.

The disconnect between older adult subgroups who are hypothesized to benefit from increased PHR use and those older adults who are adopting these systems may be partially explained by the lack of literature investigating diverse older adult opinions on PHRs and describing how to design systems for their diverse needs. Our recent systematic literature review of PHR evaluation studies that recruited older adult participants found that most literature on older adult perceptions of PHRs were derived from studies that recruited participants who were aged 60 to 70 years old, reported high levels of educational attainment, and were in "good" to "excellent" health (Kneale & Demiris, 2017). These populations do not often overlap with people who are homebound (Ornstein et al., 2015) and/or receive home care (Weisfeld & Lustig, 2015).
This study was designed to examine to what extent existing PHRs meet the needs of homebound older adults who receive home care. Our results suggest that one reason homebound older adults may not be adopting PHRs at the same rates as other older adult groups because the systems are not designed to meet their health information needs. It is important for us to better understand the needs, desires, and motivations of this subgroup population in order to encourage more widespread adoption in the older adult population.

2.2.2 Methods

2.2.2.1 Literature Review

Medline (via PubMed), CINAHL (via EBSCO), and Embase (via Ovid) were searched for peerreviewed, full-text articles that focused on the United States homebound older adult population. The database specific 'homebound' indexing term was combined with keywords and indexing terms for 'older adult.' Publications were restricted to populations in the United States, and for publication dates between 2000-2015. Publications were included if the manuscript described aspects of the United States homebound population such as demographics, health status, technology use, or care preferences. Publications were excluded if the publication described studies that focused on clinical service models, caregiver preferences, public health/safety concerns, research methods, or specific clinical measures, such as describing dietary intake or the prevalence of depression. The characteristics identified in this review were translated into key features that should be supported by PHR systems.

2.2.2.2 PHR Evaluation

Potential PHRs were identified from a website dedicated to PHR education ("myPHR", n.d.), our systematic literature review (Kneale & Demiris, 2017), and the pages from Healthit.gov that

discuss PHRs ("Stay Well: Access Wellness Resources," 2013). The list of potential PHRs from the three sources was merged, and duplicate systems were removed. The primary author (LK) accessed the public websites of the potential systems. If the website listed on the original source was no longer active, LK conducted web searches using the product name to attempt to find the system under another web address. Eligibility criteria were created to help identify standalone PHR systems that were designed for the public, met our basic accessibility requirements (e.g. accessible through a desktop web browser), and were able to be studied by our research team. PHRs were eligible to be included in our evaluation if the system: 1) allowed patients to create an account without providing any payment information, 2) operated independently of any medical devices (e.g. medical bracelets), 3) was available to any consumer regardless of healthcare system affiliation, 4) offered an English language product information website, and 5) was available on the desktop version of major web browsers.

If a website was confirmed to be active, LK reviewed the public site and eliminated all potential systems that were clearly ineligible. After the first screening, three reviewers (LK, YC, and SM) visited the public websites and assessed the systems for eligibility. Initially, two reviewers independently accessed each site to collect data. If a system was deemed eligible, the reviewers created separate user accounts and evaluated the PHR for the key features identified from the previous literature review of older adult characteristics. The reviewers scored each PHR based on the number of identified key features that the system possessed. The third reviewer resolved any discrepancies that occurred between the first two reviews.

2.2.3 Results

2.2.3.1 Literature review

Figure 2 displays the results from the literature search. The initial search resulted in 95 publications from the three databases, which included 16 duplicates. From these articles, we found five publications that describe characteristics of the homebound older adult population (Beck et al., 2009; Leff et al., 2015; Musich et al., 2015; Nahm & Resnick, 2001; Ornstein et al., 2015). We used these characteristics to identify six key PHR features.



Figure 2. Paper 1: Results from Homebound older adult Literature Search

1. Saves information regarding discontinued medications

Medication reconciliation processes are essential for people going through care transitions, and proper medication reconciliation relies on lists of current and past medications (AHRQ Patient Safety Network, n.d.). A study surveying homebound Medicare recipients found that 25.7% of those surveyed took seven or more medications (Musich et al., 2015). In addition, homebound older adults had more healthcare encounters than non-homebound older adults, such as emergency room visits (Musich et al., 2015) and hospitalizations (Ornstein et al., 2015). The combination of a greater number of medications and a greater number of medical encounters may place homebound older adults at greater risk for poor medication reconciliation processes due to a large number of transitions between care settings. Therefore, PHRs should include access to both current and discontinued medications and associated information such as discontinuation date to assist with proper medication reconciliation following medical encounters.

2. Able to customize patient outcome measures

Homebound older adults are more likely to report fair or poor health than non-homebound individuals (Ornstein et al., 2015), but their medical profiles vary. A recent study asked homebound older adults to self-report common chronic diseases: heart disease, heart failure, breathing problems, kidney dialysis, diabetes, depression, and 'other'. Diabetes, at 32.2%, had the highest number of people identify with the condition; however, 92.9% of all people surveyed also reported that they had a chronic disease that was not on the list of six conditions (i.e. 'other') (Musich et al., 2015). This suggests that homebound older adults have varied health profiles, which would necessitate unique at-home health management routines. Therefore, a PHR for homebound older adults would be most useful if the end-users can customize the patient

outcomes available for tracking within the system, which can range from biological measures such as blood pressure, to patient reported outcomes such as a pain scale. This will allow any user to be able to track the outcomes that are most important to them and their care team.

3. Accepts a portable document format (PDF) document

Older adults who receive home care have more inpatient and outpatient encounters than older adults who do not receive home care (Musich et al., 2015; Ornstein et al., 2015). There are still many paper documents that patients with chronic diseases manage at home including lab reports, medication lists, and provider notes. A recent study with people with multiple chronic diseases found that some individuals were maintaining file folders and/or paper piles for this information. More often, however, participants did not maintain the paper records and relied on their memory for record keeping (Ancker et al., 2015). Although this may be difficult for most people with multiple chronic conditions, it could be even more difficult for homebound older adults who are more likely to report cognitive impairments (Ornstein et al., 2015) and difficulties with memory (Musich et al., 2015). Instead of relying on memory, or storing paper documents in file folders, these documents could be easily scanned into a format such as a PDF and uploaded into a PHR to capture a snapshot of the visit. Storing this data may help homebound older adults better understand their medical encounters, and share necessary information from these encounters with their care team members.

4. Provides role-based proxy access

Homebound older adults have complex care management processes, and receive a variety of services from care providers. Some relationships, such as family caregiving, can be long-term. Other services, including Medicare's home health, are short-term programs (Weisfeld & Lustig, 2015). This causes many homebound older adults to develop complex caregiving arrangements

with multiple stakeholders and organizations (Leff et al., 2015). Because of these dynamic relationships, a PHR should allow a user to grant caregiver access to their PHR on a temporary or permanent basis. In addition, the user should also be able to update such access as caregiving roles change, and revoke access if an individual is no longer participating in the homebound older adult's care. This would ensure that caregivers have access to the necessary information to assist with their caregiving duties, while protecting the users' health information from unwanted or unneeded access.

5. Provides no-cost access for standard use

Half of Medicare recipients, regardless of homebound status, live below the poverty line (Weisfeld & Lustig, 2015). As a population, homebound older adults report lower income than non-homebound older adults (Musich et al., 2015; Ornstein et al., 2015). Therefore, in order to be available to all older adult home care recipients, necessary features of the PHR should be provided to the user at no personal cost. Optional features, such as automatic data entry, may be available for those individuals who wish to pay a fee.

6. Offers access through a web browser

One publication described a study that introduced the Internet and e-mail to homebound older adults. This study found that homebound older adults were unfamiliar with computers and the Internet, faced many challenges with accessing online content, but were able to overcome these challenges and find enjoyment in online material through one-on-one coaching (Nahm & Resnick, 2001). Although technology has changed since the study's publication in 2001, homebound older adults may still face barriers with accessing technology. Homebound older adult characteristics are consistent with people who report barriers to technology. Specifically, homebound older adults are more likely to be older, report lower levels of educational

attainment, and have lower incomes than their non-homebound peers (Ornstein et al., 2015). These characteristics are consistent with low levels of smart phone and tablet adoption in the older adult population (2017). Therefore, in order to reach the greatest number of homebound older adults, a PHR should be accessible through a standard desktop web browser on any computer or device. This will allow individuals to access a PHR through whatever device they may have in their home, and also through any device a caregiver may bring into their home. In addition, eliminating the need for purchasing special devices, software or hardware will reduce the overall cost of access a PHR, and reduce the learning curve needed to access the system.

2.2.3.2 PHR Review

Figure 3 displays our results from PHR screening process. From the three search sources, we identified 96 potential PHRs. Sixty-eight (70.8%) systems were excluded during the initial review. The majority of the exclusions were due to the website no longer being active or the PHR not accepting any new accounts (n=27, 28% of total systems identified).



Figure 3. Paper 1: Results from Systematic PHR Search

Table 2 displays the results from our qualitative review of the final systems. Because we eliminated all systems that were not available through a computer as part of our eligibility assessment (3 paper-based PHRs, 3 smartphone applications), all of the PHRs reviewed met at least one criterion. The criterion: 'offers no cost user option' (n=10, 83%) and 'saves discontinued medications' (n=9, 75%) were included in the most number of PHRs. Six PHRs (50%) accepted PDF documents, five PHRs (42%) provided role-based proxy access, and four PHRs (33%) allowed users to customize the tracking of patient outcome measures.

PHR Name	Saves discontinued medications	Customizable patient outcome measures	Accepts PDFs	Provides role- based proxy access	Offers no cost user option	Offers access through web browser	Number (Percentage) of Criterion Met
HealtheTracks	*	*	*	×	*1	~	1 (17%)
My Doclopedia PHR	×	×	×	×	V	~	2 (33%)
Healthspek	~	*	*	×	~	~	3 (50%)
My HealtheVet	~	*	*	×	~	~	3 (50%)
Telemedical	*	*	*	~	~	~	3 (50%)
NoMoreClipboard	~	*	×	v	\bigstar^2	~	3 (50%)
Health Companion	~	*	 ✓ 	×	~	~	4 (67%)
Your Health Record	~	~	~	×	~	~	5 (83%)
Health Manager	~	~	~	*	~	~	5 (83%)
Microsoft Health Vault	~	×	~	~	r	~	5 (83%)
MyMedWall	~	~	~	 ✓ 	~	~	6 (100%)
RememberItNow!	~	~	~	v	~	~	6 (100%)

Table 2. Paper 1: PHR Attribute Evaluation

Does not have a no-cost user account
 Requires fee for uploading documents

2.2.4 Discussion

Our study results suggest that homebound older adults who wish to adopt PHRs have limited choices. Even though we identified 96 potential PHRs, most were not available to new users (n=84, 88%). Many of the available systems did not include the features identified to be useful to homebound older adults. For example, only 33% (n=4) allowed users to customize patient outcome measures. Without being able to customize an individuals' experience, PHRs are missing the opportunity to increase the perceived benefit of the system among patients with diverse self-care routines. As found in previous studies, older adults prefer to have PHRs with robust functionality [10], and our review of literature suggests that this also holds true for homebound older adults given the diversity of healthcare profiles in this population. PHR

to customize their experience and be able to use the PHR to meet their individual health management needs.

2.2.5 Limitations

The main limitations of our study are that 1) we determined our key functionality criteria based on a literature review, and 2) we performed the PHR search on commercially available PHRs. It is possible that homebound older adults may view the perceived benefit of PHRs differently than we expect. We mitigated this risk by carefully examining the existing literature about the needs and characteristics of homebound older adults (Beck et al., 2009; Leff et al., 2015; Musich et al., 2015; Nahm & Resnick, 2001; Ornstein et al., 2015). In addition, tethered PHRs highlight different functionality ("Personal health records: what providers need to know," n.d.). This may mean that some tethered systems have interfaces that are easier to use than standalone systems. Our search did identify two PHRs that were developed as tethered systems, but were also available to the general public: My HealtheVet and NoMoreClipboard. Including these systems in our review allowed us to gather information on both tethered and standalone systems.

2.2.6 Conclusion

As more adults age in their homes, ensuring that homebound older adults have access to the tools necessary to support home-based care routines will become a greater challenge for our medical system. The homebound older adult population has different characteristics than non-homebound older adults (Leff et al., 2015; Musich et al., 2015; Ornstein et al., 2015), and these characteristics may not be considered in current PHR evaluation studies (Kneale & Demiris, 2017). This study sought to identify the PHR features that would be beneficial for the homebound older adult population, and understand the prevalence of these features in today's

tools. Our study suggests that existing commercially available PHRs are not built to meet the needs of homebound older adults. This could limit the usefulness of existing tools within this population. Future research is needed to better understand the specific needs of this population, and to engage homebound older adults in future PHR studies.

CHAPTER 3: PAPER 2: EVALUATING PERSONAL HEALTH RECORD TO PROMOTE CARE COORDINATION AMONG HOMEBOUND OLDER ADULTS

3.1 Abstract

The number of homebound older adults in the United States is growing. Homebound older adults often rely on a network of formal and informal care providers to maintain their health and wellness at home. Care coordination between these care team members is challenging, and could be supported though increased use of personal health records. Personal health records are consumer health information systems that allow individuals to securely share their health information with others. This paper describes a study that evaluates two commercially available personal health records from three perspectives: a homebound older adult, a family caregiver, and a home health nurse. Our findings discuss how the design of these two systems may create challenges for these types of users when trying to accomplish routine care management tasks. Our findings suggest that some personal health records are not designed to be an effective care coordination tool. We conclude this manuscript by offering personal health record design recommendations to better meet the goals of care coordination.

3.2 PAPER 2 FULL TEXT

3.2.1 Introduction

Personal health record systems (PHRs) are patient-facing technologies that can help individuals with chronic diseases manage their care more effectively (Gee, Paterniti, Ward, & Soederberg Miller, 2015; Wells et al., 2014). PHRs allow individuals to access and manage their personal health information, and to share this information with trusted caregivers (Markle Connecting for Health, 2003). Sharing information with medical providers, family members, and other care team members, is a valued feature for many older adult PHR users (Gee et al., 2015; Heyworth et al., 2014; Price, Pak, Muller, & Stronge, 2013; C. L. Turvey et al., 2012). Older adults have reported that using a PHR to share information with their care team has increased their quality of care because their medical providers have a greater understanding of their medical history (C. Turvey et al., 2014) and there is greater transparency between general practitioners and specialist providers (Gu & Day, 2013). In addition, PHRs have helped older adults clarify questions relating to post-discharge medication changes (Heyworth et al., 2014), became more prepared for medical emergencies (Kim et al., 2009), and improve their perception of their patient-provider relationship (Gu & Day, 2013). PHRs that allow multiple users to access the same record are highly valued by both older adults and their caregivers (Gee et al., 2015; Price et al., 2013; Woods et al., 2013).

Homebound older adults are a population that could potentially benefit from increased PHR use. Many homebound older adults turn to networks of paid and unpaid caregivers to help them manage their health conditions, overcome their mobility challenges, and 'age in place' (Weisfeld & Lustig, 2015). Paid caregivers can provide services that range from hospital-athome programs to assistance with domestic tasks like cooking and personal hygiene (Weisfeld & Lustig, 2015). Unpaid care services, conducted by family members, volunteers, and charity care workers, help individuals with household duties, transportation, and buying necessities (e.g. groceries and household products) (Weisfeld & Lustig, 2015). Caregiving networks can become complex when a homebound older adult needs multiple types of services and has multiple caregivers come into their home. In that situation, care coordination between all care team members, including the homebound older adult, paid, and unpaid caregivers, is essential for

ensuring the individual's needs are being met and their health and wellness are being protected (Leff et al., 2015).

Research has shown that PHR adoption is affected by the design of the system under study (Britto et al., 2009; Czaja et al., 2015; Liu, Shih, & Hayes, 2011; Sheehan & Lucero, 2015). Usability evaluations study how well the design of a system supports users in achieving their goals, and the users' level of satisfaction when performing tasks in the system ("Usability Evaluation Basics", n.d.). Several prior studies have assessed the usability of PHRs from an older adult perspective, but none of these studies have included other care team members in the evaluation (Britto et al., 2009; Czaja et al., 2015; Liu et al., 2011; Sheehan & Lucero, 2015). This is a significant oversight since care team members including patients, caregivers, and providers, may face unique usability challenges based on their roles. For example, a systematic literature review of barriers to PHR use found that clinicians and caregivers reported task difficulty and time constraints as significant barriers to PHR use, while patients and caregivers reported general usability problems stemming from low technology literacy, and patient adoption was affected by the presence of medical jargon in the PHR (Thompson, Reilly, & Valdez, 2016). In addition to care team role, the age of PHR user has also been shown to affect people's experiences with technology. In one usability evaluation with younger and older adults, younger adults preferred to accomplish tasks more quickly than older adults, sometimes at the expense of accuracy, while older users did not appear to be as bothered by task completion time and found technology satisfying as long as tasks could be completed accurately (Sonderegger, Schmutz, & Sauer, 2016).

