PERSONAL HEALTH RECORD USABILITY

THE USABILITY OF A PERSONAL HEALTH RECORD BY OLDER ADULTS

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CONTRIBUTIONS

The body of this thesis contains two separate papers, linked by an introduction and concluding discussion. The co-authors on these papers had roles of the second and third reader in the systematic review process, and with the second study, assisted with study design, general consultation, and manuscript review. Erin Macpherson was responsible for all aspects of these papers, including the design, data collection, analysis, and writing.

ABSTRACT

The purpose of this thesis was to explore how older adults use a Personal Health Record (PHR) within their health care, and to evaluate the role of the individual's level of physical functioning in this use. Study One was a systematic review evaluating the existing evidence on the impact of older adults' levels of physical functioning on their use of a PHR, and to assess the feasibility of a PHR as a modality to monitor physical functioning among this population. Study Two was a usability evaluation of PHR use by older adults with a chronic disease, with the goal to evaluate the actual use, and perceptions of use, of the McMaster PHR for self-monitoring of their physical functioning. The information gained from these studies will be used to inform future research and interventions to increase usability and uptake of PHRs by this population.

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Susanne Sinclair, the research coordinator for the “Detecting and Addressing Preclinical Disability” study provided assistance with recruiting study participants, and sitting in on interview sessions. The other therapists involved with this study also helped with the classification of patients’ level of physical functioning and level of computer expertise.

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Chapter 1: Introduction and Literature Review

Introduction and Outline for Thesis

The purpose of this thesis was to explore how older adults use a Personal Health Record (PHR) within their health care, and to evaluate the role of the individual's level of physical functioning in this use. Two separate, but related, studies were completed. Study One was a systematic review (Chapter 2), and Study Two was an exploratory study using the "Think Aloud" method (Chapter 3). The purpose of Study One was to systematically evaluate the existing evidence on the impact of older adult's level of physical functioning on their use of a PHR, and to assess the feasibility of a PHR as a modality to monitor physical functioning among this population. The purpose of Study Two was to evaluate the use of a specific PHR by older adults with a chronic disease, for the purposes of self-monitoring of their physical functioning. Included in this introduction is a brief literature review discussing personal health records, older adults as a demographic, applicable theories of technology acceptance, and usability testing as a methodology. A discussion of the overall findings and implications of the thesis (Chapter 4) follows the two studies (Chapter 2 and 3). Chapter 2 was prepared for publication in the journal *Current Geriatric Reports*, and was published in July 2014 [1].

Literature Review

Personal Health Record Use in Health Care

A Personal Health Record (PHR) can be simply described as any system or set of tools used by a patient to monitor or manage their health [2]. Functions of the PHR can include information collection, storage, sharing, patient-provider communication, health education, and health self-management [3]. Information included in the PHR can include: personal information, problem lists, illnesses, diagnoses, allergies, immunizations, family history,

social history, procedures, hospitalizations, preventative health recommendations, medications, provider list, laboratory test results, appointments, and home monitor data [3]. Data can be objective, such as clinical test results, or subjective, such as questionnaire responses [4]. It is important to emphasize that a PHR is managed by the individual, in contrast to an electronic health record (EHR) or electronic medical record (EMR), which is managed by a health care professional or a health institution [4]. PHRs can be paper-based, computer-based, or web-based [3]. This thesis focused specifically on the use of web-based PHRs; thus, a criterion for inclusion of studies in the systematic review required the PHR to be entirely web-based. The following definition of a PHR was used for this thesis:
"An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment" [5].

Participants for Study Two were recruited from a study testing the feasibility of an intervention by physiotherapists (PT) and occupational therapists (OT) to use a standardized patient-reported outcome called the Physical Functioning Inventory (PFI) to detect preclinical disability. The primary study uses the McMaster PHR to administer various surveys of physical functioning, facilitate online communication between the patient and the PT or OT, and provide documents containing the tailored recommendations for the patient.

Rather than being a portal connected to a health institution's data, McMaster PHR is a patient-owned and controlled PHR **[6]**. The PHR is distinct from a related program called Oscar, which is an electronic medical record (EMR) available to health care professionals. The McMaster PHR [6] was adapted from open-source software developed at Massachusetts Institute of Technology (MIT) and Harvard, and use at McMaster clinics began in 2007.

Users of the McMaster PHR can upload and manage their own personal health information, including medications, immunizations and test results, message with health care providers, family and friends, and have access to interactive health tools [6]. Users who are affiliated with Stonechurch Family Health Centre or McMaster Family Practice can also book appointments online using the McMaster PHR [6].

Personal health records have been proposed as a promising modality to implement preventative and rehabilitative programs [3, 4, 7, 8]. However, because PHR technologies are still developing [4], there has been insufficient research to date in this area [9]. It is important during this early stage of development and implementation to evaluate usability by potential users, and to incorporate what is learned into future designs. The work described in Study Two is an evaluation of the usability of the McMaster PHR by older adults.

Studying the Demographic of Older Adults

Different user groups have different attitudes towards technology and different barriers and facilitators to use [2; 3; 10]; therefore, it is important to study technology acceptance in the target population of users. It is critical to identify and act upon these specific factors influencing use in order to implement a technology successfully in a target population [11]. Older adults are a target user group that could benefit from incorporating health information technologies into their health care [2, 12]. However, a review of the literature on health informatics and aging [13] found that there is a paucity of information about the relationship between older adults and their use of health care technologies. This population faces significant challenges in using web-based technologies for health, which necessitates a distinct evaluation of technology acceptance factors for this population.

For this thesis, older adults were defined as 60 years of age and older, knowing that the characteristics of individuals included within this range will vary and they cannot be considered a homogenous group. It is understood that aging is a continual process and occurs differently for every individual, depending on social and regional factors [14]. Chronological age does not directly correlate with health factors such as physical ability or functional independence [14]. Two adults may have a very different level of physical and mental abilities at age 70, and an individual at 65 years will likely be very different from someone aged 90 years on a variety of health and social domains.

Within this thesis, the role of an older adult's level of physical functioning in their ability to use a PHR was of particular interest. Physical functioning can be defined as the ability of an individual to engage in personally important activities within his or her environment [15]. Older adults experience progressive, normative declines in physical functioning as they age, including declines in audition, vision, reaction times, coordination, flexibility, and the ability to perform motor skills [11]. Rates of chronic disease [16] and disability [17] increase with age. Ninety two percent of older adults have at least one chronic condition, and between sixty-five and eight-five percent have more than one [18]. Rates of disability double every five years after age sixty-five [19]. Health declines lead to decreased physical functioning, a decrease in the ability to independently provide self-care, a lower quality of life, and increased demands on the health care system [20]. There was a focus on physical functioning in both studies described in this thesis. Study One included articles that contain a measure of, or discussion of, levels of physical functioning, and Study Two also examined the individual's level of physical functioning.

Theories of Technology Acceptance

Research in health technology adoption has been mostly atheoretical, especially when describing use of technology by patients [21]. However, theory is helpful in developing a useful understanding of why people adopt or do not adopt a technology [21]. It is important to have a testable model based on theory in order to identify what factors are most important in explaining use, and how these factors could be modified to increase uptake [21]. A theoretical perspective was incorporated through the data extraction process in the systematic review and through the structuring of a participant survey in Study Two.

Although there are a variety of established theories of technology acceptance, the Technology Acceptance Model (TAM) and the Unified Theory of Acceptance and Use of Technology (UTAUT) are the two dominant theories used in health technology acceptance [22]. The UTAUT is an extension of the TAM [21], developed by Venkatesh et al. (2003), to create a more parsimonious and powerful model to explain the "how" and "why" of technology acceptance [23]. Whereas the TAM predicts approximately 40% of the variance in acceptance, the UTAUT can predict up to 70% [23].

The UTAUT draws the most empirically important concepts from eight existing theories that are moderately successful on their own at predicting technology acceptance [23]. These eight component theories are: the theory of reasoned action, the technology acceptance model, the motivational model, the theory of planned behaviour, a model combining the technology acceptance model and the theory of planned behaviour, the model of personal computer utilization, the innovation diffusion theory, and the social cognitive theory. The result of this consolidation was four main constructs, described below. The first three are predictors of *intention to use*, with the fourth a predictor of *actual use*.

1) *Performance Expectancy*: (to what extent does the individual believe that use of the technology will lead to improved job performance)
2) *Effort Expectancy*: (how easy the use of the technology is perceived to be)
3) *Social Influence*: (the extent to which an individual believes that others want them to use the technology system)
4) *Facilitating Conditions*: (the extent to which an individual believes that the organization and technical infrastructure are in place to support use)

Age, gender, technology experience, and voluntariness of use are moderators of these relationships.

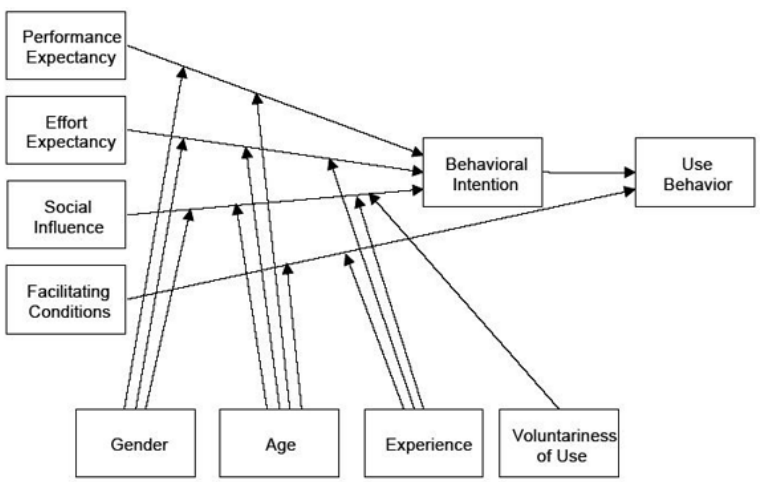

Figure 1. The Unified Theory of Acceptance and Use of Technology (Venkatesh, 2003)

Although the theory was developed relatively recently, there has been a strong uptake in its use since it was first developed. The UTAUT has been applied in multiple studies of health care technology [24]. These include the evaluation of patient acceptance of a web-based self-management tool for home care patients with chronic cardiac disease [21], exploring user acceptance of an intelligent health monitoring system for older adults at a long-term care facility in Taiwan [25], and perceptions of a variety of potential home-based telerehabilitation interventions for chronic pain in adults [8]. Users of a technology consistently scored higher on each of the UTAUT constructs than non-users did [24]. The UTAUT has also been applied to the use of computers by older adults, 50-90 years, comparing users to non-users [26], with the authors advocating for the use of the UTAUT over the TAM for older adults, because it contains important constructs relevant to predicting use in this population, such as age, gender, and technology experience.

Several limitations of this theory have been identified: The UTAUT is able to explain more of the variance in intention to use (70%) than in actual use (50%) [23]: behavioural intention does not necessarily result in the actual performance of that behaviour [27]. Another issue to consider is whether "use" necessarily leads to positive outcomes for the individual: does successful implementation of a technology lead to successful outcomes, such as improved quality of care, or lower health care costs? For this thesis, the UTAUT was used as a theoretical starting point, as suggested by Or et al. (2011), adapted for use in this particular context.

Usability Testing

Usability has been defined as the ability of a system to "be used by humans easily and effectively" [28]. Shackel (1991) proposed that usability relies on four characteristics: 1) the user, 2) the task, 3) the tool, and 4) the environment. Usability testing is a research method in which target users participate in the evaluation of a system [29]. It consists of testing the system of interest using real target users and real tasks, then performing an analysis of video/audio records and observations of what the users do and say [29]. The end goal is to identify the variables affecting use, in order to evaluate how the system is being used currently and to improve the system for future use [30].

Popular methods of usability research include heuristic evaluation, cognitive walkthrough, and the "Think Aloud" method [31]. Heuristic evaluation is an informal usability assessment done by expert evaluators (often the designers of the system) using specific criteria [32[. In

Cognitive Walkthrough, trained evaluators assess the technology while completing specific tasks [32].

The “Think Aloud” method, which was used in Study Two (Chapter 3), has target users verbalize their thoughts as they complete specific tasks using the technology of interest [32]. The concurrent ‘Think Aloud” method was used for Study Two, where participants describe their actions and feelings while completing the tasks, as opposed to the less commonly used retrospective method, where participants verbalize their thoughts after completing the tasks [31]. The concurrent method provides a more complete and detailed description of the participant's thoughts, revealing more usability problems [32].

Results from multiple usability tests, as well as interviews and quantitative surveys can be compiled in a usability report [31]. This report discusses the methodology used, the participant and task characteristics, the number and type of problems while completing the tasks, and recommendations on how to improve system design [32]. Study Two employed the “Think Aloud” Method, a semi-structured interview, and a survey, with the results summarizing characteristics of task completion, such as number of errors made or whether they ask for assistance. Major themes from the data are presented, as well as illustrative quotes and interview and survey results. This “Think Aloud” Study is presented in Chapter Three, The final chapter contains a discussion and the conclusions reached based on the work of the thesis.

The thesis contributes information about the existing evidence on the impact of older adult’s level of physical functioning on their use of a PHR, and the feasibility of a PHR as a modality to monitor physical functioning among this population. This thesis also contributes an original investigation of the use of a PHR by a population of older adults. This study supports previously identified factors affecting health information technology use, as well as exploring additional factors that may be relevant to the context of this study. Methodologically, this thesis adds to the growing body of literature using usability testing to evaluate use of health information technologies by patients.