Because homebound older adult care teams often consist of several members (Weisfeld & Lustig, 2015), it is likely these teams consist of people with a diverse range of technology

experiences, goals, and preferences. Therefore, in order to design a PHR to be used as an effective care coordination tool, all of these preferences must be considered. The purpose of this study was to assess two PHRs from three user perspectives: a homebound older adult, a family caregiver, and a home health nurse. In addition, we evaluate the modified methodology that we used to gain an understanding of perspective tasks that were appropriate to their care team role, an individual technology profile, and consider their unique backgrounds. Our results promote a greater understanding of the PHR usability challenges facing homebound older adult care teams, and how changes to design of these systems could help improve the experience for diverse PHR users. In addition, these results highlight a methodology that could be used to enhance traditional heuristic evaluations in team settings.

3.2.2 Methods²

This study performs a usability evaluation on the two PHRs (PHR A and PHR B) that scored highly in our published assessment of PHR features for homebound older adult users (L. Kneale, Choi, Mikles, Thompson, & Demiris, 2017). We used a modified version of the Chisnell and Redish's heuristics for older adult web users (Chisnell & Redish, 2005) to evaluate the usability of these systems from the perspectives of a homebound older adult, a family caregiver, and a home health nurse.

3.2.2.1 Identification of the Heuristic Evaluation Measures

We performed a literature review on heuristic evaluations for older adult users in PubMed and Embase, and identified five sets of heuristics that were developed to assess older adult usability of web-based technologies (Chisnell & Redish, 2005; Hart, Chaparro, & Halcomb, 2008;

² This section is adapted from Kneale, Mikles, Choi, Thompson, and Demiris, 2017.

Kurniawan & Zaphiris, 2005; Lynch, Schwerha, & Johanson, 2013; Zaphiris, Ghiawadwala, & Mughal, 2005). After evaluating these sets, we chose the Chisnell and Redish guidelines for older adult web users. This set of guidelines were the most appropriate for our use case because it allowed us to review each system from multiple user perspectives - homebound older adult, family caregiver, and home health - and accounts for the wide variety in characteristics in these user populations. In addition, the designers of the original methodology are experts in both human-computer evaluation and the needs of older adult web-users (Chisnell & Redish, 2005).

The Chisnell and Redish guidelines contain 20 heuristics that fit into four categories: interaction design, information architecture, visual design, and information design. In order to account for users with different levels of skills, motivation, and abilities, personas are incorporated into the evaluation methodology. This heuristic methodology is unique in that it does not seek to gain an exhaustive list of heuristic violations, but focuses on identifying the most important problems that a persona may face when performing tasks within the system. In their report, Chisnell and Redish highlight that their methodology is designed to be different than a traditional expert-led heuristic evaluations to encourage a list of frequent problems that an average target user will face in the system. This methodology first asks the evaluator to record observations using the website as the persona, and then to fit these observations into the heuristic framework (Chisnell & Redish, 2005).

3.2.2.2 Creation of Personas

Following the above methodology, our first step was to create personas for the end-users. A persona is a fictional characterization of a user that is meant to "capture the user's mental model comprising of their expectations, prior experience, and anticipated behavior" (LeRouge, Ma, Sneha, & Tolle, 2013). To meet this goal, we conducted a literature review on homebound older

adults, their caregivers, and nursing staff. We adapted our initial homebound older adult persona ('Alice') from a case study of a homebound older adult published by Leff et al. (Leff et al., 2015), our family caregiver persona ('Matthew') after a persona published by Chisnell and Redish (Chisnell & Redish, 2005), and our home health nurse persona ('Lisa') from home health nurses known to the authors (LK, HT, GD) from prior research activities.

The original Chisnell and Redish methodology advocates for a persona characteristic comparison to help the reviewers understand the main differences between the personas (Chisnell & Redish, 2005). Our persona document includes a comparison between the personas on four dimensions: chronological age, degree of physical and cognitive limitations that affect using the Internet, expertise with computers and the Internet, and PHR aptitude- the degree to which the persona feels positive or negative towards incorporating the PHR into home health routines.

3.2.2.3 Search for Commercially Available Personal Health Records

We identified existing PHRs using MyPHR.com (myPHR, n.d.) a systematic literature review (Kneale & Demiris, 2017), and the webpages on Healthit.gov ("Stay Well: Access Wellness Resources," 2013). These sites were chosen to identify systems developed for both commercial and research purposes. Three authors (LK, SM, YC) assessed the PHRs identified in this search to ensure that the PHRs were active, met the basic functionality criteria, and were available to the reviewers at no cost. The functionality criteria were developed from a literature review on homebound older adults and a previously published study by the authors that examined commercially available personal health records using a published home-health case study (L. Kneale, Choi, & Demiris, 2016). The PHRs that performed in the top quartile of the functionality

assessment were included in this heuristic evaluation: MyMedWall ("MyMedWall," n.d.) and RememberItNow ("RememberItNow," n.d.).

3.2.2.4 Initial Training of Reviewers

Three authors (LK, SM, YC) used Chisnell and Redish's published report to train themselves on the heuristic evaluation methodology (Chisnell & Redish, 2005). For training purposes, the reviewers assessed three PHRs that performed in the middle quartiles of the functionality assessment.

The original Chisnell and Redish methodology had one person review each system. This methodological choice allowed Chisnell and Redish to assess over 50 websites within the study period (Chisnell & Redish, 2005). Previous heuristic evaluation methodologies have found that 40%-60% of known usability problems can be identified using three to five reviewers (Mankoff et al., 2003). Although the goal of the Chisnell and Redish methodology is not to identify an exhaustive list, we wanted to ensure that we captured a comprehensive list of potential usability problems. Therefore, to improve the completeness and accuracy of our heuristic evaluation results, our protocol had all three reviewers evaluate each system. Because there was no standard prescribed approach what to prioritize when navigating the websites in the original protocol [14], using multiple reviewers for each system was at times challenging because each reviewer focused on different actions and functionalities when evaluating the system. In addition, it could be challenging to combine all the results from the reviewers. Therefore, after reviewing our literature review, we introduced scenarios as a companion for the personas to guide reviewers' assessment of the PHRs.

3.2.2.5 Creation of a PHR Scenario for Each Persona

Scenarios help designers understand the goals of end-user populations. Unlike personas, which promote understanding of end-user characteristics, scenarios highlight specific actions taken by individuals in the system. Due to the focus on actors and actions, scenarios promote work-oriented design and a focus on specific functionalities (Carroll, 2000). An initial scenario was created for the homebound older adult persona based on a previous literature review of PHR use among older adults (Kneale & Demiris, 2017). Our scenarios for the caregiver and home health nurse were created using previous PHR literature reviews that were focused on general adult population use (Archer et al., 2011; Thompson et al., 2016; Uslu & Stausberg, 2008) and descriptions of home health scenarios (Leff et al., 2015; Millerick, 2004). The scenarios depicted a homebound older adult, family caregiver, and home health nurse performing a series of care management tasks relevant to homebound older adults after a hospitalization. These tasks included reviewing medication lists, entering patient-reported outcome data, and accessing documentation from previous medical visits.

3.2.2.6 Validation of Personas and Scenarios

After developing the initial materials, we recruited five practicing home health nurses in the United States using online home health nursing forums. The primary author (LK) conducted phone interviews with the home health nurses to validate the personas and scenarios. Participants were offered a \$10 gift card for their time. All participants had been practicing at a Medicarecertified home health nurse for longer than one year, and provided care in a variety of settings including rural communities and large urban centers. Participants were located in the Northeast, Midwest, and Southern regions of the United States.

The home health nurse participants were asked to review all three personas and scenarios prior to the phone call. During the interview, participants were asked to provide feedback on how realistic the personas and scenarios were based on their professional experience, and offer suggestions on how to improve the accuracy of the scenarios and personas. Interviews were audiotaped and transcribed. Inductive coding was completed on the interview transcriptions to identify commonalities between the participant opinions. Participant feedback was incorporated into the final personas and scenarios. Feedback was overall positive, and many home health nurses expressed seeing potential value in a PHR for their work. The thematic concerns that arose from the initial materials were: the underestimation of the involvement of informal caregivers, the desire to have more information about pain between home care visits, and the perceived ability and/or willingness of homebound older adults to manage their own care. Based on the feedback from these interviews a few changes were made: 1) the involvement of the family caregiver persona ('Matthew') in his dad's care was increased, 2) 'adding a medication' task was moved from the homebound older adult scenario to the family caregiver scenario, and 3) documenting pain (an important patient reported outcome for home health nurses) was added to the older adult scenario.

3.2.2.7 Conducting the Heuristic Evaluation

Reviewers (LK, SM, YC) conducted the heuristic evaluation on the two PHRs described earlier. To reduce a system learning effect due to performing multiple scenarios on each system, the reviewers evaluated both systems using one persona and scenario at a time before moving on to the next persona, leaving at least a two-week period between personas.

Each system was scored on two different criteria: scenario task completion and adherence to the heuristics. Following the original methodology, the reviewers read the appropriate persona

prior to starting each round of heuristic analysis to understand the user's strengths and weaknesses. Then the reviewers followed the scenarios, embodying the associated personas, and recorded detailed observations of their experiences performing the scenario tasks. In our study, two reviewers used bullet points to record their observations for each task and one reviewer chose to write narratives to reflect his experience as the persona. After the observations were complete, each reviewer would score each scenario task using the Chisnell and Redish scale of 1 to 4, with 1 representing "task failure: this prevents the user going further" and 4 indicated "no problem: satisfied scenario".

After the initial observation and the scoring of the scenario tasks, the reviewers met to reconcile differences between the task scores and observations. Differences were reconciled through discussion and demonstration of the workflows performed during the individual evaluations. In this meeting, a final list of all observations, both positive and negative, was created. Final scores for each task were agreed upon through consensus of the three reviewers. Consensus was used to ensure that all reviewers benefited from the experiences of the other evaluations. Even though there was a scenario to follow, the reviewers still found multiple paths to accomplish each scenario, providing different reviewers with different overall experiences. Reaching a consensus allowed us to examine all reviewer experiences in order to determine the most appropriate final rating.

The list of observations was used to populate the heuristic spreadsheet. The primary author (LK) took the complete list of observations and matched the observations to the appropriate heuristic categories. The other reviewers (SM, YC) reviewed the initial matching to ensure that the observations were accurately portrayed, and that the observations were put into

the appropriate heuristic categories. After the heuristic tool was populated with observations, each reviewer individually ranked each category using the 1 to 4 rating.

After individual ratings, the evaluations were combined. Heuristic categories that differed between the reviewers were examined during an in-person meeting and final scores were finalized based on consensus between the three reviewers. Following the original methodology, heuristics that did not have any observations associated with it, either positive or negative, were not scored for that persona.

3.2.3 Results

3.2.3.1 Methodology evaluation³

We recorded observations for 50% to 80% of the heuristics for each combination of persona and system. Considering both systems together, we recorded observations for 80% (16/20) of the heuristics for each persona. There is significant overlap between the heuristics scored for each persona, but the lists of scored heuristics are not identical. Only two heuristics (10%) were not scored by any persona, in any system during the study: 1) provide feedback in other modes in addition to visual; 2) include a site map and link to it from every page. In addition, our processes allowed us to record both positive and negative observations on the system. All personas had heuristics that ranged from 1 (task failure) to 4 (satisfies heuristics). The summary of results from the evaluation is displayed in the table below.

³ This section is adapted from Kneale, Mikles, Choi, Thompson, & Demiris 2017

System		Older Adult ('Alice')	Family Caregiver ('Matthew')	Home Health Nurse ('Lisa')
	# of Heuristics Scored (%)	16 (80%)	14 (70%)	13 (65%)
	Average Heuristic Score	2.2	2.4	2.4
	# of Score 1: Task Failure (%)	5 (31%)	3 (21%)	2 (15%)
MyMedWall	# of Score 2: Serious Problem (%)	5 (31%)	5 (36%)	5 (38%)
	# of Score 3: Minor Hindrance (%)	4 (25%)	3 (21%)	5 (38%)
	# of Score 4: Satisfies Heuristic (%)	2 (13%)	3 (21%)	1 (8%)
	# of Heuristics Scored (%)	15 (75%)	10 (50%)	13 (65%)
	Average Heuristic Score	2.5	2.6	2.8
	# of Score 1: Task Failure (%)	2 (13%)	2 (20%)	1 (8%)
RememberItNow	# of Score 2: Serious Problem (%)	5 (33%)	2 (20%)	5 (38%)
	# of Score 3: Minor Hindrance (%)	6 (40%)	4 (40%)	3 (23%)
	# of Score 4: Satisfies Heuristic (%)	2 (13%)	2 (20%)	4 (31%)

Table 3. Paper 2: Summary of Results from Heuristic Evaluation

1 = Task failure; prevents this user from going further, 2 = Serious problem; may hinder this user, 3 = Minor hindrance; possible issue, but probably will not hinder this user, 4 = No problem; satisfies heuristic

3.2.3.2 Agreement between Reviewers

All final ratings for both scenario tasks and heuristics were made by consensus between the three reviewers. Consensus was reached during in-person meetings after each evaluation step: one consensus meeting for task rating, and a separate meeting for heuristic results. Even though all reviewers followed the same tasks as defined in the scenarios, there were often multiple ways for

a user to complete the task in the PHR. These multiple pathways often affected how difficult it was for the user to complete the scenario.

Task agreement between all three reviewers (across the three scenarios for both systems) was 29% (15/38). In 78% of the disagreements (18/23), two of the three reviewers had the same score and one reviewer was an outlier. Heuristic agreement between all three reviewers was 46% (37/81). Two of the three reviewers scored the heuristic the same score in 90% of disagreements (38/42). Task agreement was more difficult to achieve because the scores were influenced by the individual paths that each reviewer took in the PHR to accomplish the scenario tasks. Heuristic disagreement was caused by differences in opinion on how significant an identified usability challenge would be on the persona, and the disagreement between reviewers was limited to 1 (e.g. between a '3' and a '4') in 81% of the disagreement cases (34/42).

3.2.3.3 Overview of Evaluation Results

Table 5 displays the results from the task analysis. As described above, each persona had a unique list of tasks, and these tasks were scored in both systems.

		Homebound	l older adult	Family C	Caregiver	Home He	alth Nurse
		('A1	ice')	('Mat	thew')	('Li	sa')
	Γ	PHR A	PHR B	PHR A	PHR B	PHR A	PHR B
		Serious	Serious	No	No	No	No
	Login	problem	problem	problem	problem	problem	problem
Admın.		('2')	(*2*)	(*4*)	(*4*)	(*4*)	(*4*)
functions	-	Minor	Minor	No	No	No	No
	Logout	hindrance	hindrance	problem	problem	problem	problem
Accessing				(4)	(4)	(4)	(4)
medical	View past	failure	failure				
history	diagnosis	(1^{2})	(1^{2})				
mistory		Minor	Minor	Minor	No		
	View	hindrance	hindrance	hindrance	problem		
	Medications	('3')	('3')	('3')	('4')		
Admin. of	Duint			Task	Minor		
medications	Print			failure	hindrance		
	Medications			('1')	('3')		
	Undate					Task	Serious
	Dose					failure	problem
	2000					('1')	('2')
	Enter Pain	Task	Task				
Tracking	Score	rallure	rallure				
reported						Serious	Tack
data	View Pain					nrohlem	failure
Gutu	Score					(2)	('1')
	• • •			Minor	Serious	(-)	(1)
	View			hindrance	problem		
	UASIS			('3')	('2')		
	Download			No	No		
Organizing	OASIS			problem	problem		
medical				('4')	('4')		
documents	View					Serious	Minor
	Outpatient					problem	hindrance
	Notes					(*2*) Min an	(¹ 3 ¹)
	Upload					Minor	NO problem
	nome nearth					('3')	(4^{\prime})
	View			Task	Serious	(3)	(+)
	laboratory			failure	problem		
Managing	values			('1')	('2')		
laboratory	Enter new			Task	Task		
values	laboratory			failure	failure		
	values			('1')	('1')		

Table 4. Paper 2: Task Scores by Scenario and Personal Health Record

As shown above, personas had different experiences performing the tasks in each system. Table 6 displays a summary of the task scores by persona in each PHR. The reviewers had most difficulty completing the homebound older adult tasks, scoring 80% (n=3) of the tasks as a "task failure (1)" or "serious problem (2)." None of the homebound older adult tasks were given a "no problem (4)" score. Our family caregiver persona, however, had tasks that were easier for reviewers to complete. Five of his tasks (62.5%) scored a "minor hindrance (3)" or better. Our home health nurse tasks had greater variation between PHR systems. In one system (PHR A), the reviewers scored her six tasks evenly between the rating categories with 50% (n=3) of her tasks scoring a "serious problem (2) or below. In PHR B, more than half of her tasks (n=4, 66.7%) scored a "minor hindrance (3)" or higher.