References

1. Macpherson, E. Dhaliwal, C., Richardson, J. The Relationship between the Physical Functioning of Older Adults and Their Use of a Personal Health Record: A Systematic Review. *Current Geriatric Reports,2014,* DOI 10.1007/s13670-014-0094-5.
2. Lober, W. B., Zierler, B., Herbaugh, A., Shinstrom, S. E., Stolyar, A., Kim, E. H., et al. (2006). Barriers to the use of a personal health record by an elderly population. *AMIA Annu Symp Proc, 1,* 514-518.
3. Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K. A., & Straus, S. E. (2011). Personal health records: A scoping review. *Journal of the American Medical Informatics Association, 18*(4), 515-522. doi:10.1136/amiajnl-2011-000105
4. Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association, 13*(2), 121-126. Retrieved from http://search.ebscohost.com.libaccess.lib.mcmaster.ca/login.aspx?direct=true&db=cin20&AN=2009331308&site=ehost-live
5. Markle Foundation. (2003). *The personal health working group final report*
6. Oscar McMaster. 2011. Available from: http://myoscar.org/about-myoscar
7. Varnfield, M., Karunanithi, M. K., Saerelae, A., Garcia, E., Fairfull, A., Oldenburg, B. F., et al. (2011). Uptake of a technology-assisted home-care cardiac rehabilitation program. *Medical Journal of Australia, 194*(4), S15-S19.
8. Cranen, K., Drossaert, C. H., Brinkman, E. S., Braakman-Jansen, A. L., Ijzerman, M. J., & Vollenbroek-Hutten, M. M. (2012). An exploration of chronic pain patients' perceptions of home telerehabilitation services. *Health Expectations, 15*(4), 339-350.
9. Chun, Y. J., & Patterson, P. E. (2012). A usability gap between older adults and younger adults on interface design of an internet-based telemedicine system. *Work,* 41(Suppl 1), 349-52.
10. Yu, P., Zhang, Y., Gong, Y., & Zhang, J. (2013). Unintended adverse consequences of introducing electronic health records in residential aged care homes. *International Journal of Medical Informatics, 82*(9), 772-788. doi:10.1016/j.ijmedinf.2013.05.008
11. Czaja, S. J., Charness, N., Fisk, A. D., Hertzog, C., Nair, S. N., Rogers, W. A., et al.

(2006). Factors predicting the use of technology: Findings from the center for research and education on aging and technology enhancement (CREATE). *Psychology and Aging*, *21*(2), 333.

12. Gell, N. M., Rosenburg, D. E., Demiris, G., LaCroix, A.Z., & Patel, K. V. (2012). Patterns of technology use among older adults with and without disabilities. *The Gerontologist*, *issue*, *pages*

13. Koch, S., & Hägglund, M. (2009). Health informatics and the delivery of care to older people. *Maturitas*, *63*(3), 195-199. doi:http://dx.doi.org.libaccess.lib.mcmaster.ca/10.1016/j.maturitas.2009.03.023

14. Orimo, H., Ito, H., Suzuki, T., Araki, A., Hosoi, T., & Sawabe, M. (2006). Reviewing the definition of "elderly". *Geriatrics & Gerontology International*, *6*(3), 149-158.

15. Bonder, B.R., Dal Bello Haas, V. (Ed.). (2009). *Functional performance in older adults* (Third Edition ed.). Philadelphia: F.A. Davis Company.

16. Smith, J. May 2012. Report of the Standing Committee on Health: *Chronic diseases related to aging and health promotion and disease prevention.*

17. Seeman TE, Merkin SS, Crimmins EM, Karlamangla AS. (2010). Disability trends among older americans: National health and nutrition examination surveys, 1988-1994 and 1999-2004. *American Journal of Public Health*, *100*(1), 100.

18. Sibley, K. M., Voth, J., Munce, S. E., Straus, S. E., & Jaglal, S. B. (2014). Chronic disease and falls in community-dwelling Canadians over 65 years old: a population-based study exploring associations with number and pattern of chronic conditions. *BMC geriatrics*, *14*(1), 22.

19. Young, R., Willis, E., Cameron, G., Geana, M. 2013. "Willing but Unwilling": Attitudinal barriers to adoption of home-based health information technology among older adults. *Health Informatics Journal*, 0(0), 1-9

20. Chou, C., Chang, C., Lee, T., Chou, H., & Mills, M. E. (2013). Technology acceptance and quality of life of the elderly in a telecare program. *Cin-Computers Informatics Nursing*, *31*(7), 335-342. doi:10.1097/NXN.0b013e318295e5ce

21. Or, C. K., Karsh, B. T., Severtson, D. J., Burke, L. J., Brown, R. L., & Brennan, P. F. (2011). Factors affecting home care patients' acceptance of a web-based interactive self-management technology. *Journal of the American Medical Informatics*

Association, *18*(1), 51-59. doi:10.1136/jamia.2010.007336

22. Li, J., Talaei-Khoei, A., Seale, H., Ray, P., & MacIntyre, C. R. (2013). Health care provider adoption of ehealth: Systematic literature review. *Interactive Journal of Medical Research*, *2*(1)
23. Venkatesh, V., Morris, M. G., David, G. B., & Davis, F. D. (2003). User acceptance of Information Technology: Toward a unified view. *MIS Quarterly, 27*(3), 425-478.
24. Lee J., & Rho M.J. (2013). Perception of influencing factors on acceptance of mobile health monitoring service: A comparison between users and non-users. *Healthc Inform Res.*, *19*(3), 167-76.
25. Tseng, K., Hsu, C., & Chuang, Y, *Designing an intelligent health monitoring system and exploring user acceptance for the elderly.* Journal of Medical Systems, 2013. **37**(6): p. 1-18.
26. Nagle, S., & Schmidt, L. (2012). Computer acceptance of older adults. *Work, 41*(Suppl 1), 3541-3548. Nahm, E., Blum, K., Scharf, B., Friedmann, E., Thomas, S., Jones, D., et al. (2008). Exploration of patients' readiness for an eHealth management program for chronic heart failure: A preliminary study. *Journal of Cardiovascular Nursing, 23*(6), 463-471.
27. Venkatesh, V., Thong, J. Y. L., & Xu, X. (2012). Consumer acceptance and use of information technology: Extending the unified theory of acceptance and use of technology. *Forthcoming in MIS Quarterly, 36*(1), 157-178.
28. Shackel, B. (1991). Usability-context, framework, definition, design and evaluation. *Human factors for informatics usability*, 21-37.
29. Corry, M. D., Frick, T. W., & Hansen, L. (1997). User-centered design and usability testing of a web site: An illustrative case study. *Educational Technology Research and Development, 45*(4), 65-76.
30. Kaufman, D. R., Patel, V. L., Hilliman, C., Morin, P. C., Pevzner, J., Weinstock, R. S., ... & Starren, J. (2003). Usability in the real world: Assessing medical information technologies in patients’ homes. *Journal of Biomedical Informatics, 36*(1), 45-60.
31. Martin, B., Hanington, B., & Hanington, B. M. (2012). *Universal methods of design: 100 ways to research complex problems, develop innovative ideas, and design effective solutions.* . Osceola, WI.: Rockport Publishers.

32. 1aspers, M.W.M. 2009. A comparison of usability methods for testing interactive health technologies: methodological aspects and empirical evidence. *International journal of medical informatics*, 78, 5, 340-353

Chapter 2: Systematic Review

The Relationship between the Physical Functioning of Older Adults and their Use of a Personal Health Record: A Systematic Review

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Abstract

The objective of this systematic review was to evaluate the impact of older adults' (≥60 years) levels of physical functioning on their use of a personal health record (PHR), and to assess the feasibility of a PHR as a modality to monitor the physical functioning of older adults. The databases MedLine, Embase, Cochrane, CINAHL, AgeLine, and PsychInfo were searched in April 2014 for articles published in 2000-2014. Studies were independently reviewed, with screening, data extraction, and quality assessment done by two readers (EM, CD). Thirteen qualitative, quantitative, and mixed methods studies were included. These articles reported on nine different PHRs and were highly heterogeneous in methodologies, participant characteristics, and setting of use. Results indicated there is potential to use PHRs as a platform for monitoring of physical functioning, but also identified that physical limitations, in combination with multiple other barriers, could prevent effective use of PHRs by older adults.

Key Words

Personal Health Record; older adults; primary care; physical functioning; health information technology; technology acceptance; functional independence

Introduction

The global population is rapidly aging, and older adults have higher rates of disability, with functional and mobility limitations increasing with age [1]. An aging population also entails an increased prevalence of chronic conditions, the presence of which can further reduce levels of physical functioning and quality of life [2]. The complex, increased care required by these older adults with chronic conditions puts an enormous burden on the health care system, both in terms of financial and time resources [3]. The use of information technologies for health has been proposed as a means of managing the long-term care of older adults in a home-based setting [2] and has been projected to improve the functional independence of older adults [4], especially those persons with a chronic disease [5]. Information technologies can help to address the high complexity and fragmentation of care that older adults often experience [5], and allow older adults to take a more active role in their health [4]. Web-based Personal Health Records (PHRs) are one promising health information technology that can be used for the management of personal health information, for communication between patients and their health care providers, and for the facilitation of rehabilitation, self-management, and preventative programs. For the purposes of this review, the following definition of a PHR from the Markle Foundation will be used: *"An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment."[6]* PHRs have been suggested to decrease in-person doctor visits [7], to elicit greater adherence to self-management programs [8], and to improve overall quality of care by providing more information to patients and improving communication with their health care providers [7].

Uptake of PHRs has been lower than expected [9], particularly in certain subgroups of the population who might especially benefit from their use, including older adults and persons with a disability [10]. Uptake is affected by multiple personal and environmental factors [11], and influenced by real and perceived barriers [9]. These barriers can include cost, lack of access to computers and the Internet, low health literacy, privacy concerns, and an unwillingness to adopt a new mode of health care delivery [9]. Relative to younger adults, older adults face the added barriers of lower technology expertise [12], higher computer anxiety [12], lower computer confidence [13], poorer fine motor skills [14], and reduced short-term memory [14].

Past reviews have examined the acceptance, use, and benefits of PHRs [9], the acceptance of consumer health information technologies [15], and the use of Web 2.0 interventions for self-management in older adults [16]. There is a need to understand more fully how an individual's level of functioning can act as a barrier to PHR use, and also how the PHR may be used to monitor function in a primary care setting. Of particular interest is how the PHR might be used to alter the trajectory of the functional decline experienced by older adults. Therefore, the objective of this systematic review was to evaluate how an older adults' level of physical functioning affects the use of a personal health record, and whether the PHR can be used as a way of monitoring an older adults' level of physical functioning.

Methods

Search Strategy

MedLine (via OVID), Embase (via OVID), CINAHL, PsychInfo, CENTRAL, and AgeLine were searched. The search was broad, in order to include all relevant articles. Keyword searching was performed, using the following search terms combined with "OR" and using the "explode" function: "*personal health record**", "*personal medical record**", "*personal electronic medical record**", "*personal electronic health record**", "*patient health record**", "*patient web portal**", "*integrated personal health record**", "*personally controlled health record**", "*shared electronic health record**", and "*patient internet port*al*". The search strategy was developed in collaboration with a librarian experienced in systematic reviews. The strategy was first developed in MedLine and adapted to the other databases. The Mesh term "personal health records" was used to search for articles in the Central database. References were managed in RefWorks through McMaster University. Two authors (EM, CD) independently screened the abstracts for relevance. Any discrepancies were resolved by consensus. In the case of disagreement, a third reviewer (JR) was consulted. When it was not possible to judge from the abstract alone whether the article met the inclusion criteria, the article passed through to the full text screening phase. Full texts were screened independently by two authors (EM, CD). Reference lists of each included study were searched for articles that met the inclusion criteria. Additional articles were also included from personal reference lists, from hand searching, and from the advice of colleagues. The authors (EM and CD) extracted data independently using a standardized form. For the purposes of this review, older adults were defined as persons aged ≥60 years. Physical functioning was defined as the ability to engage in activities that are important to the individual within his or her environment [17]. Study methodologies, study settings, PHR features, participant characteristics, relevant and major results, and conclusions of the authors were recorded. The form was piloted using a test article, and minor modifications were made. If two articles described the same study, separate data extraction forms were completed for each article.

Study Selection and Eligibility Criteria

Selection criteria required articles to be full-text, peer-reviewed primary research articles, published in 2000 or later, and written in English. Qualitative, quantitative, or mixed methods research was accepted. The articles needed to discuss patients' use of, perceptions towards, or intention to use, an electronic personal health record. The mean age of participants in the studies must have been either ≥60 years, or there must have been a subgroup analysis included for those participants ≥60 years. Evaluation of how a participants' level of physical functioning affected use of the PHR, or how the PHR measured the users' level of physical functioning needed to be documented by the study for inclusion in the review.

Study Quality Score

The Mixed Methods Appraisal Tool (MMAT) [18] was chosen to provide a measure of methodological quality of included studies as both qualitative and quantitative research had the potential to answer the research objective. The MMAT is a unique tool [19] developed to assess mixed methods studies. It is the only tool that specifically assesses mixed methods research for systematic reviews [20]. Each of the quantitative, qualitative, and mixed methods approaches that apply is evaluated on four criteria. The number of criteria met divided by four gives a percentage quality score. For example, the score is 25% if only one criterion is met, and 100% if all four criteria are met. The overall quality score is the score of the lowest scoring methodology within a particular study. The measure has moderate to excellent inter-rater reliability on criteria ratings and substantial reliability on overall quality score [19].

Results

Selection Process

Initial database searching generated 2116 possible articles. Twelve hundred thirty-eight articles remained after duplicates were removed. An additional 16 articles were identified from personal lists and hand searching. Twelve hundred fifty-four articles were screened, and 249 articles were included in the full text screening. Two hundred thirty-six articles were excluded, leaving 13 articles included in the review. For a diagram of study flow, see Figure 1**.** For the reasons for exclusion for selected articles, see Table 1.

Figure 1. Flow Chart of Study Selection

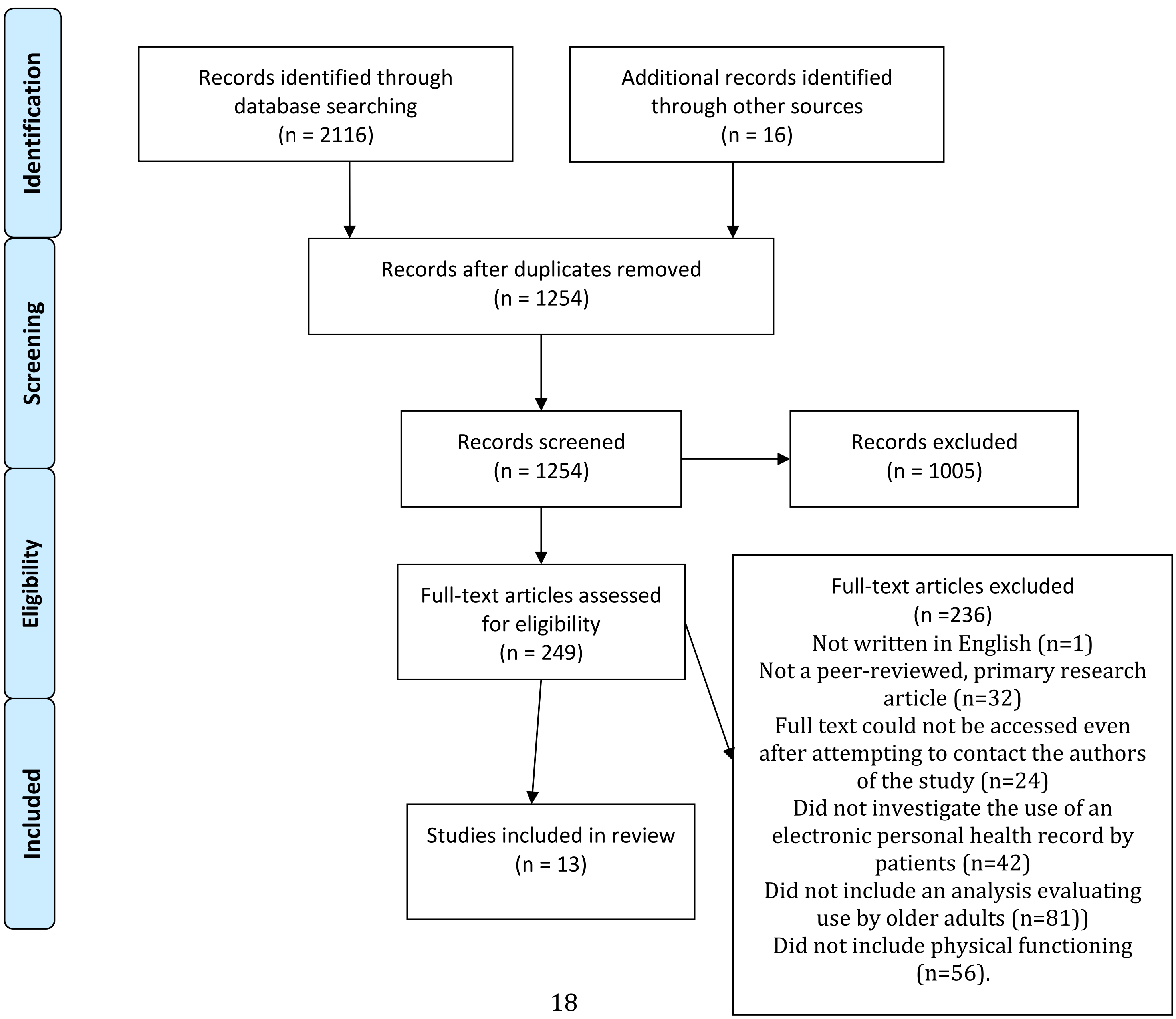

Table 1. Selected Excluded Studies

Author	Journal	Date	Title	Reason for Exclusion
Agarwal et al.	*Journal of Medical Internet Research*	2013	If we offer it, will they accept? Factors affecting patient use intentions of personal health records and secure messaging.	Mean age is 42 years, with no subgroup analysis of older adults
Backonja et al.	*Nurs.Inform.*	2012	Observations of daily living: putting the "personal" in personal health records.	Was a review, not a primary research article
Carrell & Raiston	*AMIA.Annu.Symp.Proc.*	2006	Variation in adoption rates of a patient web portal with a shared medical record by age, gender, and morbidity level	No discussion of physical functioning
Chen & Chan	*Int.J.Envron.Res.PublicHealth*	2013	Use or Non-Use of Gerontechnology-A Qualitative Study	Discusses the use of technology in general (e.g. televisions, remote controls), rather than electronic personal health records specifically
Czaha et al.	*J.Am.Med.inform.assoc.*	2013	Factors influencing use of an e-health website in a community sample of older adults	Was not an electronic personal health record- was a medicare.gov website that dealt with health insurance
Kim et al.	*Conf.Proc.IEEE*	2004	Application and evaluation of personal health information management system.	Does not provide age breakdown of participants.
Kim et al.	*Distrubuted Diagnosis and Home Health Care*	2006	Web-Based Personal-Centered Electronic Health Record for Elderly Population	No discussion of physical functioning
Lai et al.	*AMIA.Annu.Symp.Proc.*	2006	Training digital divide seniors to use a telehealth system: a remote training approach.	No discussion of physical functioning
Lam et al.	*Am.J.Manag.Care*	2013	Older adult consumers' attitudes and preferences on electronic patient-physician messaging.	Not an electronic personal health record; only allows for messaging
Leveille et al.	*Med.Care*	2009	Health coaching via an internet portal for primary care patients with chronic conditions: a randomized controlled trial.	Does not provide age breakdown of participants.
Logue & Effken	*Inform.Prim.Care.*	2012	An exploratory study of the personal health records adoption model in the older adult with chronic illness.	No discussion of physical functioning
McInnes et al.	*Inform.Prim.Care.*	2010	Disparities in health-related internet use by US veterans: results from a national survey.	Describes use of the Internet for health, rather than an electronic

				personal health record specifically
Nazi et al.	*J.Am.Med.Inform.Assoc.*	2010	Veterans' voices: use of the American Customer Satisfaction Index (ACSI) Survey to identify My HealtheVet personal health record users' characteristics, needs, and preferences.	No discussion of physical functioning
Wagner et al.	*J.Am.Med.Inform.Assoc.*	2012	Personal health records and hypertension control: a randomized trial.	Does not provide age breakdown of participants, and no discussion of physical functioning
Weitzman et al.	*Med Int Res*	2009	Acceptability of a personally controlled health record in a community-based setting: Implications for policy and design.	Mean age = 53, with no age breakdown of participants.
Woods et al.	*J.Med.Int.Res.*	2013	Patient experiences with full electronic access to health records and clinical notes through the My HealtheVet Personal Health Record Pilot: qualitative study.	Does not provide age breakdown of participants.
Xue et al.	*Int.J.Med.Inf.*	2012	An exploratory study of ageing women's perception on access to health informatics via a mobile phone-based intervention	Applications for mobile phone, not an electronic personal health record, and the mean age is <60, with no age breakdown of participants.

Characteristics of Included Studies

The 13 included articles reported on 9 different personal health records. Five articles used quantitative methods, 2 used qualitative methods, and 6 employed a mixed methods design. Five articles employed a theoretical framework in their design: The Unified Theory of Acceptance and Use of Technology (UTAUT) [21], the UTAUT and the Patient Technology Acceptance Model [22], the Technology Acceptance Model (TAM) [2], the Omaha System (an interface terminology standard) [23], and a combination of Social Cognitive Theory, goal setting theory, and organizational change theories [24]. Table 2 summarizes the key characteristics of the studies.

Table 2. Table of Summary Characteristics of Included Studies

Author and Date (# in Reference List)	Name of PHR, Country, and Setting of Use	Purpose of Study	Methodology (study quality score)	Participants	Conclusions about Physical Functioning	Benefits and Barriers to PHR Use by Older Adults
Chou et al. (2013) (2)	Telecare Service Program Taiwan Home (8.6%), community (49.5%), institution (41.9%)	To evaluate the relationships between quality of life and technology acceptance attitudes and to determine the users' experiences and attitudes towards this telecare program?	Mixed methods: structured TAM survey, open-ended questions (75%)	Mean Age: 77.8 years 56.2% Females n= 105	Although the majority of users reported no difficulties with ADLs or IADLs, 90% did not use the PHR independently. Participants also reported high distraction due to pain.	Use of a PHR could help older adults "age in place." Older adults have specific needs and challenges which should be addressed in the design and implementation of the system, including safety, accessibility, funding, and training of providers.
Kim et al. (2005) (25)	Personal Health Information Management System (PHIMS) USA Most use in computer room provided at the low-income housing facility	To evaluate the implementation of PHIMS at Everett Housing Authority, for low-income elderly and/or disabled residents, particularly usage patterns and user attitudes	Mixed Methods: usage statistics, survey, open-ended questions (75%)	Mean Age: 65.1 years Gender not provided. n= 24 (usage statistics); 12 (survey)	Most residents here are older adults or disabled. Physical limitations and/or limited computer/Internet experience prevented independent use of the PHR. Only 2 of the 12 surveyed used the PHR independently.	The authors hypothesized that a system such as this would be "useful" and" vital" for these older adults with high health care needs, and fragmented care
Kim et al. (2009) (26)	PHIMS USA Most use in computer room provided at the low-income housing facility	To assess the use and utility of PHIMS in a low-income elderly population, at the end of the 33-month study period.	Mixed Methods: usage statistics, survey, open-ended questions (75%)	Mean Age: 63.1 years 71% females n= 70 (usage statistics); 14 (survey)	Participants were limited by low physical, cognitive, and technological abilities. Low-income, disabled older adults will be less able to use a PHR, increasing health inequalities between these disadvantaged groups and those who are able to use it.	Older adults could benefit from the use of PHRs, but only a very small portion of low-income older adults are able to take advantage of it.

Kim et al. (2010) (31)	PHIMS USA Most use was in computer room provided at the low-income housing facility	To determine usage patters of PHIMS among different user groups within a low-income elderly population.	Quantitative: usage statistics, structured surveys (100%)	Mean Age: 63.1 years Gender not provided n= 70 (usage statistics); 14(survey)	Many of the current older adults with low income cannot use PHR, and even if they do, they do not use PHR effectively. PHRs need to take into consideration the physical and cognitive limitations faced by older adults	Use of the PHIMS was "very minimal". Technology expertise will increase among older adults in the future, but physical and cognitive limitations will always be a barrier.
Lober et al. (2006) (27)	PHIMS USA Most use in computer room provided at the low-income housing facility	To evaluate the barriers faced by a low income, elderly population in creating and using the PHIMS personal health record.	Mixed methods: usage statistics, surveys, and interviews (50%)	Mean Age: 69 years 82% Female n= 38	10/38 had a physical impairment of the upper extremities preventing independent use. Certain populations, such as older adults, and those with a disability, will not be able to create or maintain a PHR independently	Certain populations will not be able to create or maintain a PHR independently, including older adults and persons with a disability.
Leveille et al. (2007) (28)	PatientSite USA Recruited through the portal if they had upcoming primary care appointments	To conduct an online screening survey to recruit for a randomized trial, using a secure patient Internet portal to identify primary care patients with untreated depression, chronic pain, or mobility.	Quantitative: Structured Screening Surveys through the personal health record (50%)	22.1% of participants were aged 60+; results were reported for age categories 61% female n =981	The PHR was effective for screening primary care patients for chronic pain and mobility difficulties, in order to recruit for a randomized trial.	The authors believed that the “Internet Patient Portal” Patientsite was an effective and inexpensive method for recruitment and screening for chronic pain and mobility difficulties.
Monsen et al. (2012) (23)	No name provided USA Development only; observations and interviews were in the home of the	To evaluate PHR technology and content for older community-dwelling consumers; to evaluate the needs of community-dwelling older adults to remain at home safely after discharge from	Qualitative: interviews, recorded observations (25%)	Older adult participants were aged 65+ Gender not provided Sample size not	Within the Omaha system problem list for shared care plans, OAs validated 22 problems, which should be included in the PHR. Several addressed physical function: pain, skin, neuromusculoskeletal	PHRs can help older adults transition between health care systems, but they require tailoring in their design to match the older adults’ needs.