Persona	Total Tasks	PHR	# (%) "Task failure (1)"	# (%) "Serious problem (2)"	# (%) "Minor hindrance (3)"	# (%) "No problem (4)"
Homebound older	5	Α	2 (40%)	1 (20%)	2 (40%)	0 (0%)
adult ('Alice')	5	В	2 (40%)	1 (20%)	2 (40%)	0 (0%)
Family Caregiver	0	Α	3 (37.5%)	0 (0%)	2 (25%)	3 (37.5%)
('Matthew')	0	В	1 (12.5%)	2 (25%)	1 (12.5%)	4 (50%)
Home Health	6	Α	1 (16.7%)	2 (33.3%)	1 (16.7%)	2 (33.3%)
Nurse ('Lisa')	0	В	1 (16.7%)	1 (16.7%)	1 (16.7%)	3 (50%)

Table 5. Paper 2: Summary of Task Scores by Persona and PHR

3.2.3.4 Administrative Functions

All personas were required to login from the main PHR page, and log out when all tasks were completed. Logging in and out was straightforward for the reviewers when they were acting as 'Matthew' (the family caregiver) and 'Lisa' (the home health nurse). Each PHR followed Internet conventions by placing the login and logout buttons/links in the top right corner, and all the buttons/links worked as expected. This helped facilitate easy location and completion of these tasks for both these personas.

The reviewers ran into more difficulty with these tasks when acting as the homebound older adult ('Alice'). Logging in was most difficult, scoring a '2' (serious problem) in each PHR. What made this task more difficult for 'Alice' was the poor design of the PHR homepages. These PHR homepages had poor color contrast (e.g. green text on a blue background), small sized fonts, and were cluttered with extra information.

As shown in figure 4, one PHR had many distracting elements on its homepage. There was a large "GO" button that directed users to create an account (not to logging in), and automatically scrolling text boxes in the middle of the screen. These text boxes contained a lot of content, but nothing was related to the task of logging in. Conversely, the "log in" link was in the top, right corner with not many characteristics to make it stand out. What made this task even more difficult when reviewers were acting as 'Alice' was that neither PHR followed the Chisnell and Redish recommendation of allowing the older adult user to increase font size directly on the webpage. If 'Alice' increased the font size through the web browser settings, a horizontal scroll bar hid the "log in" link on both homepages which could make 'Alice' miss the "log in" link altogether.



Figure 4. Paper 2: Cluttered Landing Page for PHR B

1. Large button that could confuse users by taking them to an account creation website instead of the login page

 Automatic scrolling text boxes with a large amount of content
 The relatively small "log-in" link is the only way to login into the PHR Accessing Medical History

The homebound older adult scenario called for 'Alice' to access her previous cancer diagnosis. She was unable to accomplish this task in either system, despite the fact that both PHRs offered a way to store this information. The reviewers thought that 'Alice' would be inhibited by the general design of these systems with the small font, poor color contrast, and a lack of white space between content. Figure 5 displays the table of contents from PHR A that highlight these general usability design problems.



1. The entire table of contents contains difficult to read font with small font size, poor color contrast, and all capital letters

2. Many content headers have similar names including problems, current medical history, past illness, and end of life issues

Figure 5. Paper 2: Table of Contents from PHR A

Additionally, the reviewers thought that 'Alice' would find navigating both PHRs

difficult due to the poor content headings. For example, as displayed in Figure 5, 'Alice' would

have four different links to choose from that all sounded similar: "problems," "current medical history," "past illness," and "end of life issues". Each one of these links takes the user to a separate table, but only one table ("past illness") displays her cancer diagnosis.

Figures 6 and 7 show the tables associated with the "problems" and "current medical history" links. As shown in these figures, the tables introduce more medical jargon such as "Snomed Code", which may further confuse the layperson. In addition, neither table instructs the user how to view their past medical issues, either by offering a cross-link to the "past illness" table or by using headings that make it clear that the table only contains current medical conditions. The reviewers thought that the combination of the general usability issues, multiple potential content headings, and the lack of cross-links in the tables, would likely prevent 'Alice' from finding her past illness, leading her to assume that the cancer diagnosis was not in the system.

PROBLEMS 1					^
Problem Name	ICD9 Code 2	Snomed Code 2	Start Date	Modified Date	Status
Kidney disease 🥡	_		5/10/2016		Active
Frailty 🥡			5/10/2016		Active
Depression 🥡			5/10/2016		Active
Arthritis 🥡			5/10/2016		Active

1.Main headings do not link to "past illnesses" 2. Clinical jargon is used on table headings

Figure 6. Paper 2: "Problems" Table from PHR A

Medical Problem 3	Notes	
Kidney disease 🥡	Chronic since 2012	
Arthritis 🥡	of the shoulders since 2012	
Depression 🥡	since 2014	
Frailty 🍘	since 2015	

1.Main headings do not link to "past illnesses" 3. Table heading does not specify whether these problems are current/active or past/inactive

Figure 7. Paper 2: "Current Medical History" Table in PHR A

3.2.3.5 Administration of Medications

All three personas had tasks related to medication administration. In this category, the reviewers thought that both the homebound older adult ('Alice') and the family caregiver ('Matthew') would be able to find and view the medication lists. Although the small font and poor color contrast would still hinder 'Alice's' navigational ability, the clear titles that point to the medication lists would likely help 'Alice' identify and move to the correct location in both systems.

'Matthew's' task list also called for him to print out medications to take to his dad's upcoming doctor appointment. In PHR B, the reviewers thought that 'Matthew' would be able to accomplish this task with minor issues. This PHR offered a way to print the medication list from the same page as viewing the list. However, in PHR A, the reviewers thought that 'Matthew' would likely be unable to complete the task. As shown in figure 8, this PHR required a user to navigate to a separate "print" menu that was not connected to the medication list or any other documentation accessible from the table of contents.

My Medical Records - My Labs / Radiology / Other Files	Medical Record Sharing - Track My BP, Sugar, etc	Print - 1
Clinical Summary	2	Print History Print PDF History (For Elseb / CD / Thumb Drive)
Person name L K Age 66 Gender Male Ethnicity	DOB Race Preferred language	CCD/C-CDA Import and Export (Electronic Format Only) Track My BP, Sugar, etc

1. Separate print menu for all printing activities in system

2. Printing capabilities are limited to printing history or printing PDF history. More granular print options are not available

Figure 8. Paper 2: Print Menu in PHR A

Finally, the task list for the home health nurse ('Lisa') included changing the dose of one of her client's medications. Similar to 'Matthew', the reviewers thought that 'Lisa' could navigate to the medication list with no problems in either system; however, updating a current medication entry would be challenging. Neither PHR offered a way for a user to simply update a dose without deleting the previous dosage information. Therefore, 'Lisa' would be required to discontinue the current medication entry and create a new entry to keep the current and previous dose information. As shown in figure 9, PHR A would not allow 'Lisa' to save changes to an existing medication record. Further complicating matters, the text boxes in this medication section appear to be able to accept new values. However, if a user enters in a new dose and presses "next," the changes are not saved. The reviewers' thought that this would not only make this task difficult for an average user, but this could also pose a safety hazard. If 'Lisa' did not verify that the changes were made, she could think that the dose was updated but not have the system recognize the changes. Additionally, the re-entry of the medication information in both PHRs would seemingly waste 'Lisa's' documentation time, making the system more burdensome for her.

Medication							
					Please No	te : Enter the approximate date if date	is unknown Last Updated Date :09/13/20
				Medication Add			
Med Name		Strength		How Often		Prescribed Date	Notes
			Select		•		
				O Add			
Med Name		Strength	How Often		Prescribed Date	Notes	
simvastatin		20mg	Once a Da	• v	9/13/2016	dose cha	inge 🗰
0 1		1					1
Catopril		25 mg	Three time	es a day 💌	5/1/2016	for high b	blood pressure, take 1 pill one hou
0							
Candesartan		16 mg	Once a Da	3V •	5/1/2016	for high t	blood pressure, take one pill each
U							
Bisoprolol		10 mg	Once a Da	- γ	5/1/2016	for high t	blood pressure, take one pill each
•							
Furosemide		40 mg	Once a Da	т	5/1/2016	for conge	estive heart failure, take one pill ea
moved Med				Removed Medication List			Last Updated Date :07/20/2
Med Name	Strengt	h I	How Often	Prescribed Date	N	otes Reason	Removed Date
urosemide	40 mg	Select					7/20/2016
aptopril	25 mg	Three times a day	Y				7/20/2016
andesartan	16 mg	Once a Day					7/20/2016
isoprolol	10 mg	Once a Day					7/20/2016
imvastatin	40 mg	Once a Day					7/20/2016
1 2							
				Back Next O			

1. Changes to text in these boxes are not automatically saved by the PHR

There is no saved button to keep changes made to the medication record
 Selecting "next" or "back" does not save changes to the record



3.2.3.6 Tracking Patient Reported Data

Our tasks required the homebound older adult ('Alice') to enter her pain score so that the home health nurse ('Lisa') could review it. Both systems offered a way for the patient to track their pain. The reviewers did not think that 'Alice' would be able to complete this task in either system, and 'Lisa' would have significant difficulty in one PHR and be unable to complete the task in the other. PHR A had a confusing title for the patient tracking section titled: "track my BP, sugar, etc." While 'Lisa' may be familiar with the acronym "BP" and colloquialism "sugar", and understand that "etc." may include pain, the reviewers thought that 'Alice' would have difficulty understanding this title.

If 'Alice' did reach the right section, she would have to go through a complicated workflow to add a new pain value. As shown in Figure 10, users must first check the "pain" box to add a new value to the correct patient-tracking item. This would take the user to a second screen where the user could add a new value using the small, green plus sign. The lack of directions on this page, coupled with the small font and green button, made the reviewers think that 'Alice' would be unable to accomplish this task on her own.

					-
					I Flow Sheet
All A B C C	EFGHIJK	LMNOPQRS	T U V W X Y Z 0 1 2 3 4 5	6 7 8 9	
ſ	Orthostatic BP	check	Accuchek	BP / Pulse Check	7
	Creatinine Red	uction Ratio in Blood	DM and CAD Profile	Hemoglobin	
	Pain [™] 1		Respiration/Pulse oximetric	ry Uweight/BMI check	
nal Lab Eler	[Add New] nents				
mal Lab Eler	[Add New]				E Flor
nal Lab Eler	[Add New]	The Test	/Data name is : Pain		Flor
nal Lab Eler ack	[Add New]	The Test	/Data name is : Pain ge/Condition	Value/Description	Flox
nal Lab Eler ack	[Add New]	The Test Ran 5/	/Data name is : Pain ge/Condition 10	Value/Description Feeling ok at bedt/me	Flox
nal Lab Eler ack May 15 May 15	nents	The Test	/Data name is : Pain ge/Condition	Value/Description Feeling ok at bedtime In lots of pain right no	Flox
rnal Lab Eler kack May 15	nents	The Test	/Data name is : Pain ge/Condition 10 Range / Condition	Value/Description Feeling ok at bedtime In lots of pain right no Value / Description	Fic

- Steps to track pain:
- 1. First users check the test/data that they would like to enter 2. Secondly, users click on the green plus sign
- 3. Finally, users complete the text boxes associated with the patient-tracking item
 - 4. All tracking items are text boxes without instruction on how to complete

PHR B required 'Alice' to navigate to the "My Stats" section of the PHR, and toggle the "view by" drop down menus to access the "pain" chart. As shown in figure 11, Alice could only click the "add a new reading" after she had navigated to the correct pain graph. If 'Alice' added a new reading to the first chart that was presented she would be asked to rate her 'general wellness'. The reviewers felt that most users would likely miss the "view by" drop down box, including 'Alice.'



Steps to track pain: 1. Select pain from the "view by" dropdown menu 2. Click the "add a new reading" button

Figure 11. Paper 2: Tracing pain in PHR B

Finally, 'Lisa' would be required to perform the same functions in both PHR A and PHR B to view 'Alice's' pain scores. Again, due to the complexity of the workflow required to find the

pain score in each PHR, the reviewers felt that 'Lisa' would also be likely unable to accomplish these tasks correctly, or in an efficient manner.

3.2.3.7 Organizing Medical Documents

The task lists of the family caregiver ('Matthew') and home health nurse ('Lisa') included organizing medical documents. 'Matthew' was asked to view and download his father's Outcome and Assessment Information Set (OASIS) document. 'Lisa' was asked to upload her home health note, and to view a note from an outpatient cardiology appointment. As long as 'Lisa' and 'Matthew' were able to navigate to the correct areas of the PHRs, the actual tasks of viewing, downloading, and uploading the documents were straightforward in both systems. PHR A would require 'Matthew' and 'Lisa' to navigate to the correct section either by using the table of contents ("upload files") or through the website main headers ("My labs/radiology/other files"). PHR B labeled the document area as "vault." The reviewers felt that these headings were unclear, and could lead either persona to give up before accessing the correct files. In addition, both PHRs had potentially misleading headings such as "journal," "medical record sharing," and "resources." Depending on the perspective and persistence of the user, we thought that users may or may not be able to correctly find the correct area through trial and error.

3.2.3.8 Managing Laboratory Values

The final category of tasks that the personas were asked to perform pertained to managing laboratory values. In the family caregiver scenario, 'Matthew' received a mailing from his father's doctor with the results from his recent laboratory tests. 'Matthew' wanted to update his father's PHR by entering these values into the system. Again, the reviewers felt that usability problems would prevent 'Matthew' from easily performing these tasks. As with the other tasks,

finding the correct location of the laboratory values was confusing with the headings in these systems. PHR A required 'Matthew' to go to the "track my BP, Sugar, etc." menu, and PHR B required him to record the information in the confusing patient tracking graphs (as shown in Figure 11). Once 'Matthew' navigated to the correct area, he would be required to perform the complicated workflow to confirm the new laboratory values are not currently in the system, and to add the new values. As discussed in the pain tracking section, the reviewers felt that these steps would be too complicated for 'Matthew' to accomplish.

3.2.4 Discussion

When analyzing our results, it is important to note how PHRs are different from other consumer information technology tools. First of all, PHR users do not always know what pieces of information are in the system unless they entered it themselves. When other users, such as formal or informal caregivers, enter information into the system, patients may not be aware that this information exists. For example, in the homebound older adult ('Alice') scenario, she did not enter her own cancer diagnoses into the system. Therefore, we thought it was reasonable to assume that if she saw a list of diagnoses that did not include everything, 'Alice' would just assume that the information wasn't documented in the system and would not search for another location. Secondly, unlike other consumer technologies, a PHR is not the only way for users to obtain their personal health information. Healthcare consumers have many choices on how to access and organize personal health information including calling a doctor's office, receiving mailings, keeping paper documents, and accessing multiple electronic systems such as claims information from an insurer. Therefore, if a PHR is difficult to use, someone like 'Alice' or 'Matthew' may just choose to use other means of accessing the information.
Our review of commercially available PHRs found that many PHRs might not be designed to promote care coordination among homebound older adults, family caregivers, and home health nurses. Our assessment determined that administrative functions, viewing and printing medications, and organizing medical documents were the easiest tasks for our team to complete. The other tasks (viewing past diagnoses, tracking patient reported pain, updating a medication dose, and managing laboratory values) would likely be too difficult for our personas to complete.

In addition, we found some usability challenges that could create differences in the care team members' abilities to effectively use the PHRs. The reviewers thought that our homebound older adult persona 'Alice' would be most affected by the design of these systems. Neither PHR seemed to follow Chisnell and Redish's recommendations to make websites easily navigable for older adult users. Chisnell and Redish advocate improving usability by allowing users to customize font size, using a color scheme with good contrast, using cross-links to make similar tasks easier to accomplish, and minimize scrolling (Chisnell & Redish, 2005). These PHRs could have made their websites more user friendly to people like 'Alice' by following these guidelines.

Our review found that older adult users aren't the only care team members who will likely be affected by usability challenges. We gave our family caregiver persona ('Matthew') and home health nurse ('Lisa') more complicated PHR tasks, such as entering multiple laboratory values and changing medication doses. These tasks were inhibited by both general usability problems, such as finding the correct location in the PHR to perform these functions, and by complicated workflows.

3.2.4.1 Data collected through methodology⁴

Overall, this methodology allowed the authors to comprehensively evaluate the usability of two PHRs for a care team that consisted of users with different technological abilities. Using the modified Chisnell and Redish methodology, we were able to identify certain tasks in each system that would be difficult for a specific type of user to perform, as well as discover overall areas of improvement that could help improve the usability for all three types of users.

We were able to identify three different types of results by using this methodology to conduct a heuristic usability evaluation. First, this methodology allowed us to identify usability challenges that may present a challenge to any user who wishes to perform any functionality in the PHR. For example, all three of our personas found it difficult to understand the PHR structure, and struggled to use the headings to navigate through their scenarios. These types of results prompted general design recommendations that are similar to traditional heuristic evaluation recommendations, such as "improve the headings of the system menus."

In addition, this methodology allowed us to understand how performing different functions within the system created varied user experiences. For example, all three personas had to access the medication list within their scenario. 'Alice' viewed her medication list, 'Matthew' printed his dad's medication list, and 'Lisa' changed a medication dose. 'Alice and 'Matthew' had little difficulty completing their tasks, each scoring a 3 or 4 in both systems. 'Lisa,' on the other hand, found this to be one of her most challenging work items (scoring a 1 and a 2). The difference between the user experiences wasn't because 'Lisa's' characteristics made it more difficult for her to complete her task, but that the interfaces to update the medication list were poorly designed in both systems. This type of finding allowed us to make specific

⁴ This section is adapted from Kneale, Mikles, Choi, Thompson, & Demiris, 2017.

recommendations on how the PHRs could improve specific functionality, such as "improve the workflow for updating a medication dose."