	older adults	home care.		provided	function. Neuromusculokeletal function was identified by all four sources as being important, including international care plans, home care staff, expert panel, and consumers.	
Nazi et al. (2013) (29)	My HealtheVet Pilot Program USA 98% used it at home, 7% in the workplace, 3% in a VA medical centre, 3% somewhere in the community, 2% in a friend or family's home, 2% other, 2% school	To determine the perspectives of users on the impact of having greater access to personal health information, and how this increased access impacts satisfaction, self-management, communication, and health care quality of participants.	Quantitative: usage statistics and survey (50%)	Aged 61-70: 45% of respondents 71-80: 15% 81-90: 6% 8% female n= 688	Users reported some physical impairments that they believed could affect their use of the PHR: 8% hearing, 7% visual, 6% dexterity	The PHR had a positive role in this population of users with a high percentage of older adults. They note that more computer skills training and increased patient activation is required to improve effective use.
Or et al. (2011) (22)	HeartCare USA Use in homes. 57% used their own desktop computers, while the project supplied computers for the rest.	To evaluate the acceptance of a web-based interactive SM technology among home care patients, using the UTAUT and other health variables as a theoretical basis.	Quantitative:. Cross-sectional data analysis from a randomized field study using telephone surveys (100%)	Mean age: 62.5 years 40% female n=101	Perceived, upper extremity functional ability, visual functional status were not significantly association with reported intention to use the PHR. Persons with significant sensory or motor disabilities, and persons requiring in-home professional care, were excluded from the study, because the authors didn't believe they could use the PHR.	Consumer Health Information Technologies are expected to benefit users, but only if they are actually used. Training is especially needed for older adults to use technologies such as these. Frail, older patients have "unique design requirements". Using technologies can be difficult even for healthy, able users, so a

						user-friendly system is required for older adults who are facing functional decline and disability.
Richardson et al. (2012) (30)	MyOSCAR Canada Baseline assessment completed in a clinic, the remainder of the assessments were completed by the participants at their home	To assess whether adopting a population-based, rehabilitation self-management approach that focuses on physical functioning as a major health outcome in a primary care setting improves the process and outcome of care for patients with chronic conditions.	Mixed Methods: before/after design to compare intervention to control groups, focus groups (75%)	62.8 years 70% female n= 55 in each of the intervention and control groups	Participants used the PHR for online self-report of functioning, using the Physical Functioning Inventory (PFI)- 21 items measuring ADLS, IADLs, mobility activities, and moderate/strenuous activities	There will always be a divide between the technology and the ability of some people to use it. Future generations of older adults will be more able to use computer-based technologies for their health.
Robben et al. (2012) (24)	Health and Welfare Information Portal (ZWIP) Netherlands At the home of the participants.	To design a program to facilitate self-management and shared decision making by frail older people and their informal caregivers, and to reduce fragmentation of care through improving collaboration between professionals	Qualitative focus groups, small pilot study (75%)	Participants were aged 70+ Gender not provided n= 11 (focus group), 2 (pilot study)	The PHR was designed to collect information on the older adults' functioning, health social situation, and care.	A program to promote self-management delivered through a PHR has the potential to help with gaps in care for older adults as they transition through the health care system.
Robben et al. (2012) (32)	Health and Welfare Information Portal (ZWIP) Netherlands At the home of the participants.	To evaluate the implementation process of an e-health intervention for community-dwelling frail older people, informal caregivers and primary care professionals.	Mixed methods: usage statistics, surveys, interviews (100%)	Participants 70+ years. Mean ages ranged from 79.2-82.8 years among the different participating practices. Ranged from 36.8% females to 83.3% females	Participants were assessed for frailty before enrollment, but still were able to use the PHR. Physical functioning was not identified as a barrier to use by participants. Participation rate was low, but the authors thought the rate was still encouraging given the barriers facing use by this population.	Although the study had a low participation rate (49%), the authors thought the rate was still encouraging given the barriers affecting this frail population of older adults. They believe that this system can fill the "widely acknowledged need to

				among participating practices n= 290		improve the care for the growing number of frail older people..." They think it is important to include older adults in the design of a PHR.
Tseng et al. (2013) (21)	Intelligent Health Monitoring System Taiwan Nursing home	To determine the acceptance of an intelligent health monitoring system by older adults in a nursing home setting.	Quantitative: structured questionnaire (50%)	Aged 60+: 60-64(6.3%), 65-70 (21.8%), over 70 (71.8%) 59% female n= 32	They suggest that having the system set up in the hall of the nursing home might prevent those with mobility problems from using it. The authors suggest that this system will be especially useful for the families of those residents with dementia, limb atrophy, or those who can't use a computer, them to get physiological data and information about the older adults health sent directly.	The system they designed will improve older adults' access to health care, increase their interaction with their family, decrease loneliness in the nursing home, and overall increase their quality of life.

Study Quality Scores

Study quality scores ranged from 25% to 100%. The following three criteria were most commonly not met. Six studies did not describe how their qualitative findings might have been influenced by the researcher [2, 23-27]. Five studies using quantitative descriptive methods did not have an acceptable response rate of 60% or above [21, 25, 26, 28, 29]. Three mixed methods studies did not explicitly describe when and how the integration of qualitative data or results occurred [25, 27, 30]. Studies were not excluded based on quality scores.

Characteristics of Participants

Age and Gender

Mean ages of participants ranged from 62.5 years to 77.8 years. The gender of participants varied by study: the number of females ranged from 8% to 83%.

Technology Experience

Five studies reported on the participants' experience with computer and Internet use. Experience levels varied among studies, and there was no consistent method of classification. Low income and disabled participants [25, 31] and frail community-dwelling participants [32] were reported by the authors to have low computer expertise while elderly participants in a nursing home were reported to have sufficient experience to be able to use the system [21]. Two studies used self-report measures of technology experience: in one, the majority of participants were American male veterans who classified themselves as "intermediate" (33%) or "advanced" (64%) Internet users [29], and in the other, home care patients self-classified as "beginner" (32.7%) or "competent" (40.6%) computer users [22].

Health Status

The baseline health status of participants varied widely when it was reported. Users of the Personal Health Information Management System (PHIMS) implemented in a low-income housing facility had "limited physical and cognitive abilities"[26], with multiple chronic diseases [31]. Nursing home residents using the Intelligent Health Monitoring System were reported to be in generally poor health [21]. Participants in the ZWIP study [32] had been previously classified as "frail" along physical, psychological, and social domains, in a two-step process involving doctors and home care workers. In a rehabilitation study in primary care, participants had one or more chronic diseases [30]. However, 52% of the users of a telecare service for older adults in Taiwan reported average health, 20% good health, and only 9.5% poor health [2].

Characteristics of the Personal Health Records

Setting of Use

The PHRs were implemented in a number of different settings: in primary care [2, 28-30, 32], in long-term care [21], in home care [22, 23], and in the community [25]. Participants used the PHR in their homes (n=5) [22, 24, 28-30], in a computer room provided by a community housing facility (n=1) [25], in the hall of a nursing home (n=1) [21], or a combination of community and institutional settings (n=1) [2]. The PHRs were implemented in urban areas [2, 21, 25, 30], a combination of both rural and urban areas [24, 29], or the location was unclear [22, 23, 28].

Functions of the PHRs

All personal health records allowed users to enter their health information, including allergies, medications, appointments, laboratory test results, and demographic information. Six were linked with the patient's electronic health record or electronic medical record [21, 23, 28-30, 32]. All but one PHR (PHIMS) [25] allowed electronic communication with health care providers. Three other PHRs [21, 29, 32] also offered the option of sharing PHR access with family, friends, or other caregivers. The My HealtheVet PHR, offered by the Veterans Health Administration in the United States, gave users the ability to control who had access to view, edit, or enter information on their PHR [29]. The ZWIP (in the Netherlands) and Intelligent Health Monitoring system (Taiwan) both emphasized caregiver access as a critical element of their PHR; the former in order to facilitate shared decision-making [24], and the latter to allow for caregivers to remotely access and keep up to date with the user's health information [21]. Other reported functions of the PHRs included exercise analysis [2], home diet provision [2], environment assessment [2], social worker consultant [2], prescription renewals [29], and wellness reminders [29].

Participation Rate

The proportion of persons approached to adopt the PHR who did enroll was often quite low. Forty-four out of 330 (13%) of residents at a low-income housing facility chose to enroll in the pilot PHR system PHIMS when the system was offered free of charge [26]. However, the authors reported that this was typical of other studies, which have reported between 9.3% and 25% participation rate. Four thousand forty-seven users of the PatientSite PHR were sent email invitations to participate in a health screening survey through the PHR. Twenty-four percent completed this survey [28]. Thirty-two percent of those approached in a primary care setting agreed to participate in an online PHR self-management intervention [30]. Forty-nine percent of persons invited to use the ZWIP PHR by their health care provider because of a positive screening for frailty chose to enroll [32].

Training and Support

Five studies reported offering initial training to use the system. Three studies provided one-on-one support to participants in an institutional setting (clinic [2], housing facility [25] or nursing home [21]), and two provided in-home assistance [22, 32]. Three studies offered telephone support [28, 30, 32]. In two studies participants were provided with printed user manuals [22, 29], and in two other studies participants were also provided with optional paper-based records of their electronic PHR [26, 32].

Utilization of training and support was highly variable. Seventy-seven percent of all usage of PHIMS was during a 4-hour period each week where graduate nursing students were available to provide assistance [31], and 80% of participants required this assistance to use the PHR [31]. However, only 21.3% used the home visits offered to participants in the ZWIP study [32]. The authors attributed this result to participants being unwilling to allow a stranger into their home, or not wanting to burden the volunteer trainer [32]. Forty-three per cent of My HealtheVet users reported they received no training, with only 36% using the self-instruction materials provided, and 26% receiving instruction on use [29]. Ninety-four per cent of the users who did receive training found it helpful [29].

Level of Physical Functioning on PHR Acceptance and Use

Eight studies reported that the level of physical functioning of their participants affected use. Most of the users of the PHIMS PHR were older adults, with many participants reporting a disability and multiple chronic conditions [31]. Eighty per cent of these participants required assistance to use the PHR, and accessed the PHR only by using the computers and one-on-one support provided by the researchers [31]. This low level of independent use was attributed to a combination of technical barriers (a lack of computer and Internet access and expertise), cognitive barriers, and physical limitations [31]. A survey of these same PHIMS users found that 10 of 38 respondents reported a physical impairment of the upper extremities as a result of stroke, multiple sclerosis (MS), Parkinson disease, or arthritis [27]. These conditions caused weakness and decreased mobility that prevented independent use of the PHR [27]. Participants in this study also more frequently identified computer literacy, computer anxiety, cognitive impairment, and health literacy as barriers to use than physical impairments [27]. A small percentage of My HealtheVet users reported a physical impairment that affected their use of the PHR: 8% had problems with hearing, 7% problems with vision, and 6% problems with dexterity [29]. Characteristics of non-users of this PHR were not reported; the authors suggested that difficulties faced by non-users might be greater than these respondents who did adopt the PHR [29].The majority of elderly, community-dwelling participants in the Telecare Service Program reported average health overall with no difficulties with Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADL) [2]. However, 90% of these participants used the PHR only with weekly assistance from a visiting nurse [2]. These participants reported high distraction due to pain in a health related quality of life survey; the authors suggest that a pain relief intervention implemented through the PHR could be developed to address this [2]. Past research has found an increased use of health information technologies in persons with activity-limiting pain, suggesting that a PHR could indeed provide a more accessible route of health care delivery for these individuals than could traditional in-person care [10]. In a further study which evaluated patients' acceptance of a PHR within home care for self-management, the patients' perceived upper extremity functional abilities and visual functional status were not significantly associated with their intention to use the PHR [22]. However, this study excluded persons with low physical functioning (significant motor, sensory or cognitive disabilities, or requiring full-time home care) because they were considered to be unable to use the technology effectively enough to participate in the intervention [22]. Thus, this sample may not be representative of the functioning of a typical population of older adults. Among those enrolled, self-perceived physical abilities were rated highly [22]. For persons with lower levels of physical functioning, self-perceived physical abilities may have a greater impact on an individual's intention to start using a PHR.

The Assessment of Physical Functioning of Older Adults using the PHR

Eight studies included self-report measures of physical functioning within the PHR. Two studies described the development of a PHR tailored to the needs of older adults [23, 24]. Through consultation with health care providers, caregivers, and older adults, both studies concluded that it would be important for the PHR to collect measures of physical functioning such as neuromusculoskeletal function and pain. Six studies describe successful reporting of physical functioning via the PHR. Users of the PatientSite PHR were requested to complete a short online screening tool for untreated depression, chronic pain, and mobility difficulties [28]. The screening tool included questions about musculoskeletal pain (using the SF-36) and several questions about mobility difficulties. Older adults (≥60 years) comprised 22.1% of respondents, but 28.3% of persons who screened positive on at least one of the three conditions [28]. Another study within primary care collected self-report measures of physical functioning using the Rapid Assessment of Physical Activity (RAPA) and the Physical Functioning Inventory (PFI), a 21-item survey assessing Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADL), and mobility difficulties [30]. This information was collected through the MyOscar PHR, which could also be used by the patients to discuss the results of these assessments with their physiotherapist or occupational therapist. A telecare service provided by nurses at a “Healthy Life Management Center” within a regional hospital in Taiwan also asked users to report information about physical functioning [2]. Information about ADLs, IADL, mobility difficulties, and health related quality of life was collected. The physical domain of the quality of life measure evaluated distraction due to pain, the ability to move around well, and the ability to perform daily activities [2]. Some challenges to using the PHR to report functioning were identified. Limited experience and comfort with using technology may have deterred some participants from participating in the self-monitoring aspects of an intervention delivered through a PHR [30]. Individuals with greater computer expertise and comfort with use may be more willing and successful users of PHRs as a method of assessment of physical functioning. Additionally, although users of the PatientSite system were willing to report health status on the PHR [28], residents of the low-income housing facility where PHIMS was implemented may have been reluctant to submit information about their physical functioning in case this information was used to evaluate their ability to live independently at the facility. [27].