Finally, this methodology also allowed us to better understand how user characteristics affected an individuals' experience with the PHRs. We used these types of results to provide design recommendations that were targeted for specific user groups. For example, 'Alice' had the greatest difficulty with the color contrast (e.g. white font on a light blue background) and text size. 'Matthew' had the greatest challenge with navigating complex workflows because he had other tools (e.g. calling the home health nurse) that he could use to complete his scenario tasks. Finally, 'Lisa' had the greatest advantage with navigating the systems because of her understanding of clinical abbreviations (e.g. "BP), and the overlap in design between these PHRs and clinician-focused electronic health records. Therefore, this methodology could also be used to make specific recommendations to promote the use of a target end-user population. It also may help CHIT designers understand the needs of different user populations. In situations where the CHIT will be used by a variety of patient populations, such as PHRs, these recommendations could help design systems that meet the needs of all potential users.

3.2.4.2 Ease of Using the Methodology⁵

Once the reviewers were fully trained on the methodology, evaluation materials were complete, and the evaluation protocol was finalized, this methodology was relatively straightforward to follow. During the training sessions, the reviewers had the opportunity to identify details of the persona and scenario tasks that were confusing, and reconcile these details to ensure consistency between reviewers. In addition, the training allowed us to come to consensus about the abilities and weaknesses for each persona.

⁵ This section is adapted from Kneale, Mikles, Choi, Thompson, & Demiris, 2017.

Because some functionality in the PHRs was more difficult to use than others, a persona's PHR aptitude became a key factor into coming to an agreement on the final score. This was especially important when determining if a task or heuristic was a "2" (serious problem) or a "3" (minor hindrance). The characteristic comparison, designed based on the original methodology, became a key resource for helping our team come to consensus on how each persona would react during a difficult-to-use task. The reviewers also differed in how they envisioned personas with potentially similar abilities, which was an issue for the caregiver and home nurse personas who were both middle-aged adults. Faced with personas with similar physical abilities, differences in scores arose from imagined personality characteristics such as a persona's level of patience or comfort with types of websites. In contrast, scoring tasks for the older adult persona was easier since 'Alice' was more likely to fail a task due to factors that were easy to ascertain visually, such as font size and color contrast. Discussion was crucial to harmonizing the group conceptualization of a persona and reconciling scores.

The reviewers also differed in terms of their computer configurations. They used computers with differently sized screens and with different default browser settings. One important factor to consider was default browser font size and the effects of using zoom commands to change the sizes of images and text on the screen as systems differed in how they rearranged their webpages in response to these settings. Another potentially important factor was the reviewers' browser plug-ins, such as the use of plug-ins to render PDFs, which could affect how systems function. It was useful to explore computer settings and how they would alter a system's ability to meet the needs of the personas in our discussion.

Finally, our process and findings demonstrated that the Chisnell and Redish set of heuristics is robust. It has twenty overall heuristics, and up to eight sub-categories under each

heuristic. For our evaluation, we sometimes struggled to reach consensus on where an observation would fit into a single heuristic, as there appears to be some overlap between definitions. For example, it was often difficult for the reviewers to place comments into the three following heuristics: "make pages easy to skim or scan (#13)", "visually group related topics (#15), and "make it easy to find things on the page quickly (#18)". In order to put an observation into the correct heuristic, we had to continually review the original intention of these heuristics, and reach a consensus of where the observation best fit. Other heuristics for older adult web users have a smaller list (Kurniawan & Zaphiris, 2005; Lynch et al., 2013; Zaphiris et al., 2005), which may decrease the time associated with scoring and reduce the amount of perceived overlap between categories.

Although a smaller list of heuristics may be helpful for reviewers, we also found that some of our observations did not fit into any of the existing 20 heuristics. The additional comments involved observations related to workflow (e.g. "too many clicks to perform a task, 'Matthew' will probably give up"), inconsistent functionality (e.g. "However, if she clicked on any of the links under Table of Contents, the logout link is not there anymore"), and unhelpful information (e.g. "She scrolls down and finds the FAQ, but it doesn't answer her question"). These results suggest that additional work on the Chisnell and Redish heuristics may be needed to identify a comprehensive and concise set of heuristics for older adult web users.

3.2.4.3 Use of Multiple Reviewers⁶

Using only one reviewer to evaluate each website helped Chisnell and Redish evaluate 50 different websites during their study period; however, this methodological choice may have led to unintentional bias of the evaluation results (Chisnell & Redish, 2005). Since only one

⁶ This section is adapted from Kneale, Mikles, Choi, Thompson, & Demiris, 2017.

researcher evaluated each system, there was the potential for the individual researchers' biases and preconceived notions of the characteristics of a usable website to skew their results. Our protocol, by having all three reviewers evaluate each PHR, reduced the number of systems evaluated, but it also increased the amount of time spent on each system and provided for multiple perspectives to view each system. Having multiple people review each system allowed us to improve the completeness of our observations, and reduce the likelihood that bias from an individual reviewer would be reflected in our final results. We found this to be especially useful because using these systems often proved difficult, and reviewer fatigue was present when a reviewer had a particularly hard time accomplishing a scenario task. We can see this fatigue in the agreement results, where one reviewer having a different experience than the other two caused most of the disagreement. This fatigue had the potential to bias the reviewer against the system and lower the score ratings for subsequent tasks. This bias was mitigated when the results from all three reviewers were compared, discrepancies between observations were discussed, and final ratings were scored through consensus.

Using multiple reviewers allowed us to gain a better understanding of the potential enduser experiences by identifying multiple pathways to accomplish each scenario goals, and be able to adjust our original opinions if reviewer fatigue caused a rating to be too high or too low. As seen in our agreement statistics, despite the extensive training, the reviewers still conceptualized some aspects of the personas differently. This affected where they initially looked on the screen to complete a task, how they interpreted labels and instructions, and their expectations for how different controls in the systems should behave. This resulted in coverage of a wider range of probable end-user behaviors, which helped to develop a larger and more

comprehensive list of positive and negative observations for each persona and for most of the heuristic categories.

One significant challenge emerged because multiple reviewers used the same persona logins in each system, and system settings and data were not reset between reviewer evaluations. Therefore, if a reviewer erroneously entered data in the wrong spot in the system for data entry scenario tasks, the reviewers that tested the system afterwards may mistakenly believe that this was the right place to access the data. One way to get around this reviewer error would be to reset the PHR after each reviewer, or create mirror PHR accounts for each reviewer. Resetting the PHR after each review would increase the time that each review took by eliminating the potential for reviewers to conduct the evaluations concurrently. Creating separate reviewer PHR accounts would require more set-up time, including finding a distinct email address for each reviewer account.

3.2.4.4 Time to complete tasks⁷

Some researchers may look to a heuristic evaluation to reduce the time and money spent on a usability study. Our methodology still required a significant amount of resource investment. We did not have expenses related to participant recruitment and retention, but we spent a significant amount of time preparing for and conducting the research. For example, the reviewers finalized the evaluation protocol, and were trained over the course of a two-month period.

The primary author (LK) conducted most of the preparation activities including preparing the materials, validating the personas and scenarios, and setting up the PHR systems. All reviewers, however, participated in extensive training. This training was helpful for us to ensure that our materials were robust, and that all three reviewers had a similar understanding of the

⁷ This section is adapted from Kneale, Mikles, Choi, Thompson, & Demiris, 2017.

personas, tasks, and heuristic guidelines. Conducting full reviews on systems not included in the final analysis was found to be very helpful in expediting the actual time spent on the PHR systems included in the final evaluation, though it initially increased workload.

Despite the investment in time, the strength of this methodology is the robust design recommendations generated from the results. From the results of this one study, we were able to identify design recommendations based on overall aesthetics and system design, classify problematic workflows, and illuminate the differences between user populations. For our study goal, the robust nature of these results was worth the time investment; however, we recognize that not all usability studies have the same goals.

3.2.4.5 Use of Personas and Scenarios⁸

The Chisnell and Redish methodology is unique because it uses personas to capture the diversity of abilities within a larger end-user population to enhance the heuristic evaluation process. We found that the personas were most helpful combined with scenarios. The personas and scenarios allowed us to define tasks that were most important based on an individual's role, and specifically evaluate these tasks in each system. Standardizing the tasks in each system allowed us to better compare our results, identify tasks that were consistently hard to accomplish, and understand how overall usability could be improved through general system enhancements such as increased font size.

3.2.4.6 Use of Observations before Heuristics⁹

Another characteristic that makes the Chisnell and Redish method unique is the use of observations to drive the heuristic evaluation instead of evaluating all heuristics in a list. Our

⁸ This section is adapted from Kneale, Mikles, Choi, Thompson, & Demiris, 2017.

⁹ This section is adapted from Kneale, Mikles, Choi, Thompson, & Demiris, 2017.

study found this to be an efficient way to capture information about the ease of use of a system without having to access each system page. This was especially helpful since we were evaluating PHR systems that were complex and that contained multiple pages, menus, and functionality.

Using data from three reviewers, we were able to develop a comprehensive list of observations that led to populating most heuristics for each persona. There were only two heuristics that were not scored for any user, in any system: "provide feedback in other modes in addition to visual" (#9) and "include a site map and link t it from every page (#12)." The original methodology involved using a tactile mouse to provide haptic feedback. We did not use any assistive devices in our review. Future heuristics, however, may wish to consider haptic devices as well as evaluating the text-to-speech functionality if these devices are regularly used within the end-user population. In addition, neither system reviewed used site maps as part of their design.

Using the observations to drive the heuristic evaluation also prompted the reviewers to focus on the more negative aspects of the systems because problems were easier to spot than positive aspects of the system. The purpose of our study was to evaluate the usability, and to identify potential problems for home health care teams, therefore having more negative observations than positive observations met our research needs. This methodology may not be appropriate for researchers looking to accurately compare the number of positive and negative aspects in a single system.

3.2.4.7 Implications for Design

Having one or more care team member opt out of the PHR because of usability challenges would reduce a PHR system's effectiveness for care coordination. For example, if 'Lisa' wanted to understand 'Alice's' pain level between visits, she would not be able to use a PHR to do so

unless 'Alice' was able to successfully enter her pain information and 'Lisa' could retrieve it. Therefore, it is important for all care team members to be able to use the PHR for their tasks. Our results show that a least some commercially available PHRs are not following guidelines for older adult web users. This could potentially reduce the likelihood that some older adults ultimately adopt these tools, which in turn would discourage patient engagement. However, this does not mean that all tasks have to be usable for each care team member. The care teams in these scenarios had distinct role and tasks. In care teams with division of labor, the PHR only has to work well for the particular user/task combination. Perhaps PHRs that allowed more customization based on roles/tasks could be one way to improve the usability for all, by reducing the number of tasks available in the PHR that are irrelevant to a particular person. Therefore, we suggest that more team-oriented usability studies be conducted on PHRs to ensure that the most important functions to a care team role are both available and usable. By focusing efforts on rolebased design, the cost of evaluating the usability of PHRs can be reduced to only the problems that would directly affect the system's ability to become a care coordination tool.

In addition, the Chisnell and Redish heuristics recommend that technologies reduce the need for users to rely on their memory to perform tasks (Chisnell & Redish, 2005). One way to support this is to develop PHRs with the capability to passively enter data into the system, and/or alternative methods to retrieve information. Some older adults with chronic diseases have used connected medical devices, such as blood pressure monitors and glucometers, to automatically record health readings (Harte et al., 2014). In addition, other researchers have begun to explore using voice-activated controls to help older adults retrieve information from PHRs (Greysen, Chin Garcia, Sudore, Cenzer, & Covinsky, 2014). This could help our users bypass some of the usability challenges that were found to enter or access important PHR information. For example,

a voice operated smart speaker could be used to help individuals locate specific informationsuch as 'Alice' asking whether her cancer diagnosis was recorded. This would eliminate the need for 'Alice' to manually search the PHR for this information. Additionally, imagine how easy it would be for our homebound older adult 'Alice' to enter her daily pain score if she could simply say: "today my pain score is 6." Neither PHR that we reviewed included these newer technologies. In order to increase the usability of PHRs for all users, future systems should investigate how these emerging technologies could enhance existing workflows.

3.2.4.8 Limitations

Although we don't suggest that two PHRs are representative of the design of all systems in the marketplace, our results are still important for understanding how usability challenges can reduce the effectiveness of care teams by hindering the tasks available to certain team members. The main limitations of our study are that 1) we determined the functionality criteria based on a literature review, 2) we performed the usability study using expert reviewers, and 3) it is difficult to account for the effect of training on the usability of these systems. It is possible that homebound older adults may view the perceived benefit of PHRs differently than we expect. We mitigated this risk by carefully examining the existing literature about the needs and characteristics of homebound older adults (Beck et al., 2009; Leff et al., 2015; Millerick, 2004; Musich et al., 2015), and performing a systematic literature review on older adult's opinions of PHRs (Kneale & Demiris, 2017). In addition, although we used a heuristic evaluation methodology that allowed us to specifically consider the perspective of a homebound older adult through a profile that was validated by home health nurses (L. Kneale, Mikles, Choi, Thompson, & Demiris, 2017).

In addition, it was difficult to account for the effect of training. Some PHR users, such as the home health nurse ('Lisa'), may use a PHR regularly for their job duties, and quickly learn how to overcome usability challenges. Other users, such as the family caregiver ('Matthew'), may only be using the PHR at irregular intervals. Therefore, even if 'Matthew' was trained on the PHR features and navigation, he may or may not be able to recall this information when accessing the system. For our evaluation, we placed emphasis on the PHRs being usable, even for the first time or infrequent user.

3.2.5 Conclusion

This study evaluates the usability of two commercially available PHRs. These systems were chosen because they were found to have a high number of features relevant for home care clients. We recognize that the design of the two PHRs in this review may not be generalizable to all systems in the marketplace; however, our results still highlight an important problem. These two PHRs do not appear to be designed to support effective care team coordination. We found that usability problems will likely inhibit all care team users of the system, and will be most problematic for our homebound older adult patient. Homebound older adults may be a difficult population to design technology for; however, as the population grows we should expect more patients to want to adopt these tools. Therefore, we need to explore how to modify the design of existing systems to fit homebound older adult needs. This will not only promote the adoption among the homebound older adult population, but among other users who may have similar characteristics. Only by designing PHRs to be universally usable can we truly count on these tools to enhance patient engagement and care coordination among team members.

CHAPTER 4: PAPER 3: RECRUITMENT OF HOMEBOUND OLDER ADULTS FOR A PERSONAL HEALTH RECORD PILOT STUDY

4.1 INTRODUCTION

The purpose of this chapter is to describe my efforts to recruit and retain homebound older adults for a PHR evaluation study through partnerships with Seattle-area home health agencies. The paper describes my recruitment procedures, and outlines the results from these procedures. In addition, I summarize lessons learned for others who wish to involve homebound older adults in technology-based healthcare systems research studies.

4.2 PAPER 4 FULL TEXT:

4.2.1 Introduction

In today's healthcare environment, patient activation is growing in importance as evidence emerges that it can be an important predictor of health outcomes, patient experience, and healthcare expenditures (Cunningham, Hibbard, & Gibbons, 2011; Greene et al., 2015; Hibbard & Greene, 2013). Patient activation "emphasizes patients' willingness and ability to take independent actions to manage their health and care" (Hibbard & Greene, 2013, pg. 204). Activated patients have higher rates of participation in self-care routines, rate their relationship with their care providers higher, and use the emergency room less often than non-activated patients (Hibbard & Greene, 2013).

Older adults who are homebound face substantial barriers to patient activation. Homebound older adults have more chronic conditions, complex medication schedules, and report higher levels of cognitive and functional impairment than their non-homebound peers (Ornstein et al., 2015). In addition, many services available to homebound older adults are unable to address individual barriers to patient activation, such as behavioral health issues and/or literacy (Musich et al., 2015). Finally, recent reductions in federal funding of home-based care programs have caused some homebound older adults to experience gaps in healthcare services (Musich et al., 2015). The combination of these factors may reduce an individual's patient activation, which may, in-turn, lead to poorer outcomes and patient experiences.

Recently, the United States Department of Health and Human Services (HHS) suggested that healthcare providers use personal health records (PHRs) to support patient activation among their patient populations. PHRs allow individuals to access, manage, and share their personal health information (Detmer et al., 2008; 2003). Intervention studies have shown that PHRs have the potential to increase patient activation (Solomon et al., 2012), promote health behaviors (Chrischilles et al., 2014), and improve the patient-clinician relationship (Heyworth et al., 2014; Nagykaldi et al., 2012). Because of the HHS promotion of these tools since 2009, the number of PHRs available healthcare consumers has increased. In fact, one recent study has estimated that 75% of all U.S. patients will have access to at least one PHR by 2020 (Ford et al., 2016). Much of this improvement has been the direct result of the HHS policy called Meaningful Use, which was part of the 2009 American Reinvestment and Recovery Act (Ford et al., 2016).