Discussion

The purpose of this review was to evaluate the impact of older adults' level of physical functioning on their use of a PHR and to evaluate the feasibility of a PHR as a modality to monitor the physical functioning of older adults. Only a small percentage of articles screened included an assessment or discussion of physical functioning and its relationship to PHR use. In studies that did evaluate physical functioning, independent and effective use of a personal health record was restricted by physical limitations [21, 25-27, 29]. These physical limitations pose a significant barrier to the use of PHRs by older adults, who are typically facing functional decline. These physical barriers should also be considered in the wider context of the multiple factors affecting the use of PHRs by older adults. The studies documented a lack of computer and Internet access [25, 26, 31, 32], low computer skills [22, 25, 27, 29-31], cognitive limitations [22, 24, 27], low health literacy [22, 26, 27], and security concerns [2, 27, 32] as common barriers to use. Together with physical barriers, all of these barriers could contribute to non-use or ineffective use of a PHR.

The studies included in this review represent a higher functioning sample than the general population of older adults. Older persons recruited to studies that involve the use of the PHR may have a greater interest in computers, be healthier, more educated, more "internet-savvy" [28], and more motivated [26, 29] than persons who decline involvement. These voluntary users would likely use the PHR more successfully than the general population [26]. In some cases, persons with low physical functioning were prevented from enrolling in the study entirely, as this attribute might limit a person's participation and engagement with the PHR [22]. Older persons, or persons with a disability experiencing low physical functioning, may not be able to overcome physical or other barriers to use. Self-exclusion, researcher exclusion, or actual inability to use can lead to an inequality in effective access to health care technology. As PHRs become a more frequent mode of health care delivery, this inequality in use could potentially widen health disparities between users and non-users [27, 31].

There was consensus by the authors that use of a PHR could improve the health of older adults and persons with chronic disease [2, 22-26, 29]. Use of a PHR could help to centralize older adults' health care information, which is often fragmented due to multiple care providers [24]. Caregivers could use the PHR to keep up to date with a user's health status from a distance [21], and to participate in shared decision making with the older adult and the health care provider [24].The use of PHRs has been proposed as a modality to meet the high health care needs of a global aging population [9, 24], and as a resource for use by older adults to maintain functional independence in their community [2, 24]. Tools for screening and self-monitoring delivered through PHRs have the potential to identify functional decline. There is opportunity for physical therapists to engage PHR technologies as a mode of delivery of self-management programs. However, more research is needed on whether use of a PHR for these functions leads to improved health outcomes [28, 30].

These proposed benefits rely on the system actually being used [22] and used effectively [27]. Uptake of a PHR among persons approached to participate was low [27, 31, 32]. Even among persons who participated voluntarily, frequency of use was minimal and often not maintained over the research period [25, 26, 32]. The health needs of the individual affected use; for example, one user reportedly increased usage during times when they were ill [32]. This is consistent with other research suggesting that individuals with chronic diseases and disabilities are most interested in PHR use [9] and are highly motivated to use a PHR to manage their high health care needs [7]. Although usage was minimal, 11 out of 12 survey respondents reported high satisfaction with the PHIMS PHR [25], and users of the telecare system generally believed it was beneficial for their health [2]. It is possible that participants might see the potential benefits of use, but be unable to do so due to specific barriers. Persons who are most at risk of functional decline may be the least able to use a PHR as a way of self-monitoring or self-managing physical functioning. However, as the global population ages, older persons with chronic conditions and poor functional status may remain in their homes, receiving the majority of their healthcare from primary care. PHR usage may increase the stability of the health and functional status of this patient group, and decrease the degree to which they access acute care. Therefore, more research is needed about what factors best predict uptake of successful PHR use. Theories such as the TAM and UTAUT can assist in developing a useful and testable model to explain patient use of PHRs. For example, Or et al. used the UTAUT to evaluate the multiple factors affecting uptake of a PHR for a self-management program in home care patients [22].

Overall, the place of PHRs in the health care of older adults is uncertain. To promote use in older adults, the unique physical, cognitive, and social needs of this population must be considered. Larger text sizes, higher screen contrasts, less information on each page, speech recognition, the option of a paper-based copy, one-on-one assistance to use, and extensive training and technical support should be considered. Automated data entry has been suggested [27] and appears to be effective for nursing home patients [21]. Rather than requiring input from the user, physiological monitors were connected to this PHR. Data was automatically uploaded, to be immediately available to the user, their health care provider, and their caregivers.

Future generations of older adults will be more experienced with computers and the Internet and might therefore engage more easily with a PHR. However, it is likely that there will always be a gap between the current technology and the skills of the older person. There is an important role for physical therapists to work with information technology (IT) specialists and engineers to develop approaches to simplify access for older adults. They can clarify the functional difficulties that need to be overcome and what is required from the technology to assess physical functioning.

Limitations

Studies that did not explicitly include older adults in their sample were excluded. Although this restriction was necessary in order to answer our research question, we cannot know if we excluded studies in which older adults were approached to participate, but chose not to enroll. We also limited articles to studies that examined the use of an electronic personal health record. Other types of health information technologies which may be beneficial for older adults were excluded, such as remote home monitoring of physical health [33] [34], mobile apps [35], and paper-based [36] or USB-based [37] personal health records. Although every effort was made to perform a comprehensive search, the diversity of this field of research may have resulted in our inadvertently omitting relevant articles. It is difficult to generalize conclusions drawn from these articles due to the heterogeneity of studies. Each PHR performed different functions and was implemented in a unique context, with a specific demographic of users. Using the mixed methods appraisal tool helped to address the heterogeneity of study methodologies, but an overall lack of clarity in the studies, and the current lack of randomized controlled trials made it challenging to review this emergent area of research.

Conclusions

The purpose of this article was to undertake a systematic review of the literature examining the use of personal health records by older adults. Thirteen articles were reviewed. Declining physical functioning reduced older adults' ability to use a PHR effectively. There is some evidence that a PHR can be an effective modality for monitoring the physical functioning of older adults. Acceptance of a PHR does not always lead to effective and sustained use or future health benefits. PHRs should be designed with the unique needs of older adults in mind, and adequate training and support should be provided to ensure effective use.

Conflict of Interest

Erin Macpherson, Cara Dhaliwal, and Julie Richardson have no conflict of interest to declare.

References

Papers of particular interest, published recently, have been highlighted as:

• Of Importance

•• Of major importance

1. Seeman, T.E., Merkin, S. S., Crimmins, E. M., & Karlamangla, A. S. , *Disability trends among older Americans: national health and nutrition examination surveys, 1988–1994 and 1999–2004.* American Journal of Public Health, 2010. **100**(1): p. 100.
2. Chou, C.C., et al., *Technology acceptance and quality of life of the elderly in a telecare program.* Comput Inform Nurs, 2013. **31**(7): p. 335-42.
3. Ludwick, D.A., Doucette, J. , *Adopting electronic medical records in primary care: Lessons learned from health information systems implementation experience in seven countries.* . International Journal of Medical Informatics, 2009. **78**(1): p. 22-31.
4. Czaja, S.J., Charness, N., Fisk, A. D., Hertzog, C., Nair, S. N., Rogers, W. A., & Sharit, J. , *Factors predicting the use of technology: findings from the Center for Research and Education on Aging and Technology Enhancement (CREATE).* . Psychology and aging, 2006. **21**(2): p. 333.
5. Weiner M, C.C., Tierney WM, Overhage JM, Mamlin B, Dexter PR, et al. , *Using information technology to improve the health care of older adults.* . Ann Intern Med 2003. **139**(5 (Part 2)): p. 430-436.
6. *Connecting for Health. The personal health working group final report.* . 2003, Markle Foundation.
7. Young, R., Willis, E., Cameron, G., Geana, M. , *"Willing but Unwilling": Attitudinal barriers to adoption of home-based health information technology among older adults.* Health Informatics Journal, 2013. **0**(0): p. 1-9.
8. Varnfield M, K.M., Saerelae A, Garcia E, Fairfull A, Oldenburg BF, et al. , *Uptake of a technology-assisted home-care cardiac rehabilitation program.* . Med J Aust, 2011. **194**(4): p. S15-S19.
9. * Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K.A., Straus, S.E. , *Personal Health records: A scoping review.* . Journal of the American Medical Informatics Association,, 2011. **18**: p. 515-522.

This review provides an informative overview of the definitions, functions, uses, proposed benefits, and barriers, of PHRs.

10. Gell NM, R.D., Demiris, G., LaCroix, A.Z., Patel KV. , *Patterns of Technology Use Among Older Adults With and Without Disabilities.* The Gerontologist 2012
11. Tang, P.C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z., *Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption.* Journal of the American Medical Informatics Association,, 2006. **13**(2): p. 121-126.
12. Nagle, S., & Schmidt, L. , *Computer acceptance of older adults.* Work,, 2012. **41(Suppl 1)**: p. 3541-3548.
13. Chun, Y.J., & Patterson, P. E. , *A usability gap between older adults and younger adults on interface design of an internet-based telemedicine system.* Work, 2012. **41(Suppl 1)**: p. 349-52.

14. Taylor, M.J., Stables, R., Matata, B, Lisboa, P.J.G., Laws, A., Almond, P. , *Website design: Technical, social and medical issues for self-reporting by elderly patients.* Health Informatics Journal, 2013. **0**(0): p. 1-15.
15. Or., C., Karsh, B., *A Systematic Review of Patient Acceptance of Consumer Health Information Technology*. J Am Med Inform Assoc, 2009. **16**: p. 550-560.
16. * Stellefson, M., Chaney, B., Barry, A.E., Chavarria, E., Tennant, B., Walsh-Childers, K., Sriram, P.S., Zagora, J., *Web 2.0 Chronic Disease Self-Management for Older Adults: Systematic Review.* Journal of Medical Internet Research, 2013. **15**(2): p. e35 1.

This paper evaluates the implementation and use of "Web 2.0" informtion technologies for chronic disease self-management in adults aged 50 or greater.

17. Bonder, B.R., Dal Bello Haas, V., *Functional Performance in Older Adults*. Third Edition ed. 2009, Philadelphia: F.A. Davis Company.
18. * Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P., & Rousseau, M.C., 2011. *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews.*

This paper gives an overview of the Mixed Methods Appraisal Tool, providing guidelines for the use of the tool and the criteria for assessment.

19. Pace, R., Pluye, P., Bartlett, G., Macaulay, A. C., Salsberg, J., Jagosh, J., & Seller, R. , *Testing the reliability and efficiency of the pilot mixed methods appraisal tool (MMAT) for systematic mixed studies review.* International journal of nursing studies, 2012. **49**(1): p. 47-53.
20. Crowe, M., & Sheppard, L., *A review of critical appraisal tools show they lack rigor: alternative tool structure is proposed.* . Journal of Clinical Epidemiology, 2011. **64**(1): p. 79-89.
21. Tseng, K., Hsu, C., & Chuang, Y, *Designing an intelligent health monitoring system and exploring user acceptance for the elderly.* . Journal of Medical Systems, 2013. **37**(6): p. 1-18.
22. * Or, C.K., Karsh, B. T., Severtson, D. J., Burke, L. J., Brown, R. L., & Brennan, P. F. 2011. *Factors affecting home care patients' acceptance of a web-based interactive self-management technology.* . Journal of the American Medical Informatics Association. **18**(1): p. 51-59.

This study provides an example of application of the Unified Theory of Acceptance and Use of Technology (UTAUT) to the uptake of a PHR for self-mangement.

23. Monsen, K.A., Westra, B. L., Paitich, N., Ekstrom, D., Mehle, S. C., Kaeding, M., et al. *Developing a personal health record for community-dwelling older adults and clinicians: Technology and content.* . Journal of Gerontological Nursing, 2012. **38**(7): p. 21-25.
24. Robben, S.H., Huisjes, M., van Achterberg, T., Zuidema, S. U., Olde Rikkert, M. G., Schers, H. J., et al. , *Filling the gaps in a fragmented health care system: Development of the health and welfare information portal (ZWIP).* . JMIR Research Protocols, 2012. **1**(2): p. e10.
25. Kim, E., Mayani, A., Modi, S., Kim, Y., & Soh, C. , *Evaluation of patient-centered electronic health record to overcome digital divide.* . Conference Proceedings:Annual International Conference of the IEEE Engineering in Medicine & Biology Society, 2005. **2**: p. 1091-1094.

26. Kim, E., Stolyar, A., Lober, W. B., Herbaugh, A. L., Shinstrom, S. E., Zierler, B. K., et al. , *Challenges to using an electronic personal health record by a low-income elderly population.* Journal of Medical Internet Research, 2009. **11**(4): p. 1-9.
27. Lober, W.B., Zierler, B., Herbaugh, A., Shinstrom, S. E., Stolyar, A., Kim, E. H., et al. , *Barriers to the use of a personal health record by an elderly population.* . AMIA Annual Symposium Proceedings/AMIA Symposium, 2006: p. 514-518.
28. Leveille, S.G., Huang, A., Tsai, S. B., Weingart, S. N., & Iezzoni, L. I. , *Screening for chronic conditions using a patient internet portal: Recruitment for an internet-based primary care intervention.* Journal of General Internal Medicine, 2008. **23**(4): p. 472-475.
29. Nazi, K.M., Hogan, T. P., McInnes, D. K., Woods, S. S., & Graham, G. , *Evaluating patient access to electronic health records: Results from a survey of veterans.* . Medical Care, , 2013. **51**(3 (Suppl 1)): p. 552-6.
30. Richardson, J., Letts, L., Chan, D., Officer, A., Wojkowski, S., Oliver, D., et al. , *Monitoring physical functioning as the sixth vital sign: Evaluating patient and practice engagement in chronic illness care in a primary care setting--a quasi-experimental design.* BMC Family Practice , 2012. **13**(1): p. 29.
31. Kim, E.H., & Kim, Y. , *Digital divide: Use of electronic personal health record by different population groups.* . Conference Proceedings: Annual International Conference of the IEEE Engineering in Medicine & Biology Society, 2010, 2010: p. 1759-1762.
32. Robben, S.H., Perry, M., Huisjes, M., van Nieuwenhuijzen, L., Schers, H. J., van Weel, C., et al. , *Implementation of an innovative web-based conference table for community-dwelling frail older people, their informal caregivers and professionals: A process evaluation.* BMC Health Services Research,, 2012. **12**: p. 251.
33. Liddy, C., Dusseault, J. J., Dahrouge, S., Hogg, W., Lemelin, J., & Humber, J. (2008). Telehomecare for patients with multiple chronic illnesses Pilot study. Canadian Family Physician, 54(1), 58-65., *Telehomecare for patients with multiple chronic illnesses Pilot study.* Canadian Family Physician, 2008. **54**(1): p. 58-65.
34. Chiu, K.H., & Yang, Y. Y. , *Remote monitoring of health status of the elderly at home in Taiwan.* . Telemedicine and e-Health, 2010. **16**(6): p. 717-726.
35. Xue, L., Yen, C. C., Chang, L., Chan, H. C., Tai, B. C., Tan, S. B., ... & Choolani, M., *An exploratory study of ageing women's perception on access to health informatics via a mobile phone-based intervention.* . International journal of medical informatics, 2012. **81**(9): p. 637-648.
36. Weinert, C., Cudney, S., & Kinion, E., *Development of My Health Companion© to Enhance Self-Care Management of Chronic Health Conditions in Rural Dwellers.* Public Health Nursing, 2010. **27**(3): p. 263-269.
37. Heise, B., Asche, C., & Oderda, L., *RAISE (Rapid Access Integrating Safer Entry) for the Elderly: Readiness of Older Adults to Adopt a Universal Serial Bus Personal Health Record for Medication Reconciliation.* Ageing International, 2011. **36**(2): p. 295-302.

Chapter 3: Evaluating the Usability of a Web-Based Personal Health Record by Older Adults

1. Background and Purpose

Web-based Personal Health Records (PHRs) are a promising health information technology that can be used to manage personal health information, communicate with health care providers, and provide access to reliable health information. A broad definition of a PHR is: "*An electronic application through which individuals can access, manage and share their health information and that of others for whom they are authorized, in a private, secure, and confidential environment*" [1] A recent review found that the benefits of online PHR use among adults aged ≥45 years included: improved access to and management of one's health care data, improved communication with health care providers, improved self-management of chronic disease, and increased positive health care behaviours [2].

Due to their high rates of chronic conditions [3], disability [4], and challenges with everyday functioning and mobility [4], older adults might be a segment of the population most likely to benefit from the use of a PHR [5], and might have the most motivation to start using a PHR for health purposes [6]. For example, in one study, adults with activity-limiting pain and breathing limitations were more likely to adopt technology for health purposes [5]. The authors hypothesized that using the Internet for health purposes made communication and other health-related tasks easier and more accessible [5]. The use of information technologies could help manage the high complexity of health care needs and the fragmentation of care that many older adults experience [7]. Personal health records may allow older adults facing mobility limitations to maintain an active, independent role in their health care from home [8,9]. It was also proposed that PHR use could improve collaboration between a patient and their caregiver [9]. Web-based health applications such as PHRs are a promising technology for the delivery of self-management programs, with potentially higher adherence to web-based programs than traditional in-person programs [10]. Using a PHR to access preventative and rehabilitative programs could be an important tool in managing the high prevalence of disability and chronic conditions among older adults.

However, uptake of PHRs to date has been low [6]. General barriers to use include lack of access to computers and the Internet, lack of technology expertise, cost, privacy/security concerns, low health literacy, and a preference for traditional modes of health care delivery [6]. These barriers can be real or perceived [6]. Persons with a disability or a chronic disease are most highly motivated to use a PHR, but this interest does not necessarily lead to actual use [6]. Older adults face additional barriers, experiencing declines in upper extremity mobility, visual acuity, hearing, and short-term memory as they age [11]. They also tend to have less technological expertise, higher computer anxiety, and less access to computers than do younger adults [12].

Research on the use of web-based PHRs has focused mainly on outcomes, such as hospital readmission rates or patient mortality, rather than evaluating the use of the system from the user's perspective [13, 14]. Usability testing is a research method that focuses on the process of technology usage. This research approach is essential to the design of effective interactive health care technologies [15], but there is a current lack of understanding of optimal usability [6,16]. In usability testing, target users participate in the evaluation of a system [17]. This evaluation identifies the specific factors affecting successful or unsuccessful use, including characteristics of the technology interface and personal characteristics of the user, such as psychomotor skills [16]. There have been usability differences identified between older and younger adults in the use of an online site for health purposes [18]. However, research on how physical and cognitive limitations affects the usability of web interfaces for health has been limited [11,18,19]. This exploratory, descriptive study will evaluate the usability of the McMaster PHR (myoscar.org) by older adults. Given the potential benefits of web-based PHRs, and their increasing interest within the health care system [6}, it is important to evaluate their use in a clinical setting. This study used the “Think Aloud” Method, a common type of cognitive interviewing, to explore how these older adults use this PHR for this particular function.

2. Methods

2.1 Participants

Participants were recruited from persons currently enrolled in an ongoing study involving a clinical cohort of persons with chronic conditions. These patients use an online PHR to monitor their physical functioning over an 18-month period at a Family Health Centre in Hamilton, Ontario. Participants were ≥ 44 years with at least one chronic condition. The inclusion criteria for the primary study are in Appendix 1. Individuals were purposively selected for the current study if they were ≥60 years, and they were due to complete their Time 3 assessment online (i.e. approximately six months from baseline). Participants were selected by the primary study coordinator to satisfy the desired range of computer expertise. Using previously suggested categories [20], participants were rated by clinicians based on a single PHR training session using a laptop computer as a "non-user", "beginner user", or "familiar user. A range of these expertise levels was included in the study.

2.2 Setting

Sessions were completed in a quiet room in a primary care clinic. Participants used a Lenovo Thinkpad T430s laptop computer with a mouse to complete the tasks. Sessions were audio and video recorded, and later fully transcribed. An investigator (EM) took handwritten notes of any observations. The Hamilton Integrated Research Ethics Board (Project Number 14-462) approved the study.

2.3 The Think Aloud Method

The Think Aloud method is the most frequently used usability test in health care research [15]. Participants are asked to verbalize their actions and thoughts as they complete tasks using the technology being tested [21]. The participants are selected as representative users of the technology [15], and tasks are chosen to be realistic and reflective of actual use [15]. If participants are representative of the real system users, it has been suggested that a sample size of 8-12 persons is sufficient to detect 80% of usability problems; however, 12-15 participants would be needed to perform inferential statistics [22].

2.3 Tasks

Participants were instructed to verbalize their thoughts and actions as they completed five tasks using the McMaster PHR. The interviewer demonstrated an example task for the participant before they were asked to begin. Participants were prompted to continue talking if they fell silent for more than 10-15 seconds. Tasks most frequently undertaken by participants as part of their participation in the primary study using the McMaster PHR were selected. These tasks were:

1) Logging onto their account using a username and password they had been provided at the start of study participation;
2) Accessing their message inbox, and sending a “test” message;
3) Accessing a document containing the tailored recommendations from their physiotherapist or occupational therapist;
4) Completing the Preclinical Mobility Scale on the PHR. Participants were asked to rate their ability within the past six months to walk 2.5 km. and 0.5 km., and climb a set of stairs;
5) Completing the Rapid Assessment of Physical Functioning (RAPA) on the PHR. The RAPA is a nine-item, self-report questionnaire used to assess strength, flexibility, and frequency and intensity of physical activity among older adults (>50 years) [23].

Although the investigator tried to let the participant complete the task independently, help was provided if the participant was unsure of how to proceed, or became frustrated. This is consistent with recommendations [24] that the researcher should act as a listener, encouraging the participant’s communication, while still intervening when necessary to continue the session. Transcripts were analyzed using a conventional content analysis. The goal of this type of qualitative analysis is to develop a richer, subjective understanding of the phenomenon of study [25]. Transcripts were read in their entirety, with explicit and inferred communication systematically coded for themes or patterns. Two researchers (EM, JR) first coded two interviews independently, then decided together on an initial set of codes. The primary investigator (EM) then analyzed the rest of the interviews, refining the coding scheme as additional codes were developed.

2.4 Pre/Post Task Surveys

A short survey was given at the start of the session, asking the participants about their use of computers and the Internet, including computer ownership, Internet usage, and opinions towards using a PHR within their health care. Following the Think Aloud session, participants were asked about their experiences with the tasks, and their opinion on the use of the McMaster PHR. These surveys were analyzed to provide participant demographic information and for important themes. The interview questions are included as Appendix 2.

2.5 UTAUT Survey

The participants also completed a survey adapted from the Unified Theory of the Acceptance and Use of Technology (UTAUT) [26]. The UTAUT merges eight existing theories explaining behavioural intention to use a technology into one unified theory. It identifies the following components as the key determinants of technology adoption: 1) *facilitating conditions*, 2) *social support*, 3) *performance expectancy*, and 4) *effort expectancy*. Age, gender, technological expertise, and voluntariness of use as important moderators. The investigator adapted the original UTAUT survey to examine the use of the McMaster PHR for this current study. Computer anxiety was added as an additional construct, given it has been frequently noted as being high in older adults [6,8,11]. A question asking whether participants had used the PHR “as much as they should” was used as a self-reported measure of effective use [27]. Participants were asked to rate their agreement from 1 (strongly disagree) to 5 (strongly agree) for each of the statements. The UTAUT survey questions are included in Appendix 3.

3. Results

3.1 Participant Characteristics

A sample of twelve older adults completed the study. Their ages ranged from 61-90 years, with a mean age of 71.5 years. Their experience with computers ranged from no current computer usage to highly frequent use for work (n=1) or volunteer (n=1) purposes. All but one person had access to a desktop computer at home, and several also mentioned having tablets (n=4), e-readers (n=1), or smartphones (n=2). All the participants had Internet access at home, and all but one person accessed the Internet on a daily basis. Three out of the twelve participants reported a physical limitation that might affect their ability to use a computer independently: macular degeneration (1), hand tremor (1), and stroke leading to visual and cognitive limitations (1).

3.2 Task Completion

All participants required some assistance to complete one or more of the tasks. This was most often guidance on where to click next, or clarification of a survey question. Due to visual limitations, one participant required the interviewer to complete all the tasks for them. The biggest challenge for most participants was finding and starting the surveys- once they initiated the tasks, most participants found them relatively easy to complete. Several participants commented that the wording of some of the questions on the surveys could have been clearer, so participants knew how to respond appropriately to the content of the survey questions. Many participants also found exiting the survey to be confusing and unclear, as they were required to press "next" rather than "save and close" to correctly save and exit the survey. A summary of task completion rates is provided in Figure 1. A detailed table of task completion characteristics is provided as Appendix 4.

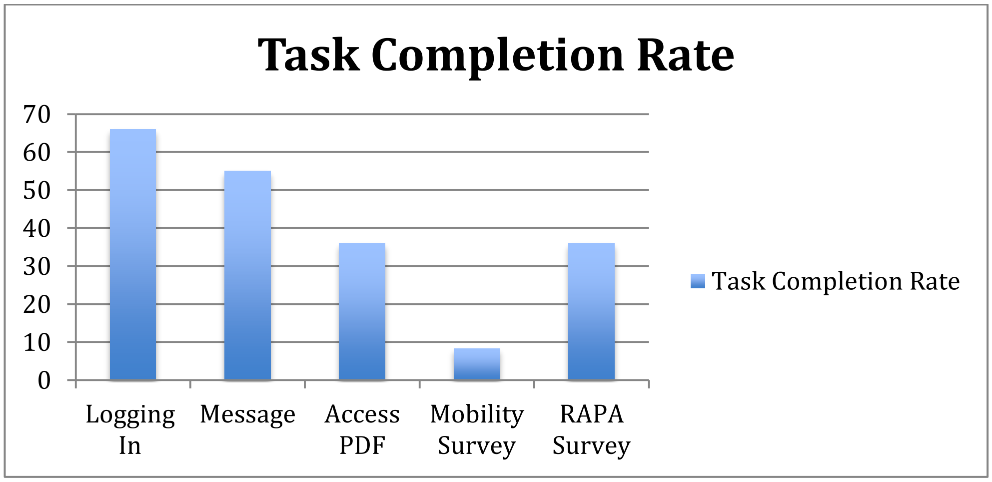

Figure 1. Percentage of Participants who could independently complete the tasks.