Home health agencies were excluded from these recent health information policy initiatives, including Meaningful Use (Ruggiano, Brown, Hristidis, & Page, 2013). This exclusion has been particularly worrisome because there is limited knowledge about how information technology in home health agencies differs from clinic-based care environments. In addition, excluding home health from these efforts creates additional health data silos, and may exacerbate existing communication and care coordination issues (Ruggiano et al., 2013).

In order to fully understand the potential of PHRs in home health, more research is needed that will involve homebound older adults in evaluation studies. Previous literature has documented that challenges with recruiting homebound older adults for research studies; however, these studies have focused on recruiting homebound older adults for nutrition interventions (McAuley, McCutcheon, Travis, & Lloyd, 2005; Ritchie & Dennis, 1999). The purpose of this paper is to describe the opportunities and challenges of recruiting homebound older adults for a personal health record evaluation study through partnerships with home health agencies. We present our recruitment protocols from a partnership with three home health agencies, and the outcomes of these efforts. Our results highlight the opportunities and challenges of recruiting homebound older adults for studies involving consumer health information technologies.

4.2.2 Methods

4.2.2.1 Overview of PHR evaluation study procedures

Our study recruited homebound older adults who were enrolled in home health nursing services following a hospitalization. Older adults were eligible if they were referred to home health following an inpatient admission, able to provide informed consent, had Internet and an Internetenabled device in the home, able to read and write in English, did not disclose a cognitive impairment during eligibility screening, and were able and willing to provide informed consent.

Participants were asked to participate in three to four sessions with the study team. Participants who were enrolled in home health for less than one month during the study period were asked to participate in three research sessions: baseline, home health exit, and study exit. Participants who were enrolled in home health for longer than one month during the study period were asked to participate in four interview sessions: baseline, home health midpoint (around 30 days after baseline), home health exit, and study exit.

After informed consent, participants were introduced to the PHR used in this study. Participants were provided training on the system that included supporting account creation, providing an overview of the features, and answering any participant questions. After the training, participants were asked to talk about their initial impressions of the system. This interview included questions about how the tool could be used in the home health care routines, and what features appeared most and least helpful. After the interview, participants were asked to complete a couple short questionnaires. Participants could choose to complete these questionnaires on paper or orally (as administered by the research team member). The questionnaires asked participants about their previous technology experience, their electronic health information seeking behaviors, and scored their patient activation level. Subsequent meetings included additional system training, participant interviews about their interactions with the system, and their patient activation level. At the end of each subsequent meeting, participants were offered a \$25 cash gift card for their time.

4.2.2.2 Identification of partner home health agencies

We approached nine home health agencies in the Seattle metropolitan region through e-mail, cold calling, and personal contacts. The research team had personal contacts at four (44%) home health agencies. Only one agency that was contacted without a personal connection returned communications. Five agencies were willing to meet with our research staff to discuss the project, and three agencies (33%) were willing to support recruiting efforts. Of the agencies that did not wish to participate, one agency cited concern about competing interests for their clinical

staff and a perceived lack of nurse acceptance. One agency cited a concern about conforming to internal research policies and regulations.

4.2.2.3 Potential participant approach: home health agency A

Home health agency A is a large Medicare-certified home health agency. This agency is associated with a large hospital system in the metropolitan region. Home health agency A offers a wide-range of in-home services including nursing, therapy, and home care. Most of the home health referrals are generated from one regional 400+ bed hospital within the system. This agency recruits from urban and rural patient populations.

The research team worked with the agency to approach all older adults at the start of home health nursing services. The referral process that was used is displayed in figure 12. This process was created with, and championed by, the director of the home health agency over a period of several months.



Figure 12. Paper 3: Referral Process for Home Health Agency A

As noted in figure 12, both a referral form and a study flyer were used to advertise this study. Study flyers were included in all start of care packages. These packages are routinely left with all home health clients at the start of care. Included in this documentation are important information about agency A's home health services, contact information for individual home health providers, and paper education material for their client's self-management routines. The referral form was used to guide the initial approach of potential participants. Clinicians were asked to approach all new clients, regardless of perceived eligibility, and use the referral form to ask whether they could share the older adult's contact information with the research team. If the potential participant agreed, the referral form would be completed with his or her contact information. If the potential participant declined, the clinicians were asked to complete basic information about the patient including reason for refusal, client age, and racial/ethnicity identity. This conversation was expected to happen at the start of care, or within the first two home health visits. Home health clinicians used electronic health record notes to communicate that the referral form had been completed.

Referral forms were completed on paper, scanned by home health agency staff, and sent to the research team via secure email. The referral forms were expected to be sent to the research team within 48 hours of completion. To encourage referral form completion, a monthly raffle was conducted for the home health clinicians. Any completed referral form (including both positive and negative responses) counted as one "raffle" ticket for a \$25 gift card to a local grocery store.

4.2.2.4 Potential participant approach: home health agency B

Home health agency B is a small, independent agency that focuses on providing private home health and home care services following hospitalizations. Because of the size of this organization, leadership preferred to only approach individuals who were likely to be eligible for the study. The primary investigator of this study attended a care manager staff meeting to introduce the study. After that meeting, the care managers went through their census to identify

people that would likely be eligible. Potential subjects were contacted by phone or in-person to ask for permission to pass along their contact information to the study team. Similar to the process with agency A, the referral form and research flyer were used to guide the initial conversation with potential participants.

4.2.2.5 Potential participant approach: home health agency C

Partner organization C is a medium-sized Medicare-certified home health agency with an average census around 400 clients. This organization is part of a national corporation, and has two Seattle-metropolitan offices. Home health agency C had a third approach to identifying potential subjects. This agency first identified home health nurses who were interested in the study, and then asked each nurse to inform their clients of the opportunity. Similar to the other two agencies, the study flyer and referral forms guided the initial study introduction.

4.2.2.6 Eligibility screening and informed consent procedures

The study team collected all referral forms. First, all referral forms were reviewed for completeness. Any referral forms that said a person agreed to be contacted by the study team, but did not include the necessary contact information (e.g. phone number and name of client) were sent back for review. Any information from forms that were collected from clients who refused further contact by the study team were entered into the study database including age, racial/ethnicity information, and refusal reason. In order to maintain data integrity, the exact refusal reason was captured in the study database as it was written on the form. If an individual was open to being contacted by the study team, and the referral form contained contact information, we attempted to contact the individual by phone up to three times. If a client was not reached on the first attempt, a voicemail message was left using the University of

Washington Internal Review Board (IRB) approved script. A second attempt was made a few days after the first attempt, and the last attempt was made about a week after the initial contact.

If an individual was reached during these phone calls, the study team described the study procedures and answered questions about the study. If an individual was interested in the study, the research team member performed eligibility screening by phone. After a person was both eligible and willing to participate, an in-person meeting to obtain informed consent was scheduled. If the individual was not interested to participate or was ineligible, the research team member documented the contact attempt and reason for refusal or ineligibility in the study database.

4.2.3 Results

4.2.3.1 Home health agency A

Home health agency A recruited participants from mid-November 2016 through January 2017. During this time 46 referral forms were completed. Table 6 shows the results from these recruitment efforts by month. As shown in this table, we received 46 referrals in three months, with December being the month with the largest number of referrals. We consistently received a majority of referrals that indicated wiliness for the care team to contact potential participants. We were able to reach between 14% and 50% of the individuals who had a positive referral after three contact attempts. Of the people who were reached, about 33% of the individuals contacted were both eligible and willing to consent.

	Total	# (% total) Negative referrals	# (% total) Positive referrals	# (% total) Positive referrals without contact info.	# Reached (% of positive referral)	# Consente d (% of reached)	# of Staff	Time between referral date and transfer to research team
Nov. 2016	9	3 (33%)	6 (67%)	1 (17%)	2 (40%)	1 (50%)	4 (n=8)	Avg.: 4 days Med.: 3 days (n= 6)
Dec. 2016	19	5 (26%)	14 (74%)	0 (0%)	2 (14%)	1 (50%)	3 (n=8)	Avg.: 4 days Med.: 3 days (n=7)
Jan. 2017	18	8 (44%)	10 (56%)	0 (0%)	5 (50%)	1 (20%)	2 (n=2)	Avg.: 9.5 days Med.: 1.5 days (n=8)
Total	46	16 (35%)	30 (65%)	1 (3%)	9 (31%)	3 (33%)	6 (n=18)	Avg: 6.1 days Med.: 2 days (n=21)

Table 6. Paper 3: Summary of Referrals from Home Health Agency A

The part of the referral form that was least likely to be completed was the name of the agency staff completing the form. Staff names were included in 21 forms (46%), and six different staff names were listed. In addition, one positive referral was completed without any patient identifying information (client name, staff name, or client phone number) in November. Two forms in January were turned more than one month after the referral- at 32 and 33 days. Excluding these referrals form the calculations would bring the average number of days between the referral date and transfer to research team to 1.8 days (median 1 day) for January.

As described above, the referral forms offered space to document reason(s) for patient refusal, potential participant age, and racial/ethnicity identification. The referral form was a free text box completed by the home health staff members. Some referral forms used quotations that suggested direct quotes from potential subjects (e.g. "I'm too old and just not interested"), while others seemed to document an abstraction of the conversation (e.g. No computer, not interested.) The racial and ethnicity categories were taken from the Outcome and Assessment Information Set C (OASIS C) to be consistent with information captured from the enrolled participants.

All sixteen of the negative referral forms documented at least one reason for refusal to be contacted by the study team. Three forms (20%) cited two reasons for refusal. Two forms cited both 1) not having access to a computer and 2) not being interested, and one form documented 1) age as a refusal reason and 2) a lack of interest in the study. All refusal reasons were separately included in the analysis below (e.g. people who cited more than one reason were counted in both categories).

Six people (37.5%) did not want to participate because they did not believe that they had access to the required technology, and another six people (37.5%) were generally not interested. Three people (18.8%) were too overwhelmed with their current medical condition to participate. Specifically, these forms stated: "I'm going through so much, really I can't'," "too much", and "overwhelmed, does not want anything else." Four people (25%) cited various other reasons for declining. These reasons were: "too many people in my business," "has a smart phone but no apps and wants to keep it that way," "it's just one more thing," and "I'm too old." The person who said they were too old was 92 years old.

Table 7 associates the categories for refusal with the documented demographics. Due to missing information on forms, not all demographics were documented on each refusal form. The majority of refusal forms (63%, n=12) came from people who identified as white. Only two of the referral forms documented a race or ethnicity other than white. One referral form was completed with someone who identified as Asian ("does not do computer"), and one person identified as American Indian/Alaskan Native ("does not have a computer"). The average age of the twelve of these individuals who provided their age was 72.4 years old (n=12).

Refusal Category	#	Race/Ethnicity Documented	Average Age (n)
No access to technology	6	American Indian/Alaskan Native (n=1), Asian (n=1), white (n=2)	75.6 (n=5)
Not interested	6	White (n=6)	79 (n=6)
Overwhelmed by care	3	White (n=2)	63.5 (n=2)
Other	4	White (n=2)	77 (n=2)
Total	19	American Indian/Alaskan Native (n=1), Asian (n=1), white (n=12)	72.4 (n=12)

Table 7. Paper 3: Initial Refusal Categories and Demographics of Potential Participants

Of the 30 individuals who completed a positive referral form, nineteen (41%) were unable to be contacted within three attempts. Thirteen of these forms (68%) had race/ethnicity documented, and 77% (n=10) of these referrals were from people who identified as white. Two referrals were from people who identified as Hispanic or Latino, and one was from a person who identified as American Indian/Alaskan Native. Age was completed on three forms. Two participants were 55 years old and one was 77 years old.

Most of the potential participants contacted declined or were not eligible for study participation. Of the nine participants reached, six (67%) of the participants declined to enroll in the study or were ineligible. Two people (33%) were ineligible to participate. One person had already been readmitted to the hospital, and the other was a caregiver of someone who was unable to speak due to his medical condition. The remaining four people declined for various reasons: "no internet in the home," "not interested in anything else right now," "overwhelmed with treatment and so swamped with people visiting," and "my mother is not interested in anything like that at this time."

Additionally, we received two calls from people who found our contact information in the flyer. Both participants stated that their home health staff did not introduce the study to them, but they found the research information in the start of care packet. One participant was ineligible

to participate because she was a caregiver of someone who was only receiving therapy services.

The other participant was eligible, interested, and enrolled in the study.

In the end, the study team enrolled four groups of participants from home health agency A. The details of these participants are described in table 8.

	Date Referred	Time Between Referral and Transfer to Team	Time Between Transfer to Team and First Contact	Age of Participant	Race/Ethnicity (mark all that apply)	Enrolled with other participants
P1	11/18/16	4 days	3 days (2 nd attempt)	77	White	Paid caregiver
Р2	1/4/17	1 day	Same day (1 st attempt)	92	White	Paid caregiver
Р3	Unknown	Unknown (referral sent 12/30/17)	Same day (1 st attempt)	58	White	No
Р5	Participant contacted research team			58	White	Paid caregiver

Table 8. Paper 3: Participants Enrolled

4.2.3.2 Home health agency B

Because of the recruiting process from partner organization B, it is unclear how many potential participants were approached. Our team received one referral form, and the person on the form was consented to the study. This participant (P4) was 71 years old, and identified as a white male. The study team was given his contact information on the same day that he was approached, and we were able to reach him by phone within 24 hours to discuss the study procedures.

4.2.3.3 Home health agency C

Home health agency C identified three home health nurses that would be willing to approach their clients about the study. At least one potential participant was identified, but this person was

readmitted to the hospital before he or she could be enrolled in the study. Due to the lack of reporting mechanisms from the nurses, it is unclear how many other individuals were approached.

4.2.4 Discussion

Previous literature suggests that leaving home health out of the broader discussions of health information system technology is damaging for home health agencies, the broader healthcare system, and ultimately patients and families. Working with home health agencies to recruit homebound older adults for health information technology evaluations could provide more information on how these tools can be used to support homebound older adults. Personal health records are one tool that has been popularized in clinic-based care environment, but the application of these tools is unclear for home health. This study contacted nine home health agencies in the Seattle metropolitan area, and partnered with three agencies for recruiting efforts. Each agency worked with the research team to develop a unique recruitment protocol, while staying within IRB-approved study procedures.

Through our study, we identified agencies that were willing and able to work with our team, home health nurses who were engaged in our research activities, and home health clients who wanted to, and were eligible to, enroll in our study. Although these results were promising, we also encountered several challenges with our recruitment processes. Based on our research, we suggest three opportunities for future studies to improve their recruitment procedures, namely to 1) explore both facilitators and barriers to participation in consumer health information technology (CHIT) studies, 2) use technology to reduce the time between potential participant approach and transmission of their contact details to the study team, and 3) promote diversity in participants through partnerships with multiple agencies.

4.2.4.1 Explore both facilitators and barriers to participation in consumer health information technology (CHIT) studies

Identifying home health agencies that were willing and able to partner with our team was difficult. Most home health agencies in the area did not return our multiple contact attempts. Our study formed relationships with three home health agencies. These agencies represented different home health organizational models. Home health agency A was part of a large regional healthcare system, home health agency B was a small, independent organization, and home health agency C was a regional branch of a national home health provider. This suggests that many types of home health agencies can overcome barriers to research participation if the right environmental conditions are present. In our study, facilitating factors of participation seemed to be 1) agencies that had been involved in prior research activities, and 2) agencies that were introduced to the study team through existing relationships.

Working with agencies that have participated in research activities before reduced the initial barrier to participation. Even if our team was working with home health staff who were new to research, there were still organizational processes and support in place to guide our relationship. For example, home health agency A had to gain formal approval in order to participate in our study. Because of their previous experiences with research, we were able to share our materials approved by our IRB, and satisfactorily answer their questions about patient safety, confidentiality, and the consent process. In addition, working with agencies that have previously participated in research increased our chances of having contact information within the organization. All the agencies that participated in this study were known to the research team before the study initiation.

It is also important to note that Washington State is a pilot state for the Centers for Medicare and Medicaid Services' Home Health Value Based Purchasing program. This program started in January 2016, and individual agency performance is expected to affect CMS payments starting in 2018 ("Home Health Value-Based Purchasing Model,"). In addition to the value based purchasing program, uncertain national¹⁰ and Washington State budgets¹¹ have caused further uncertainty home health agencies. Despite these environmental changes, we were able to identify partner organizations, and carry out our study procedures during this timeframe. This suggests environmental uncertainty may not be a barrier for research participation from all agencies.

One barrier to participation seemed to be a perceived lack of home health nurse participation. One agency that we approached specified this as a reason for not participating in the study. In addition, home health agency A only had six different staff complete the 46 referral forms. In home health agency B, it is unclear how many nurses actually approached potential participants. Previous research has found that gatekeepers can be a challenge for studies that recruit participants through clinicians (Barnes et al., 2005; Gurwitz et al., 2001). Although this was a perceived barrier in our study, the root cause(s) of why home health nurses may be reluctant to participate in referral efforts was unclear.

Future research should explore both facilitators and barriers to participation in consumer health information technology (CHIT) studies. Partnership with research organizations could benefit home health agencies, research studies, and homebound older adults. Home health agencies could gain increased access to new tools and explore their application in home health

¹⁰ Meyer, H. (2017, September 8). CMS' proposed home health payment model alarms providers. Would it boost access for medically complex patients? Modern Healthcare. Retrieved from http://www.modernhealthcare.com/article/20170908/NEWS/170909902

¹¹ Lord, J. (2017, June 4). Commentary: Help caregivers provide care for seniors, others. HeraldNet. Retrieved from http://www.heraldnet.com/opinion/commentary-help-caregivers-provide-care-for-seniors-others/

environments. Research teams could expand their understanding of how homebound older adults and their caregivers could use CHIT during health transitions. Finally, homebound older adults and caregivers can be given the opportunity to try new tools and provide feedback on how future tools could be developed to improve their effectiveness in this healthcare context.

4.2.4.2 Use technology to reduce the time between potential participant approach and transmission of their contact details to the study team

We had the greatest success enrolling individuals in our study if we were provided with their contact information as close as possible to the introduction of the study to the potential subject. On average, home health agency A was able to transmit potential participant data 4 to 6 days after the person was approached about the study. Sixty percent (3/5) of our participants, however, who enrolled in our study were contacted by the research team within one day of the initial approach. Having immediate access to potential participant contact information helped to facilitate the initial discussion because the potential participants often remembered the conversation with their nurse and were prepared for the call from our research staff.

In our study, communicating the contact information the same day that the conversation with the potential participant took place was not always logistically possible. Home health agencies A and C wanted to approach patients during face-to-face encounters, and asked the nurses to bring hard copies of the referral forms back to the central office. These forms were then scanned and sent to the research team via secure email. Because of the distributed nature of home health, many nurses were not able to immediately drop off the forms at the central office. In addition, the scanning and emailing of the forms was subject to office availability and delayed during weekends and vacations. To further complicate our processes, the majority of referrals from home health agency A were conducted between Thanksgiving 2016 and New Year's Day

2017, with 26% (n=12) of all referral approaches happening during the week between Christmas and New Year's Day.

We propose future researchers investigate ways to use technology to reduce the time elapsed between gathering contact information during the initial approach and sending this information to the research team. Perhaps taking advantage of the technology tools that are already in home health encounters, such as the electronic health records, could help facilitate faster communication between the home health agency and the research team. For example, a special note type could be placed into the record where the nurse could record the information on the referral form. Then daily, automatic reports could be generated to pass along to the researchers that only include the information in these notes. In addition, using existing tools could reduce the burden of documenting the referral on home health nurses, and allow researchers to get referrals during all the times that home health nurses work, including nights, weekends and holidays.

4.2.4.3 Promote diversity in participants through partnerships with multiple agencies Because of the nature of the industry, home health agencies often see the majority of their clients in one geographic location. It has been established that an individual's zip code is a significant social determinant of health (Graham, 2016). Even our largest partner agency, home health agency A, only served clients who lived in two Washington State counties. All of the participants who enrolled in our study were from an urban or suburban environment and identified as white. This lack of diversity will inhibit the generalizability of our findings, and may reduce the opportunity to identify new facilitators and barriers of using PHRs within the home health population. Future research is needed to better understand how to identify and recruit home health clients from diverse geographical areas for HIT research. Only through this concerted

effort can we begin to comprehensively identify the benefits and barriers of using consumer HIT within the home health environment.

4.2.5 Conclusion

Our study demonstrates that it is possible to partner with home health agencies to evaluate consumer health information technology (CHIT) tools. Our work highlights the benefits and opportunities of partnering with home health agencies to recruit homebound older adults following a hospitalization. In addition, we suggest that future researchers who are interested in recruiting homebound older adults for CHIT tools enhance their efforts by better understanding the facilitators and barriers for home health agency participation, and by improving communication between stakeholders. Specifically, we suggest that future researchers explore both facilitators and barriers to participation in consumer health information technology (CHIT) studies, 2) use technology to reduce the time between potential participant approach and transmission of their contact details to the study team, and 3) promote diversity in participants through partnerships with multiple agencies.

CHAPTER 5: PAPER 4: ASSESSING THE FEASIBILITY AND PRELIMINARY EFFECTIVENESS OF PERSONAL HEALTH RECORDS FOR HOMEBOUND OLDER ADULTS: A PILOT STUDY

5.1 INTRODUCTION

Patient activation, or a "patients' willingness and ability to take independent actions to manage their health and care" (Hibbard & Greene, 2013, pg. 204), is a key component of the patientcentered health system (Dentzer, 2013). Recent literature has shown that some patient populations, on average, have individuals with lower patient activation than other populations (Cunningham et al., 2011). Patients who have high patient activation are more likely to be participate in their care, form productive relationships with their medical providers, and perform self-care routines to manage their health and wellness (Greene et al., 2015; Hibbard & Greene, 2013). Patient populations comprised of people with high patient activation receive fewer emergency services, have lower health costs, and improved patient outcomes (Greene et al., 2015). Populations of individuals with lower patient activation can improve the activation of their patients through targeted health service interventions (Crouch, Rose, Johnson, & Janson, 2015; Hibbard, Mahoney, Stock, & Tusler, 2007; Nagykaldi et al., 2012). These interventions included increasing access and use of an electronic patient portal (Crouch, Rose, Johnson, & Janson, 2015; Nagykaldi et al., 2012).

Homebound older adults are one patient population that may need increased services to cultivate patient activation among its individuals. Homebound older adults have physical barriers that prevent them from easily accessing clinic-based health services (Leff et al., 2015). In addition, they are more likely to have cognitive impairment, identify with groups that face health

disparities, and have limited incomes (Ornstein et al., 2015). Together these factors may create significant barriers to fully engaging in their health and wellness.

Personal health records (PHRs) are consumer health information technologies (CHIT) that have been shown to increase patient activation (Crouch et al., 2015; Nagykaldi et al., 2012). PHRs support patients to access, manage, and share their personal health information (2003). Previous studies have found that older adults are able and willing to use PHRs as part of their care self-management; however, most of these studies have been conducted with so called "young" older adults (aged 60 to 70 years old) who are participating in clinic-based outpatient care (Kneale & Demiris, 2017).

The goal of this paper is to report on a pilot study that explores the feasibility of conducting a PHR evaluation with homebound older adults following a hospitalization. In addition, we evaluate the potential relationship between patient activation, PHR use, and home health outcomes for this population.

5.2 Methods

5.2.1 Procedures

We recruited homebound older adults and their caregivers via home health agencies in the Puget Sound area. Homebound older adults were eligible if they: were referred to home health following an inpatient admission, were able to provide informed consent, had Internet and an Internet-enabled device in the home, were able to read and write in English, did not disclose a cognitive impairment during eligibility screening, and were able and willing to provide informed consent. Caregivers were eligible if they read and spoke English, were self-described caregivers of an enrolled older adult participant, and consented to the study procedures. A full description of recruitment methods is described in Chapter 4.

Once enrolled, participants were asked to participate in three to four sessions with the study team, depending on the length of their home health services. Participants who were enrolled in home health for less than one month during the study period were asked to participate in three research sessions: baseline, home health exit, and study exit. Participants enrolled in home health for longer than one month during the study period were asked to participate in four interview sessions: baseline, home health midpoint (around 30 days after baseline), home health exit, and study exit.

5.2.2 Conceptual model

To describe the relationship between homebound older adult characteristics, patient activation, and desired health services outcomes, we adopted Andersen's Phase-3 Model of Healthcare Utilization. This model was chosen for this study because it depicts how a single intervention can improve the overall outcomes for a health care service (Andersen, 1995). Andersen's Phase-3 model has three main constructs: primary determinants of health utilization, health behaviors, and health outcomes. It depicts the relationship between these three constructs as a linear, causal relationship. Specifically, the total effect of the primary determinants causes individuals to engage in specific health behaviors which, in turn, drives health outcomes (Andersen, 1995). This model has been used in previous literature to describe the relationship between patient characteristics and patient activation in home care settings (Ryvicker et al., 2013).

Andersen's original Phase-3 model can be found below in figure 13, and the model used for this dissertation is shown in Figure 14. As displayed in these figures, our version maintains much of Andersen's model. The main difference between our model and the original Andersen's Phase-3 model is that patient activation is sole health behavior, and perceived health status was removed from the health outcomes construct. Both of these choices were made to apply the

model to the study goal (to evaluate the relationship between PHR use, patient activation, and reported home health quality measures). Patient activation was considered to be an appropriate item for the health behavior construct because certain measures of patient activation have been shown to be a dynamic value that is influenced by patient demographics, healthcare system experiences, and an individuals' external environment (Greene et al., 2015; Hibbard & Greene, 2013).



Figure 13. Paper 4: Andersen's Original Phase-3 Model



Figure 14. Paper 4: Modified Andersen's Phase-3 Model

5.2.3 Data collected

Table 9 outlines the data collected for each component of the conceptual model.

Andersen Phase-3	Model Categories	Categories of Data Collected	Data Collection Tool(s)	
	Develotion	Demographics	Outcome and Assessment Information Set-C (OASIS-C); Demographics Questionnaire	
Primary	characteristics	Comfort with technology	National Health and Aging Trends Study Technology Environment questionnaire (NHATS Technology Environment); E- health Literacy Scale (EHEALS); Participant interactions	
Determinants		PHR use	Participant interviews	
	Healthcare system	Home health needs	Outcome and Assessment Information Set-C (OASIS-C); Self-report home health needs, caregiver-reported home health needs	
	External environment	Residential infrastructure	Participant interviews	
Health behavior	Patient activation	Patient activation	Patient Activation Measure Short Form (PAM-13)	
Outcomes	Evaluated health status	Home health value based purchasing	Outcome and Assessment Information Set-C (OASIS-C); Participant interviews; Home health utilization questionnaire	
	Consumer satisfaction	measures- version 2017 (HH-VBP)	Consumer Assessment of Healthcare Providers and Systems- Home Health Survey (HH CAHPS) questionnaire	

 Table 9. Paper 4: Data Collected for Model

5.2.3.1 Primary determinants

Andersen's model uses primary determinants to represent fixed patient-specific variables that influence specific health behaviors (Andersen, 1995). Andersen's Phase-3 model and this study's conceptual model have three categories of primary determinants: population characteristics, healthcare system, and external environment. Previous studies have shown a potential causal relationship between each of these factors and patient activation.

In this study, two types of population characteristics were collected: demographic information and comfort with technology. Demographic information, such as identification with

racial and ethnic minority populations (Cunningham et al., 2011), and age (Magnezi, Glasser, Shalev, Sheiber, & Reuveni, 2014). Demographic information was collected through the Outcomes and Assessment Information Set (OASIS) and a demographics questionnaire. The OASIS is a standardized instrument that is administered by all home health practitioners who plan to submit home health services for reimbursement through Medicare or Medicaid. These data form the basis of the home health case-mix profiles, and are used to calculate the patient quality measures for the Home Health Value-Based Purchasing Program ("OASIS C Based Home Health Agency Patient Outcome, Process and Potentially Avoidable Event Reports,"). At the time of our study, the Centers for Medicare and Medicaid required all agencies to complete the OASIS-C measure set ("OASIS C Based Home Health Agency Patient Outcome, Process and Potentially Avoidable Event Reports,"). In the cases where collection of OASIS-C was not feasible, a demographics questionnaire was administered that asked participants about their age, gender, racial/ethnicity identity, health insurance payer, and the reason for their most recent hospitalization. The demographics questionnaire was completed on paper. Participants chose whether to complete the paper questionnaire without assistance, or to have the questions read to them and answer orally.

Comfort with technology has been shown to influence older adult perceptions of PHRs (Noblin, Wan, & Fottler, 2012; Taha, Czaja, Sharit, & Morrow, 2013). Therefore, each participant's comfort with technology was also measured using three modalities: the National Health and Aging Trends Study Technology Environment questionnaire (NHATS Technology Environment), the E-health Literacy Scale (EHEALS), and through participant interactions. The NHATS is a yearly study that gathers information on a representative sample of adults in the United States aged 65 and older ("NHATS at a Glance,"). This study used a paper-version of the
National Round 1 study interview protocol for technological environment (Study, 2015). In addition, participants were asked to complete a paper-version of the E-health Literacy Scale (EHEALS). EHEALS was developed to measure an individual's perceived skill at using information technology for health situations (Norman & Skinner, 2006). This scale has been determined to be both reliable and valid to use with older adult populations (Chung & Nahm, 2015), and high e-health literacy has been associated with increased PHR use (Noblin et al., 2012). Finally, comfort with technology was also assessed during participant interactions (participant interviews and PHR training). Both participant interviews and PHR training sessions were audio-recorded to support data analysis.

The second category of Andersen's primary determinants is the healthcare system. These factors describe the services that a person needs from the healthcare system and their access to these services. In the original model, this category captured information such as health insurance and the geographic accessibility of healthcare services (Andersen, 1995). In this study, a condition of participation was that participants were receiving home health services from one of the partner home health agencies. Therefore, all study participants had overcome any accessibility and finance challenges to home health services prior to enrollment in the study. However, each participant received a unique set of home health needs, before and after their more recent hospitalization. Home health nurses assess home health needs at the beginning and end of the home health encounter using the OASIS-C. In cases where collection of this information through the OASIS-C was not feasible, a paper-based home health need questionnaire was administered to the patient at baseline, either written or orally. In addition, the caregiver baseline questionnaire asked the caregiver to describe the services that he or she provides to the

homebound older adult. The other variable component of a participant's healthcare system was PHR use. This study did not require participants to use the PHR in a standard way, but to try to incorporate the PHR features into their normal healthcare routines. Therefore, participant interviews asked participants to describe how often, and in what capacity, the PHR was used during the study period. These sessions were audio-taped for future data analysis.

Finally, Andersen's model acknowledges that the physical, political, and economic environment affects an individuals' ability to perform health behaviors (Andersen, 1995). For our study, participants were asked to describe their residential infrastructure as it related to their PHR use during participant interviews. Additionally, this infrastructure was also observed during the in-person sessions. Specifically, each participant was asked if he or she would like to enroll with their caregiver (paid or unpaid) and, if so, to describe their relationship with the caregiver. Participants were also asked to describe their barriers to accessing the PHR, and whether they had support from others with using the PHR during the study period.

5.2.3.2 Health behavior

Patient activation was assessed by the Patient Activation Measure Short Form (PAM-13). The PAM-13 is a subset of the original 22-item Patient Activation Measure (PAM) survey. The PAM, and subsequently the PAM-13, was developed to gather perceptions of how well chronically ill individuals can manage their complex care routines overtime. It was created using Rasch psychometric methods and is a Guttman-like scale (Hibbard et al., 2005; Hibbard et al., 2004). This means that individuals with a higher PAM score also have higher patient activation, and each item on the instrument only measures one construct (Conrad & Smith, 2004). The PAM-13 groups questions into four categories: believes active role important, confident and knowledge to take action, taking action, and staying the course under stress (Hibbard et al., 2004). The scale is administered using a 5-point Likert scale with answers to each question including: strongly disagree, disagree, agree, strongly agree, and not applicable.

The PAM-13 was chosen because it has become the standard way to measure individual patient activation (Dentzer, 2013; Greene et al., 2015). In addition, the PAM-13 has been found to be reliable and valid when tested on a group of multi-morbid older adults (Skolasky et al., 2011), and separately found to be valid and reliable among rural adults (Hung et al., 2013). Finally, the PAM-13 has been used to gather information on patient activation in previous studies that evaluate personal health records (Toscos et al., 2016; Woods et al., 2017) and patient portals (Crouch et al., 2015; Nagykaldi et al., 2012; Solomon et al., 2012).

The PAM-13 was administered to all older adult participants during study session. This version of the PAM-13 was a paper questionnaire and similar to other paper questionnaires, the older adult chose to complete the questionnaire on paper or orally. If clarifying questions arose about how to best answer an item, participants were prompted to choose the answer that best fit their situation. In the PAM-13 version used in this study, the fifth choice was labeled "neutral" instead of "not applicable."

5.2.3.3 Home health outcomes

For this study, health outcomes were calculated based on the 2017 home health value-based purchasing (2017 HH-VBP) measures. These measures assess four categories of outcomes during home health encounters: unplanned medical encounters, improvements in medication management, improvement in activities of daily living (ADLs), and improvement in patient satisfaction. There is evidence that actions taken by activated patients can lead to these outcomes.

First, adult patients who have a high PAM score have been found to seek more appropriate medical care, including preventive health services, and have fewer unmet medical needs (Greene et al., 2015). Seeking appropriate medical care has been hypothesized to reduce unplanned medical encounters among homebound older adults (Leff et al., 2015). Secondly, one recently published study found that self-reported medication adherence was influenced by an individual's PAM score in a population of 352 Italian-speaking adults with chronic illnesses (Graffigna, Barello, & Bonanomi, 2017). ADLs could be influenced by exercise (Bossers et al., 2016; Donald, 2009) and/or diet (Lindegaard Pedersen, 2016; Pedersen, Pedersen, & Damsgaard, 2016). Activated individuals are more likely to report following prescribed diet and exercise programs (Greene et al., 2015), and previous studies have found that patients with high PAM scores are statistically more likely to participate in regular exercise, know their recommended weight, and pay attention to food labels (Hibbard et al., 2007). Finally, activated patients report better experiences with their medical providers (Greene et al., 2015). Specifically, these studies have found that high PAM scores relate to fewer care coordination problems, higher-quality interactions with medical providers, and more out-of-office contact with physicians (Greene et al., 2015).