3.3 Major Themes

Seven major themes were identified from the qualitative analysis of the transcribed interview sessions. Each of the themes is described below.

3.31 Varied Use of the Internet for Health Purposes

Participants were frequent and long-time users of computers and the Internet for various tasks, including email, database searching, online banking, online shopping, Facebook, and Pinterest**.** Participants reported using the computer "every chance they get" and probably "too often." However, only three participants reported regularly using the Internet to access health information (such as checking symptoms), and four others did so very occasionally. They expressed a preference for obtaining health information from a known, reliable source, particularly their primary care physician: "*I have a bit of a distrust looking for stuff online, especially medical stuff.*" None had used the McMaster PHR (or another PHR) in any capacity except to fill out the surveys as part of the primary study.

3.32 Limited Use of the McMaster PHR

Many participants had not completed the surveys at the appropriate time point in the primary study, noting forgetting, a lack of time, and not knowing how to use the PHR as reasons. When asked if they use the PHR "as much as they should," the most common response was "disagree." *"I see that there could be a potential with it, but I'm not particularly using it."* Many participants commented that they had a lack of familiarity with the program, because of the limited and infrequent use. There is a six-month gap between the time when participants first complete the set of surveys, and when they are asked to log in to complete the surveys again: "*I haven't been into (the PHR) for six months. You want me to remember something?"*

3.33 Lack of Knowledge about the Functions and Scope of the McMaster PHR

The majority of participants had a very limited understanding of what a PHR was, and the possible functions of the McMaster PHR (e.g. to record their medications and immunizations, or to message their doctor). *"I haven't used it much. The only thing I use it for is to answer these surveys. I don't use it for anything else. I don't know what else there is on it."* Another participant commented that they *"didn't even know it could be used for something else."* Participants seemed interested in learning more about the possible functions of the PHR, and how they could begin to use it to a greater extent.

3.34 Discrepancy between Perception of Task Ease and Actual Performance

In general, tasks were rated as being fairly easy to complete; however, all participants needed some assistance to complete them. The participants were assisted quite quickly if they were struggling with a task. If they had been at home they might have taken more time to problemsolve through the task: *"But at home, if I had to do this, I would probably play around and push buttons till I got somewhere …I would probably get there in the end."*

3.35 Variability in Perceived Benefit

When asked if they planned to continue using the PHR for the rest of the study, the average response was overwhelmingly affirmative. However participants reported they were less certain about participating in another research study using the same PHR as its mode of delivery. Three persons said that they would use it; one person said they would not, and the remaining eight respondents were unsure. Participants did see the role of a PHR in health care as an emerging trend; however, several participants did not see the need for them personally to use it: *"…if it was, you know, a member of my family, and they were not well, and you know, you want to keep track of things- I could see that. But for me I don't think so."* One participant noted that because they view themselves as currently healthy, they do not see the need for regular monitoring of their health at all: *"…I don't have anything to track right now (…) at the moment, it's kind of like, it's nice, but gosh, what do I need it for."* Four said they would require more information about the PHR and what it would be used for if they were to continue using it. One expressed concern about the privacy of the PHR. One participant particularly liked that the study was proactively trying to maintain and improve the level of physical functioning for older persons, and were enthusiastic about receiving individualized advice on how to do so: *"I realize I can't do what I used to do, but I truly think I can do more than what I'm doing. But, I need help- exercises or something, to strengthen."* However, although this individual was eager to receive recommendations, they had not accessed any of the documents sent to them by their physiotherapist though the PHR, even though they were available to them.

3.36 Availability of Family and Caregiver Support

Ten out of 12 respondents reported having family, friends, or caregivers who would be able to help them to use the PHR. Most often this was the participant's spouse or children. One person brought her husband to the interview session, and he provided support with answering the survey questions. Another participant's son uses the PHR for her, because of her visual limitations and lack of ability to use a computer. However, she reported that although she *"… can ask (him) lots of questions (…) he's a very busy person and I don't like to keep bugging him."*

3.37 Lack of Computer Confidence

Even though only a few participants reported having high computer anxiety, many of the participants exhibited a lack of confidence in using a computer (e.g., with knowing if they had properly clicked a link or knowing what to do if the program froze). A couple of participants worried they might accidentally hit the wrong button and making an uncorrectable mistake: *"I could delete everything, couldn't I. Now that's a scary thought."* One participant commented that computers "*…have a mind of their own (...) the last time we went on, we had trouble, it wasn't listening."* Some participants were unwilling to proceed if they were unsure of how to, but others noted that they would "*play around and push buttons till I got somewhere."*

3.4 UTAUT Survey Results

The mean scores from all participants are included in Table 1. See Appendix 3 for a breakdown of scores for each question within the constructs.

UTAUT Constructs	Mean Score (Scale of 1-5) (Standard Deviation)
PERFORMANCE EXPECTANCY	3.00 (1.24)
EFFORT EXPECTANCY	3.28 (1.07)
SOCIAL INFLUENCE	3.23(0.75)
FACILITATING CONDITIONS	4.06 (0.76)
COMPUTER ANXIETY	2.48 (1.58)
BEHAVIOURAL INTENTION TO USE	4.11 (0.43)
SELF-REPORTED EFFECTIVE USE	2.75 (1.36)

Table 1. Summary of UTAUT Survey Responses

4. Discussion

This study evaluated the usability of an online PHR by older adults involved in a research study using the PHR as a means of self-monitoring one's physical functioning. The study identified several common usability issues with the PHR interface and content, but overall found that participants were interested in using a PHR to manage their health, and had access to computers and the Internet to do so. As the health care system increasingly adopts the use of PHRs, it is important for studies to investigate how technology users within trial interventions such as these interact with the technology. Older adults have a high incidence of chronic disease and disability, and therefore monitoring of physical functioning might be especially useful for this age group. Understanding the additional challenges they may encounter when using an online technology is important. This study sought to understand the experience of older adults' use of the McMaster PHR during their participation in a self-monitoring intervention study.

Overall, participants were largely able to complete the tasks, but most participants required at least some direction from the investigator to do so. In their interview responses, participants reported more confidence in their ability to successfully use the PHR than the task completion rates show. This discrepancy is consistent with another study's findings [14]. During the study session, the majority of participants tended to be very unsure of how to proceed during at least part of the session, frequently asking for clarification. However, when they were at home using a familiar computer, participants might have found it easier to progress through the tasks on their own by using trial and error. Nahm (2004) [19] reported that older adults completing a similar "Think Aloud" session also tended to "freeze" when unsure of how to complete a task, and were unwilling to attempt to perform a task independently, frequently requiring assistance from the investigator. This could be in part due to anxiety from being observed in a research environment. However, in general, older adults do need more help to learn how to use a new technology, and this need increases with age [12]. A previous study comparing the use of an Internet-based telemedicine system by older (mean age of 61 years) versus younger adults (mean age of 27 years) found that the older adults required more time to complete the tasks, were more unsure of how to proceed to the next task, and assigned more self-blame when they could not complete the tasks [18]. Older adults may have a fear of inconveniencing others to request help in using or learning to use a technology and may be reticent to learn from younger generations [28]. They may anticipate that their age or health status is not optimal to engage with this technology, especially as it related to preventive approaches to health.

An interactive health care information technology needs to be designed to be usable for a specific population [27]. Any challenges in navigation or execution of tasks that are experienced in the general population are magnified when used by older adults, who face additional barriers to use [27]. For example, many participants in this study noted that the on-screen text was difficult to read. Having larger font sizes and more space between lines would make this site more accessible to these users [19]. Cognitive limitations and low health literacy often faced by older adults could be addressed by providing a glossary of health-related terms [18]. More explanation of what the survey questions were asking (e.g. clear definitions of light, moderate, and vigorous physical activities on the survey page) would help the participants in this study complete the surveys accurately and independently at home. Having these definitions of terms used in the surveys available on each page might decrease a participant's uncertainty in answering questions, and increase the accuracy of survey responses. Older adults generally find it challenging to infer the next correct step in using a technology, spending more time on each web page to ensure their next click is the right one [18]. Older adults also tend to find it particularly challenging when there are multiple steps required to complete a task [20]. For example, in this study, participants found accessing their tailored recommendations from their therapist as a Portable Document Format (PDF) file particularly challenging, as the task involved navigating through several pages. If these recommendations were more easily accessible, ideally participants would access them more frequently. Accessing surveys via drop-down menus was a major problem for these participants, as it has been for other older adults in previous studies as well [20]. Simplification of navigation, by avoiding multiple drop-down menus, will help users interact with the system more easily and may increase rates of survey completion.

Future research should evaluate how caregivers who provide technical support might influence patient responses [20]. Older adults might receive more help from a family member or other caregiver to complete these surveys when completing online rather than on paper [20]**.** It is important to consider how a caregiver might guide responses or otherwise influence the patient's responses [20]. Nonetheless, the use of a PHR with the help of another individual is a key way of engaging older adults who might not be able or willing to access the PHR independently. A caregiver could also assume control of the PHR completely in the case of the patient who is not able to access it himself or herself. Participants in this study seemed largely willing to share their PHR access with a caregiver, provided it was medically necessary, and access was to an immediate family member only.

Participants who are likely to derive the most benefit from being enrolled in a program such as this are individuals who might be least likely to actually participate. The study's inclusion criteria required access to a computer and the Internet, and a working email address. Many older adults do not have a computer or the required skill level to be enrolled in this study. Persons who chose to participate in the primary study likely had a relatively high level of computer expertise and a high willingness to use the computer and the Internet, compared to a general population of older adults. Persons with more severe cognitive and/or physical limitations would also be excluded. Several participants commented on this disparity: *"I like that you're using the computer, but I don't think it would be applicable to a lot of people my age, who don't touch a computer, ever."* At 90 years, the oldest participant interviewed no longer had a working computer, and considered dropping out of the study for this reason, despite being highly enthusiastic about improving their physical functioning through participation in the study. She was able to remain in the study because her son offered the participant both access to his computer and assistance in completing the tasks. The study coordinator has also provided in-home assistance to them in the past. A study examining the use of an online PHR by older adults with high rates of disability found that participants reported a substantial benefit from the PHR, but their ability to use it restricted their access [11]. Use was facilitated by one-on-one assistance from a nurse who periodically visited the participants' place of residence [11]. Supports such as these should be routinely offered to participants to ensure equal access to these programs. Cost could also act a barrier to PHR usage that could increase health disparities between high and low-income individuals. Low-income individuals use a computer and the Internet less, and are less likely to access self-management programs [28]. It will be important to ensure that PHR usage is accessible to all, so as to not reinforce or increase these health disparities.

We see a cohort effect with the use of computers and the Internet: older generations have been less likely to adopt this technology [8,11]. One of the participants (aged 90) commented, *"we* *were never brought up with computers, and when you get older, and you try to learn all that, just, just forget it."* However, recent polls of older adults have found that they are willing to use technology in their lives [29], especially computers and mobile phones. Another of the participants (aged 66) recognized *"Digital is becoming the new printed word".* Younger generations of older adults might be more willing to incorporate new technologies into their health care**.** Older adults will still face age-related challenges but will have more existing technology expertise [8], which could make it easier for them to use a PHR effectively. It will be important to ensure that with this increased usability, older adults actually do use the technology, and that this use translates into improved health outcomes.

4.1 Limitations

Several limitations of this study should be noted. There was a range of ages and computer abilities among participants, and all were reasonably communicative. However, the web-based nature of the primary study may have selectively recruited older adults who are more able and willing to use a computer than the general population of older adults. Although the investigators tried to sample a range of functional levels, the sample was biased towards higher functioning individuals. Usability results are only specific to the use of this particular technology for these particular tasks. The sessions were completed at a clinic, rather than the participant's home on their own computer, where they would typically be using the PHR. Several participants noted that the computer display was different at the clinic than on their home computer, and this difference may have affected their ability to complete the tasks comfortably. Future studies might conduct usability tests in more naturalistic settings. "In the field" usability studies will give additional insight into the barriers and facilitators to use in a realistic context [16].