The HH-VBP collects this information through claims data, OASIS measures, and the Consumer Assessment of Healthcare Providers and Systems- Home Health Survey (HH CAHPS) (Caron, Leone, & Rutherford, 2016). Due to study restrictions, this study used patient interviews, OASIS-C datasets, and a questionnaire based from the HH CAHPS to capture this information.

5.3 Results

5.3.1 Feasibility of data collection

We first designed the study to collect much of the participant data through a participant's OASIS-C data set. This method was chosen to reduce the burden on participants, reduce the costs of data collection, and to ensure study data reflected the home health value based measurement data. After challenges arose with accessing the OASIS-C data set, all data were collected through participant interviews and questionnaires.

5.3.1.1 OASIS-C Dataset

As described above, the original procedures called for participants to grant the research team with consent to their OASIS-C datasets. The University of Washington Internal Review Board granted approval to collect this information by obtaining participant consent through a Health Insurance Portability and Accountability Act (HIPAA) waiver form. Granting the research team HIPAA authorization was discussed with two participants (P1 and P2). P1 granted the research team permission to access the data and P2 did not.

When approached participants to sign the HIPAA waiver form, both P1 and P2 were unaware that their home health nurses collected these data and neither had seen this information before. The researcher explained the purpose of the OASIS-C dataset, and the purpose of including it in our study. P1 granted the study team permission with no additional questions. P2 asked if it was required for them to participate. After informing P2 that it was not a condition for participation, P2 declined to provide the study team access.

After obtaining permission to access their OASIS dataset from P1, the research team approached the home health agency to collect this information. It soon became apparent,

however, that the home health agency did not have internal mechanisms to share this information with the research team. In addition, the agency was not prepared to consent to sharing the data based solely off the signed University of Washington HIPAA waiver form. After discussions with the research team, the home health agency suggested that their staff would also have to obtain approval using the home health agency HIPAA authorization forms in an independent meeting with the client. After repeated contact attempts, it was unclear if this conversation took place between P1 and her home health nurse before P1 was readmitted to the hospital.

5.3.1.2 Participant Interviews

All participants in this study were generous with their time. Each recorded interview session lasted between 9 minutes and 91 minutes. Table 10 shows the recorded times for each interview. The total time spent in the study ranged between 20 minutes (P1) and 146 (P4) minutes. The research team estimates that an additional 10 to 20 minutes were spent at the beginning and end of each session on exchanging pleasantries, explaining study procedures, and obtaining permission to record.

	P1/C1	P2/C2	Р3	P4	P5/C5	Total (average)
Baseline interview and training	11*	41	56	55	44	207 (44)
Midpoint interview	9	N/a	N/a	N/a	5+	14 (7)
Home health discharge interview	N/a	N/a	52	N/a	47	99 (49.5)
Study exit interview	N/a	31	12	91	40	174 (43.5)
Total Recorded time	20	72	120	146	136	494 (99)

Table 10. Paper 4: Participant Interview and Training Times in Minutes

* Training not recorded + Recording malfunction

Participant fatigue was not observed in any interview session; however, differences in symptom burden from participants were noted. P1 had the greatest symptom burden during the interview sessions. She was the only participant who was on oxygen during the interview sessions, and she often had to pause during the interview to catch her breath. P1's interviews were notably shorter than the other participants, but she also was the only participant who did not have her PHR training interactions recorded. In addition, she was also the only participant who never used the PHR system outside study procedures.

In addition, the home health participants in this study were very trusting with their personal health information. Participants, unprompted, often shared intimate details about their health status and personal lives during the participant interview sessions. Participants were also willing to share their personal health record data with the researcher. In addition, none of the participants expressed any privacy or security concerns with the personal health record during consent or study procedures, even when prompted.

Caregivers and older adult participants were given the option to complete study procedures together, or in separate meetings. Both the older adult and caregiver had to agree before scheduling joint interview sessions. All caregivers enrolled in this study participated in the interviews at the same time as the homebound older adult. Since all caregivers in this study were paid for their caregiving duties, this implies that caregivers were likely "on the clock" during the time it took to complete the participant in their interviews. Occasionally, a caregiver tried to multitask during the interviews. For example, one caregiver made lunch for the older adult while listening to the questions, and only sat down with the older adult when they had a comment or were asked a direct question. In all interviews, expect for participant group 2, the homebound older adult was observed to dominate the participant interviews. In participant group 2, the caregiver was the primary user of the system, and was more talkative during the interviews than the homebound older adult.

5.3.1.3 Participant Questionnaires

The homebound older adult participants completed up to six individual questionnaires. Each of these questionnaires was administered one time during the study period, except for the PAM-13. The PAM-13 was administered during each study session. P1, P2, and P4 chose to complete all of their questionnaires orally, and P3 and P5 completed all questionnaires on paper without assistance.

The study participants easily completed the demographics, NHATS technology environment, E-heals, and home health needs questionnaires. These questionnaires, with the exception of P1 and P2, were completed during the baseline study visit. P1 and P2 did not complete the demographics questionnaire nor the home health needs questionnaire at baseline because the study procedures at that time called for these data to be collected through the individual's OASIS-C dataset. The Consumer Assessment of Healthcare Providers and System-Home Health Survey (HH-CAHPS) was administered at home health exit. P3 and P5 were the only two participants to successfully complete this survey. P1 was readmitted to the hospital before home health exit, and P2 and P4 declined to complete the survey due to survey length.

The older adult participants completed the PAM-13 during each research session. Most of the participants began to recognize the questions, and inquired the reason for the repeated survey. Some participants even expressed concern that they did not remember their previous answers, as they wished to be consistent. In addition, participants often had a difficult time choosing the "correct" answers based on the available choices. One of the common complaints was that their health status was changing, and often their providers were unsure of their course of treatment. Therefore, answering questions such as, "I am confident that I can take actions that will help,

prevent, or minimize some symptoms or problems associated with my condition" was difficult due to the overall uncertainty in their care plans.

Caregiver participants were asked to complete one questionnaire, about their demographics and relationship to the homebound older adult, during the study period. This questionnaire included four questions about demographics and the 8-item NHATS technology environment, all caregivers completed this questionnaire on paper, and none of the caregivers expressed any difficulty with this task.

5.3.1.4 Scheduling Interview and Questionnaire Sessions

Homebound older adults have a unique healthcare environment. Because of their homebound status, these individuals receive many care providers in their home. Because these participants were in home health services during much of the study procedures, the participants received regular visits from home health nurses, physical therapists, and occupational therapists. In addition, many of the participants also had home care aides help with domestic tasks and personal care, and/or received home-based care from non-healthcare entities (e.g. Meals on Wheels).

The number of different visitors made scheduling some face-to-face sessions difficult. In addition, many participants were unable to predict their home-based provider schedules. Therefore, some research sessions were cut short when a home-based care provider unexpectedly arrived. Further, some sessions were canceled when research sessions and home-based care provider appointments overlapped.

5.3.2 Outcomes of data collection

5.3.2.1 Primary Determinants

As described in Figure 14, there were three categories of primary determinants: population characteristics, healthcare system, and external environment. Because of the challenges with the OASIS-C, all demographics were collected through the patient demographic questionnaire. Tables 11 and 12, below, show the demographic information and study details for all study participants. Eight participants were recruited for this study: five homebound older adults and three caregivers. The study periods for these individuals lasted between 4 and 17 weeks. On average, participants were enrolled in the study for 8.75 weeks (median 6 weeks). Two participants, one homebound older adult (P1) and one caregiver (C1), withdrew from the study because of P1's unexpected re-hospitalization.

Demographics	Participant Number							
	P1	P2	P3	P4	P5			
Age	77	92	58	71	58			
Gender Identity	Female	Female	Female	Male	Male			
Race/Ethnicity Identity	white	white	white	white	white			
Health Insurance Payer (s)	Medicare	Medicare	Medicare Medicaid	Medicare	Medicaid			
Reason for most recent hospitalization	Unknown*	Unexplained weakness	Surgical site infection	Rash	Severe anemia, kidney failure, rhabdomyolysis			
Number of completed interviews	2	2	3	2	4			
Study period (weeks)	6 weeks	5 weeks	10 weeks	4 weeks	17 weeks			

Table 11. Paper 4: Homebound Older Adult Participant Demographics

* Denotes incomplete data due to early study withdrawal

	Participant Number					
	C1	C2	C5			
Age	55	44	52			
Gender Identity	Female	Female	Female			
Race/Ethnicity (check all that apply)	white	white	white, Asian, native Hawaiian or other pacific islander			
Years participating in home health clients' care	6-10 years	3-5 years	Less than 1 year			
Number of completed interviews	2	2	4			
Study period (weeks)	6 weeks	5 weeks	17 weeks			

Table 12. Paper 4: Caregiver Participant Demographics

In addition to demographics, comfort with technology was also measured for all participants. Table 13 displays the comfort with technology measures for the homebound older adult participants. Table 14 displays a summary of the responses from the study version of the National Health and Aging Trends Study technology environment questionnaire for all participants (older adults and caregivers).

As shown in table 13, most participants were comfortable with technology. The mean EHEALS score for homebound older adult participants was 3.78 (median: 3.8), and all homebound older adults were either averagely or highly skilled using the PHR. The study team did not observe P2 using the PHR, as her caregiver was the primary user.

Participant	Assessed Skill Navigating the PHR	Mean EHEALs Score (max: 5.0)	Technology in the home*
P1	Average	3.4	Cell phone, other phone, computer
P2	N/a	3.9	Cell phone, other phone, computer
Р3	High	5.0	Other phone, computer
P4	High	2.8	Cell phone, other phone, computer
Р5	High	3.8	Other phone, computer

Table 13. Paper 4: Summary of Comfort with Technology Measures: Older Adult Participants

* The NHATS does not ask participants about tablets or other portable devices The NHATS asks individuals to describe their access to technology, and their regular Internet habits. Table 14 includes participant answers to the health related NHATS questions. As shown below, all participants except P1 had used the Internet for a health-related purpose in the month prior to the survey. Most participants (63%, 5/8) have used the Internet for obtaining information about their health information, but three (37.5%) have used the Internet to contact their medical providers. This includes the P2, who was our older participant at 92. This implies that at least some of the participants actively used their health system patient portal.

In the past		Participant Number							
month have you	P1	P2	Р3	P4	P5	C1	C2	C3	Total
Gone online to order or refill prescriptions?	No	No	No	Yes	Yes	No	No	Yes	3/8
Gone online to contact medical providers?	No	No	Yes	No	Yes	Yes	No	No	3/8
Gone online to handle health insurance matters?	No	No	No	Yes	No	Yes	No	Yes	3/8
Gone online to get information about your health conditions?	No	Yes	Yes	No	Yes	Yes	Yes	No	5/8
Total	0/4	1/4	2/4	2/4	3/4	3/4	1/4	2/4	

Table 14. Paper 4: National Health and Aging Trends Study Technology Environment Questionnaire

5.3.2.2 Healthcare system

The healthcare system was assessed through paper-based home health need questionnaire and PHR use. The only participant to use the PHR on a regular basis was P5. P5 found the PHR helpful to track his blood glucose ratings and other important health measures, and to share these data with his physician. The other participants only played around with the system between visits, but did integrate the tool into their health and wellness activities. The first participant group (P1 and C1) had challenges with regularly accessing the system through P1's computer. The second group (P2 and C2) attempted to use the PHR to track daily health measurements, but usability challenges caused C2 to continue to track these data on paper. P3 and P4 did not find the PHR useful for their current health needs.

Homebound older adult home care needs were assessed through the home health needs survey, and the caregiver baseline survey. P1 and P2, due to the revision in the study procedures, did not complete the baseline survey with the self-reported care needs. In addition, P3 and P4 did not have caregivers enrolled in the study. Table 15 displays the results from the self-reported prehospitalization care needs.

		P3	P4	P4
	Self-care	Some help	Every week	No help
Before Hospitalization	Walking	Some help	N/a	No help
	Moving	No help	Every time	No help
	Household tasks	Some help	Some help	No help

Table 15. Paper 4: Homebound Older Adult Self-Reported Need Factors

Before hospitalization, the needs of the enrolled participants varied. P5 did not require any help, but P4 needed significant help with moving and self-care activities.

All participants had more needs following their most recent hospitalization. Because of the changes to the study procedures, P1, P2 only have caregivers who assessed their needs. P3 and P4 reported their own needs. P5 had both self-reported and caregiver reported needs. Table 16 describes the home health needs for each participant. Despite having the most pre-hospitalization needs, P4 reports having the least amount of post-hospitalization needs (only transportation and personal care). P1 and P2 needed help with all activities except financial assistance. P5 stated that he needed help with all activities but financial assistance, but his caregiver said that she also supported P5 with "exercising". Finally, P3 had the most needs, stating that she needed help with all activities.

		P1*	P2*	P3	P4	P5	Total
Companionship	Talking, reading, keeping company	Yes	Yes	Yes	No	Yes Yes*	80% (4/5)
Transportation	Driving to doctor's appointments, driving for errands	Yes	Yes	Yes	Yes	Yes Yes*	100% (5/5)
Homemaking	Shopping, cleaning, preparing mealsYesYesYesNo		No	Yes Yes*	80% (4/5)		
Personal care	Feeding, bathing, toileting, dressing, grooming	Yes	Yes	Yes	Yes	Yes Yes*	100% (5/5)
Healthcare assistance	Help with medications, wound care	Yes	Yes	Yes	No	Yes Yes*	80% (4/5)
Financial assistance	Paying bills, managing budgets	No	No	Yes	No	No No*	20% (1/5)
Other	Please specify	No	No	No	No	No Exercising *	20% (1/5)
Total Number of Needs		5/7*	5/7*	6/7	2/7	5/7 6/7*	

Table 16. Paper 4: Homebound Older Adult Current Need Factors

* Denotes caregiver assessed need

5.3.2.3 External environment

Finally, the participant's external environment was assessed through participant interview questions regarding their residential infrastructure. Table 17 highlights the different PHR support structures and devices used in this study. As noted above, P1, P2, and P5 enrolled with caregivers in the study. P3 and P4 did not, but P4 lived with a spouse.

The type of the Internet-enabled device used in this study was discussed as a facilitator in several participant interviews. For example, P1 was experiencing high symptom burden during the study. She only had access to the PHR from her desktop computer, which was located in a separate room from her main living space and bedroom. In order to access this room, P1 had to maneuver her walker and a portable oxygen tank to the computer. In her interviews, she stated that she had been unable to use the PHR between study sessions because of the difficulty with accessing the system through the computer.

Similarly, P2 usually spent her time in the living room, which was in a separate room from the computer. Although C2 was able to move easily between the living room and the computer, C2 had to take the health measurements in the living space. C2 experienced trouble using the mobile application to enter in health measurements. Therefore, her workflow was to complete the measurements on a paper-log, and then transfer it to the PHR at the computer. After performing this double data entry several times, C2 gave up tracking the measures in the PHR.

	P1	P2	P3	P4	P5
Caregiver enrolled	Yes- paid home care aid	Yes- paid home care aid	No	No	Yes- paid home care aid (spouse)
Living Situation	Lives alone	Lives with paid caregiver	Lives alone	Lives with spouse	Lives with non-spouse family
Devices used in study	Computer	Computer/Mobile application	Tablet	Tablet/Computer	Tablet

Table 17. Paper 4: Patient Environmental Context

5.3.2.4 Health Behaviors

Below is a table that shows the trends in patient activation throughout the study. Between two and four PAM scores were collected on each participant during the course of the study. In all participants, except for P1, raw PAM scores changed less than 10%. P1 had a 12% reduction in her raw PAM score during the last study meeting before she was readmitted to the hospital. P5 was the only participant who reported a positive change in his raw PAM score, and increased a patient activation level during the study period.

Participant Number	Participant Group PHR Usage Level	Weeks in study	PAM Level (raw score) at Study Start	PAM Level (raw score) at Midpoint	PAM Level (raw score) at Home Health Exit	PAM Level (raw score) at Study Exit	Total % Increase
P1	None	6	Level 4 (46.1)	Level 3 (40.4)	N/a	N/a	-12.7% (-5.7)
P2	Low	5	Level 3 (39.0)	N/a	N/a	Level 3 (39.0)	0% (0)
Р3	None	10	Level 4 (52.0)	N/a	Level 4 (48.0)	Level 4 (48.8)	-6.2% (-3.2)
P4	High	4	Level 2 (36.4)	N/a	N/a	Level 1 (34.1)	-6.3% (-2.3)
P5	High	17	Level 3 (42.9)	Level 4 (45.5)	Level 4 (44.0)	Level 4 (45.0)	4.9% (2.1)

 Table 18. Paper 4: Trend of Patient Activation Measure (PAM) Scores for Older Adult

 Participants

5.3.2.5 Home health outcomes

As described above, home health outcomes were measured through participant interviews and questionnaires. Outcome measures were based from the 2017 HH-VBP measures, and focused on four outcomes: unplanned medical encounters, improvement in medication adherence, improvement in ADL functioning, and improvement in patient satisfaction.

Two participants (P1 and P3) reported unexpected medical encounters in the study. P1 had an unexpected hospital readmission that caused her to withdraw from the study between her midpoint session and home health exit. P3 reported calling for an ambulance between home health discharge and study exit. She was not admitted to the hospital.

Medications were an important topic in participant interviews. The PHR has features that are designed to assist in medication regimens; however, none of the participants chose to use the PHR to help with medication adherence. P5 entered in his medications, and set up the medication reminders, but found the number of alerts not useful in supporting his routines.

The only participant who commented on how the PHR could help improve ADL functioning was P5. P5 was suffering from a large wound in his leg caused by a fall. Since this patient classified himself as "pre-diabetic," he was asked to track his blood glucose during the home health encounter to promote wound healing. This was the primary way that he used the PHR. Interestingly, he noted that he did not expect to track his blood glucose after the wound healed. When asked why, he stated, "I don't know if I'll have the… you know it would be smart to [track glucose] but you know how you get going in life".

As described above, we only captured two discharges from home health. Table 19 shows the data from these two participants. Both of these individuals had high satisfaction with their home health care agency.

Participant Number	PHR Usage Level	# (%) of Care of Patients Measures	# (%) of Communication Measures	# (%) of Specific Care Issues	Home health agency rating	Would you recommend?
Р3	None	4 (100%)	5 (83%)	7 (100%)	9	Definitely Yes
Р5	High	4 (100%)	5 (83%)	6 (85.7%)	9	Definitely Yes

Table 19. Paper 4: Home Health Value Based Purchasing Measures (CAHPS Measures)

5.4 DISCUSSION

The results from this study show that some homebound older adults and their paid caregivers are willing and able to participate in longitudinal PHR evaluation studies. In this study, we recruited eight participants who each spent, on average, over ninety minutes discussing their views about the personal health record system used for this study and how it could fit into their home health

routines in two to four research sessions. In addition, homebound older adult participants were willing to complete between one and five questionnaires per session.

5.4.1 Andersen's Phase-3 Model conceptual model fit

This study used a modified version of Andersen's Phase-3 Model. As described in further iterations of this model, the linear relationship between the primary determinants, health behaviors, and health outcomes may be too simplistic to fully represent the relationship between these factors (Andersen, 1995). However, this model was chosen for our study because the more complex models would require collecting more data from participants, and performing more complex data analyses. From this small number of participants, we did not find a relationship between PHR use and patient activation, or patient activation and home health outcomes. This may mean that other models that would be better suited to represent the relationship between these factors. In addition, future research is needed to understand how PHRs can support desired behaviors in the homebound older adult population and/or contribute to home health outcomes.

5.4.2 Feasibility of study procedures

The only study procedure that was not feasible was collecting individual OASIS data sets for our participants. The participants in this study were able to answer the questionnaires and provide meaningful assessments of the PHR during interviews. However, our specific results on collecting data for each construct in our model can be used inform future research.

5.4.2.1 Primary determinants

As described in our model, primary determinants were categorized into three categories: population characteristics, healthcare system, and external environment. Generally, these data were easy to collect from the participants. The participants in this study expected to be asked questions about their demographics and comfort with technology. Similar to other studies that evaluate PHRs with older adult users (Kneale & Demiris, 2017), only older adults who felt comfortable with technology enrolled in our study. As described in previous work (Kneale & Demiris, 2017), the lack of diversity the characteristics of the participations may limit the generalizability of the findings from this PHR evaluation. Therefore, future research should focus on enrolling diverse homebound older adults in subsequent PHR evaluation studies. This may require researchers to reduce barriers to participation (e.g. provide Internet-enabled devices) or develop purposive sampling techniques to purposely recruit diverse participants.

As described above, interviewing participants about PHR use was both feasible and worthwhile with homebound older adults and their caregivers. Previous PHR evaluations with older adult users have used surveys and system logs to gather this information (Kneale & Demiris, 2017). Using semi-structured interviews allows the research team to more thoroughly probe facilitators and barriers of use. For example, P3 and P4 did not find the PHR useful for their current needs, but were able to offer some suggestions on how another system could be better designed to meet their needs. Future research can further our understanding of the application of personal health records for homebound older adults by developing research protocols that interview more homebound older adults.

Finally, from our study, the residential infrastructure appears to be an important component of PHR use. Homebound older adults have limited mobility, and easy accessibility may mean more than just having a computer in their home. Future studies could explore this potential relationship by formally studying home infrastructure needs, and outlining how PHRs can be successfully implemented in the homes of homebound older adults.

5.4.2.2 Health behavior

Participants were able and willing to complete the PAM-13. Most participant raw PAM scores changed less than 10% throughout the study period, but most people also did not use the PHR for their health information needs. In fact, all participants except P5, had PAM scores that decreased over the study period. Incidentally, P5 was the only participant who used the PHR for health information management. Future studies could explore the relationship between PAM and PHR use, by comparing the PAM score of homebound older adults who have and have not adopted PHRs.

In addition, because most participants had declining PAM scores, more research is needed to better understand the expected trajectory of patient activation for homebound older adults at the end of home health encounters. On one hand, one might expect that homebound older adults should have higher PAM scores at home health discharge. This might indicate that the home health services helped the older adult navigate his or her changing health needs. On the other hand, ending home health services may make individuals uncertain, and this could be reflected in the small reduction of PAM scores over of the study period. Without better understanding the connection between home health services and PAM scores, it is difficult to tell whether future studies should expect to find a relationship between PHR use and patient activation during home health encounters.

5.4.2.3 Home health outcomes

This study attempted to measure the home health value based purchasing measures as an outcome of the study. Without having access to OASIS-C datasets, it is difficult to gather all the data that are being submitted to the Centers for Medicare and Medicaid Services. However, it was interesting to note that neither of the home health clients who were approached to provide

authorization to their OASIS knew that this information was being collected during their home health visits. Perhaps this is a symptom of a larger challenge with transparency of home health data collection. Future research can explore home health client understanding of the types and purpose of the data being collected during home health visits, and whether these data should be more available to home health clients and their caregivers.

5.4.3 Limitations

The main limitations to this study are the small sample size, and the updates to the study procedures. Due to the challenges that we faced recruiting homebound older adults described in paper 3, and the additional challenges faced with obtaining the OASIS data from a partner home health agency, it was important to adjust our procedures. Unfortunately, the changes to the study procedures were not approved by the Internal Review Board in time to apply to either P1 or P2. Despite these challenges, the data presented in this study can inform future studies exploring consumer health information technology, like personal health records, with homebound older adults. As this population grows in size and in its desire to connect with providers through these tools, more research is needed to better understand the commonalities and differences that homebound older adults have to other adult patient populations.

5.5 CONCLUSIONS

In conclusion, this study shows that it is possible to perform a PHR evaluation study with homebound older adults and their caregivers. The homebound older adult participants in this study were knowledgeable about computers, health information, and how personal health records could fit into their health and wellness routines. Despite these successes, this study also demonstrates that are still many open questions to how homebound older adults could use PHRs

to manage their health information. First, it is unclear what outcomes should be expected from PHR use. Our limited sample did not show a strong link between PHR use and patient activation. Perhaps future research could explore other health behaviors that could improve with PHR use in the homebound population, such as care coordination or health literacy. From this study, it appears that some homebound older adults do not understand all of the data being collected from them during home health encounters. Perhaps PHRs could play a role in increasing the transparency of the services provided during home health encounters.

In addition, this study did not find many older adults who found the PHR that we used useful in their health and wellness routines. This suggests that the perceived benefit was low among our population, or that the PHR system that we used was not designed to meet their needs. Future research can work with older adults to better understand how older adult view PHRs, and weigh the risks and benefits of PHR use. In addition, PHR designers should

Finally, there are some considerations that future researchers should consider when designing PHR evaluation studies with homebound older adults. Homebound older adults receive many home-based visitors and often have limited time during the day. In addition, symptom burden may be high following a hospitalization. Therefore, researchers should focus on gathering the most important data through interviews or other flexible procedures to encourage more homebound older adults to participate.

CHAPTER 6: CONCLUSIONS

This dissertation explores the application of personal health records (PHRs) with homebound older adults.

The first paper evaluates existing personal health records systems for homebound older adult users. I discuss the how I defined key PHR features from a literature review, and evaluated the prevalence of these factors among publically available systems. This study found that there are few commercial PHRs that are available to homebound older adults, and many of these systems are missing important features. Future work should further explore the requirements that homebound older adults have for PHRs, and how systems can be better designed to meet these needs.

The second paper explores the usability of two PHRs that had a high number of features that were deemed desirable for homebound older adults. This usability study modifies the Chisnell and Redish methodology (Chisnell & Redish, 2005) to perform a heuristic evaluation from the perspective of a homebound older adult, family caregiver, and home health nurse. Our findings demonstrate that even if a PHR has features that are desirable to homebound older adults, the way the system is design may still hinder effective care coordination among homebound older adult care team members. This paper offers design recommendations based on our findings to develop PHRs that are more aligned with homebound older adult care team activities, and calls for more usability studies to evaluate systems from multiple perspectives.

The third paper describes my efforts working with home health agencies to recruit homebound older adults following a hospitalization. In this paper, I review the recruitment procedures from three home health agencies and the outcomes of these efforts. Unexpected challenges arose during the recruitment. These challenges include identifying partner agencies,

motivating home health nurses to approach potential participants, and contacting prospective participants. This paper concludes by providing suggestions on how future researchers can improve their recruitment of homebound older adults for consumer health information technology research.

Finally, paper four describes a pilot study that was designed to explore the relationship between individual patient characteristics, PHR use, patient activation, and home health outcomes. This study found that, in general, homebound older adults are willing and able to use personal health records. However, not all study procedures were successful with this population. Homebound older adults were generous with their time, and offered many important insights during the participant interviews. In this paper, I suggest developing procedures with shorter duration and focusing effort on collecting qualitative interviews. This will help us better understand the nuances of their experiences with PHRs, and better define the quantitative measures that would be appropriate outcomes of PHR use.

6.1 CONTRIBUTIONS

This work has expanded our knowledge in several key areas.

6.1.1 Evaluation of a novel method to use scenarios and personas to enhance a usability heuristic evaluation

This dissertation evaluates a methodology to use scenarios and personas to enhance a usability heuristic evaluation. In paper one, I describe my efforts to modify the Chisnell and Redish Heuristic methodology (Chisnell & Redish, 2005) to assess the usability of two personal health records from three perspectives: homebound older adult, informal caregiver, and home health nurse. This work shows that adding personas and scenarios can allow researchers to collect different types of a traditional heuristic evaluation. These methods could be used to enhance any

future heuristic evaluation that seeks to gain insight to how different users experience a single consumer health informatics system.

6.1.2 Recognition of an absence of functionalities useful for homebound older adult

The first paper in this dissertation also discusses the continued need to improve PHR designs in order to fit today's homebound older adult consumers. Homebound older adults are more likely to have chronic illnesses, physical and psychological limitations, and identify in populations that face health disparities, such as racial and ethnic minorities than their non-homebound peers (Ornstein et al., 2015). These characteristics may create unique barriers to PHR use, but could also help motivate homebound older adults to use these tools. Unfortunately, as paper one shows, even if a homebound older adult were interested in using a PHR, there are few existing systems that are designed for their care environment. Furthermore, most PHRs in the marketplace are missing key features that would make them an effective health information management tool for many healthcare consumers. Finally, as paper two demonstrates, even if the features are available there are questions to whether the homebound older adult could effectively use a PHR for care coordination among his or her care team members.

6.1.3 First PHR study with homebound older adults and their caregivers

Homebound older adults have not been specifically recruited for previous PHR evaluation studies (Kneale & Demiris, 2017). My results indicate that homebound older adults are often willing and able to provide significant feedback on PHR use for their care. In addition, researchers are able to overcome challenges with recruitment in this population to enroll participants for study periods up to 17 weeks. As Paper 3 describes, home health agencies can work with researchers to identify potential study participants. Home health agencies, due to their

scope of work, are one of the few health service sites specifically designed to support care transitions. Together, home health agencies, homebound older adult participants, and health services researchers can design and implement studies to learn more about the application of PHRs in homebound older adult care routines.

Paper 4 examines a pilot study that recruited homebound older adults and their caregivers to evaluate a personal health record. Specifically, this study looked at using a modified model of Andersen's Phase-3 Health Utilization mode to describe the relationship between patient characteristics, PHR use, patient activation, and home health outcomes. Findings from our small study do not support a strong link between these items in homebound older adult participants. Other models should be explored to better characterize the effect of PHRs on homebound older adult health behaviors and home health outcomes. In addition, our study found that qualitative interviews were the most effective method to gather opinions on PHRs for use in home health. Future studies should focus on gathering more qualitative data from homebound older adults to understand the unique barriers and facilitators of PHR use within home health.

6.2 LIMITATIONS AND TRADEOFFS

As with all studies, these methods had some limitations.

The main limitation of Paper 1 is that this study did not assess PHRs that were attached to health systems (e.g. "tethered" PHRs). Besides the logistical challenges of reviewing PHRs associated with specific health systems, this choice was also made to reflect the current PHR markets. Although some health systems offer dynamic PHRs, none of these systems are open to the public. Therefore, not all homebound older adults could use a tethered system. In order to ensure that the PHRs that were reviewed would be assessable to any homebound older adult with Internet connection, we excluded all PHRs that required specific health system membership.

Paper 2 relied on a heuristic evaluation with experts to complete the usability study from the perspective of homebound older adult, family caregiver, and home health nurse users. This choice was made for several reasons. First, this allowed me to explore how incorporating scenarios and personas into a heuristic usability study can enhance the types of data collected. Secondly, heuristic usability studies have been found to be as effective as a precursor to end-user evaluations (Liu et al., 2011). Finally, the heuristic evaluation approach using personas and scenarios allowed me to gather information on how PHR use may be affected by personal characteristics while fitting with the study's budget and time restrictions.

Paper 3 describes our efforts to recruit from home health agencies. The main limitation of this work is that home health providers were not formally interviewed as part of this study. The barriers described in paper two are derived from my study data and informal conversations. Because these challenges were not anticipated, our study methodology did not allow for home health agency staff to be formally enrolled as study participants. Future work could explore the challenges of recruitment from the home health agency perspective.

Finally, the main limitations of the third paper are the small sample size and limited generalizability of our findings. For the pilot study, five participants were recruited, and four participants finished all study procedures. In addition, the pilot study procedures were altered throughout the course of the study, and this caused variation in the data that was collected from each participant. Finally, the participants recruited for the pilot study were younger older adults, and lacked racial and ethnic diversity. In addition, all participants had access to the Internet and an Internet-enabled device in their homes. Because all participants shared these characteristics, the findings from our pilot study may not be generalizable to the entire homebound older adult

population. Despite these limitations, the findings from this study can support successful future work within this research setting.

6.3 **OPPORTUNITIES FOR FUTURE WORK**

The findings from this study present the opportunity for future work. In this section, I highlight the four main areas of future work.

6.3.1 Gathering perspectives from diverse homebound older adults

As described above, homebound older adults are able and willing to participate in PHR evaluation studies following a hospitalization, but this study recruited a homogenous sample of homebound older adults. One area of future work is to partner with more home health agencies to recruit a more diverse sample of homebound older adults. Perhaps reducing the study burden and/or removing the requirement that individuals have their own Internet-enabled devices could encourage broader participation in future studies.

6.3.2 Obtaining home health nursing perspective

The results presented in this study rely on interactions with homebound older adults and their caregivers, and from researcher observation. Future studies could explore the perspective of home health nurses to better understand barriers to recruiting homebound older adults, and the application of PHRs in home health environments.

6.3.3 Understanding the role of home care aides in homebound older adults' health One unique aspect of this study is that the three caregivers who participated were paid home care aides. Traditionally, home care aides are responsible for helping homebound older adults with domestic and personal health tasks, such as cleaning, cooking, personal hygiene, and

transportation. This study suggests that these aides can play an important role in the health information management and self-care routines of their clients. This could indicate that home care aides are an underexplored resource in improving the care of homebound older adults. Future work could investigate the different relationships between homebound older adults and their care aides, and how technology could be used to enhance their interactions.

6.4 CONCLUDING REMARKS

The homebound older adult population is growing, and the demand on these individuals to manage their personal health information is also increasing. This population has not been systematically involved in the design, implementation, or evaluation of personal health record (PHR) systems in previous literature. This dissertation aims to address this gap and showcases that evaluating PHR applications with homebound older adults is generally feasible; however, there are many unexplored questions of how this technology should be designed and deployed most effectively within this population. Therefore, we need to start to engage homebound older adults and their caregivers in formal PHR formative and summative system evaluations. Without such studies, we may be losing an opportunity to identify and build systems that meet the needs of this important patient population.

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