References

1. Markle, F. *The personal health working group final report*. 2003.
2. Kim, K., Nahm E. Benefits of and barriers to the use of personal health records (PHR) for health management among adults. *Online Journal of Nursing Informatics (OJNI).* 2012. **16**(3).
3. Chou, C.-C., et al. Technology Acceptance and Quality of Life of the Elderly in a Telecare Program. *Computers Informatics Nursing*, 2013. **31**(7): p. 335-342.
4. Seeman T. Disability trends among older Americans: national health and nutrition examination surveys, 1988, 1994 and 1999 and 2004. *Am J Public Health*, 2010. **100(1)**(100).
5. Gell, N.M., et al., *Patterns of Technology Use Among Older Adults With and Without Disabilities. The Gerontologist*, 2012.
6. Archer, N.F et al., Personal Health Records: a scoping review. *Journal of the American Medical Informatics Association*, 2011. **18**: p. 515-522.
7. Weiner, M., et al., Using information technology to improve the health care of older adults*. Annals of Internal Medicine*, 2003. **139**(5_Part_2): p. 430-436
8. Czaja, S.J., et al., Factors predicting the use of technology: findings from the Center for Research and Education on Aging and Technology Enhancement (CREATE*). Psychology and aging*, 2006. **21**(2): p. 333.
9. Tang, P.C., et al., Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*, 2006. **13**(2): p. 121-126.
10. Varnfield, M., et al., Uptake of a technology-assisted home-care cardiac rehabilitation program*. Medical Journal of Australia*, 2011. **194**(4): p. S15-S19.
11. Lober, W.B., et al., Barriers to the use of a personal health record by an elderly population*. AMIA Annu Symp Proc*;, 2006. **1**: p. 514-518
12. Nagle, S. and L. Schmidt, Computer acceptance of older adults. *Work*, 2012. **41**(Suppl 1): p. 3541-3548.

13. Fonda, S.J., et al., Usability test of an Internet-based informatics tool for diabetes care providers: The comprehensive diabetes management program. *Diabetes Technology & Therapeutics*, 2008. **10**(1): p. 16-24.

14. Segall, N., et al., Usability evaluation of a personal health record. *AMIA Annual Symposium proceedings, AMIA Symposium*, 2011. **2011:** p. 1233-1242.

15. Jaspers, M.W.M. A comparison of usability methods for testing interactive health technologies: methodological aspects and empirical evidence. *International journal of medical informatics*, 2009. **78**(5): p. 340-353.

16. Kaufman, D, Starren, J., Usability in the real world: assessing medical information technologies in patients.. *Journal of biomedical informatics*, 2003. **36**(1): p. 45-60.

17. Corry, M.D., Hansen, L.User-centered design and usability testing of a web site: An illustrative case study. *Educational Technology Research and Development*, 1997. **45**(4): p. 65-76.

18. Chun, Y.J., Patterson, P.E. A usability gap between older adults and younger adults on interface design of an internet-based telemedicine system. *Work*, 2012. **41**(Suppl 1): p. 349-52.

19. Nahm, E., et al., Usability of Health Web Sites for Older Adults: A Preliminary Study. CIN: *Computers, Informatics, Nursing*, 2004. **22**(6): p. 326-334.

20. Taylor, M.J., et al., Website design: Technical, social and medical issues for self-reporting by elderly patients. *Health informatics journal*, 2013.

21. Hanington, M.B.B., Hanington, B.M., Universal methods of design: 100 ways to research complex problems, develop innovative ideas, and design effective solutions. 2012, Osceola, WI.: Rockport Publishers.

22. Kushniruk, A.W., Patel, V.L., Cognitive and usability engineering methods for the evaluation of clinical information systems. *Journal of Biomedical Informatics*, 2004. **37**(1): p. 56-76.

23. Topolski, T.D., et al., The Rapid Assessment of Physical Activity (RAPA) among older adults. *Preventing chronic disease*, 2006. **3**(4): p. A118.

24. Boren, T., Ramey J., Thinking aloud: reconciling theory and practice. *Professional Communication, IEEE Transactions on*, 2000. **43**(3): p. 261-278.

25. Hsieh, H.F., Shannon, S.E. Three approaches to qualitative content analysis. *Qualitative health research*. 2005, 15 (9): 1277-1288.
26. Venkatesh, V., et al., User Acceptance of Information Technology: Toward a Unified View. *MIS Quarterly*, 2003. **27**(3): p. 425-478.
27. Or C, et al. Factors affecting home care patients' acceptance of a web-based interactive self-management technology. J Am Med Inform Assoc., 2011. **18**(1): p. 51-9.
28. Health Council of Canada. (2012). Self-management support for Canadians with chronic health conditions: A focus for primary health care. http://healthcouncilcanada.ca/rpt_det.php?id=372#sthash.fzLgQwSq.dpuf
29. Chen, K. and A.H.-s. Chan, *Use or Non-Use of Gerontechnology-A Qualitative Study*. International Journal of Environmental Research and Public Health, 2013. **10**(10): p. 4645-4666.

Appendix 1. Primary Study Inclusion and Exclusion Criteria

Inclusion Criteria:

- Persons ≥44 years
- Able to communicate in English
- Have one or more chronic conditions. The ICD-9 billing codes for these chronic diseases will be used to select the sample: rheumatoid arthritis, back pain, cardiac arrest, heart failure, chronic obstructive pulmonary disease, stroke, diabetes, emphysema, hypertension, low back pain, multiple sclerosis, osteoarthritis, osteoporosis, Parkinson's disease, and cerebral vascular accident
- Have had at least 3 physician visits in the past year
- Are able or willing to access an email address.

We will recruit approximately 33 patients from three defined stages of functional ability. The levels of functioning are:
(1) No difficulty in physical functioning but the patient has made modifications to the tasks they complete or have changed the frequency with which they complete these tasks;
(2) Early changes or difficulty in physical functioning;
(3) Established difficulty in physical functioning, experiencing significant or longstanding difficulties with physical functioning, mobility or activities of daily living. (Fried, 1996). The Research Coordinator, a physiotherapist, will review each patient's Electronic Medical Record (EMR), and assign a physical functioning rating based on the patient's age, number and type(s) of chronic condition(s), duration of chronic conditions, work status, disability insurance, mobility status, activities of daily living, use of gait aids, recent surgeries and hospitalizations, use of a ty parking pass, falls, Worker Safety and Insurance Board claims, level of physical activity and smoking. The patient's physician will be consulted about the assigned rating and if there is a disagreement will adopt the physician's rating.

Exclusion Criteria:

- Notation in the EMR about a diagnosis of dementia or cognitive impairment.
- The Research Coordinator will also ask eligible participants the following three questions to establish whether they are sufficiently computer literate to participate:
  (1) Do you have access to a computer in your home?
  (2) Do you have an email address that you access?
  (3) Are you able to access your email independently?

Appendix 2. Interview Questions

Pre-Task Interview

1. How would you rate your overall level of computer expertise?

   (non-user, a beginner user, a familiar user)

2. How often do you use a computer?
3. How often do you use the Internet?
4. Do you have a computer (desktop, laptop, or tablet) at home?
5. Do you have Internet access at home?
6. What tasks do you perform using the Internet?

   ☐Email

   ☐Online Banking

   ☐Google or other database search

   ☐Online shopping

   ☐Health information searching

   ☐Personal health record

7. What was your experience, with using myOSCAR before your participation in the "Detecting Preclinical Disability" Study?
8. Is there someone (a spouse, child, friend, other family member) who would be able to help you with using a computer?
9. How willing would you be to provide family, friends, or other caregivers access to your PHR?
10. Do you have any physical limitations that might prevent you from using a technology such as a personal health record (e.g. visual impairments, cognitive impairments, and mobility difficulties)?
11. How willing are you to use an online personal health record system as part of your health care in the future?

Post-Task Interview

How easy did you find these tasks on a scale from 1 to 10, with 1 being easiest and 10 being the most challenging?

What did you like about the myOSCAR system?

What did you not like about the myOSCAR system?

Do you have any suggestions for improvement for MyOscar?

Could you have been better prepared to use myOSCAR as part of the "Detecting Preclinical Disability" Study?

Appendix 3. UTAUT survey (Participants' mean responses are included, with standard deviation in brackets

Please rate your agreement with each of the following statements regarding your use of the McMaster PHR.

1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree
○	○	○	○	○

PERFORMANCE EXPECTANCY:	*To what extent does the individual believe that use of the technology will lead to improved health*

PE1	I find the system useful for managing my health **2.58** (1.38)
PE2	Using the system gives me better access to the health care system **2.92** (1.24)
PE3	Using the system is helpful for my health **3.42** (1.56)

EFFORT EXPECTANCY:	*How easy the use of the technology is perceived to be*

EE1	It is easy for me to interact with this system. **3.08 (1.16)**
EE2	It has been easy for me to learn to use the system. **3.5** (1.17)
EE3	I find the system easy to use. **3.33** (1.15)

SOCIAL INFLUENCE:	*The extent to which an individual believes that others want them to use the technology system*

SI1	Family and friends have encouraged me to use the system. **1.92 (1.31)**
SI2	Health care professionals have encouraged me to use the system**. 3.67** (1.07)
SI3	I see the use of a system such as this as an emerging trend. **4.25** (0.75)

FACILITATING CONDITIONS	*The extent to which an individual believes there is the organizational and technical infrastructure to support use*

FC1	I have the computer skills to use the system. **4.08 (1.16)**
FC2	I have the knowledge to use the system. **4.16** (1.19)
FC3	I have the physical and mental skills to use the system. **4.08** (1.16)
FC4	Family members or friends are available to help me use the system**. 3.75** (1.06)
FC5	Support personnel are available to help me with the system. **4.17** (0.94)

COMPUTER ANXIETY	
ANX1	I feel nervous or anxious using the system**.2.42** (1.44)
ANX2	I hesitate to use the system for fear of making mistakes I cannot correct. **2.58** (1.62)
ANX3	The system is somewhat intimidating to me. **2.5 (**1.62**)**

BEHAVIOURAL INTENTION TO USE	
B1	I plan to use the system throughout the period I am enrolled in this study**. 4.75 (0.45)**
B2	I think I would use the system again in the future, after the study is completed. **3.67** (1.15)
B3	I am willing to use the system in my health care. **3.91** (1.08)

SELF-REPORTED EFFECTIVE USE	
U1	I use the system as much as I should. **2.75 (1.36)**

Appendix 4. Table of Task Completion Characteristics

	Received Assistance to Complete Task	Incorrect Actions	Observations of Participants' Experiences
Task 1: Logging in	**Completed Independently: 8/12** Needed assistance with: Remembering username and password (2) Entering username and password (2)	Enters Username or Password Incorrectly (3); Difficulty typing in information (2)	One participant seemed embarrassed and frustrated because she couldn't remember her login information and forgot to bring it with her. Three participants brought in their login information written down on a sheet of paper.
Task 2: Sending Message	**Completed Independently: 6/11** (one participant did not do this task) Needed assistance with: Getting to inbox (1) Selecting recipients (2) Sending message (2)	Entering info into text box (2), clicking mouse to get to inbox (1), Entering recipient name (2),	Frustration that program was slow to respond and froze (2) Confusion about how to proceed at some point during the task 6) Surprised that there were unopened messages in the inbox (1) 2 participants mentioned having difficulty at home with sending or receiving messages
Task 3: Accessing Recommendations	**Completed Independently: 4/11** (one participant did not do this task) Needed assistance with: Finding message informing about recommendations (1) Finding document (1) Downloading the document (3) Exiting out of document (4)	Went to click to close whole browser rather than exiting the current tab with the pdf downloaded document (1)	Commented that the print in the documents was too small (3) Put on glasses to read message (1) Commented that he/she would like to see and print only their personally tailored recommendations, without the many pages of general information (1) Received print-out of recommendations from the research coordinator to take home because didn't have a computer and printer at home (1)
Task 4: Completing Preclinical Mobility Scale	**Completed Independently: 1/12** Needed assistance with: Finding the surveys page (6) Selecting the correct survey (6) Opening the correct survey (4) Completing the survey (2)	Looks for survey in wrong location (7) Tries to open survey incorrectly (3) Opens the incorrect survey (1) Skips survey questions	Unsure of what they're being asked to do (2) Commented that they're confused or don't know how to proceed (5) Seemed frustrated with task (2) Not sure what is the most appropriate response to a survey question (4) Finds the print too small (2)

	Saving and exiting out of survey correctly (2)	(1) Exits out of survey incorrectly (2)	Finds the order of questions in survey confusing (1) Finds the questions with distance in kilometres (as opposed to miles) to be challenging (3) Finds the way to exit out of survey confusing (2) Due to visual limitations one participant found the survey very difficult to complete, and another participant required the interviewer to use the computer and read the questions aloud.
Task 5: Completing RAPA Survey	**Completed Independently: 4/11** (one participant did not attempt this task) Needed assistance with: Finding the surveys page (1) Selecting the correct survey (5) Opening the correct survey (4) Saving and exiting out of survey correctly (1) Completing the survey (1)	Looks for survey in wrong location (2) Opens the incorrect survey (3) Answers question incorrectly due to misunderstanding what it is asking (2) Clicks too many times (1)	Surprised when shown how to access surveys (1) Embarrassment at not realizing he should scroll down to read more text (1) Commented that instructions to complete the survey should be visible to them throughout the survey (1) Finds exiting the survey confusing (3) Unsure of what constitutes a light, moderate, or vigorous activity (6) Confused by the wording of the question (4) Unsure of how to respond to a question (6) Computer is responding slowly, affecting completion of the survey (1) Finds the font size too small (1) Requires guidance with survey content (3)

Chapter 4: Discussion

Summary

This thesis explored the use of Personal Health Records (PHRs) by older adults. The first study was a systematic review of the published literature on the role of physical functioning on the use of PHRs in older adults. Results of the systematic review indicated that PHRs may be a promising platform for monitoring physical functioning, but unsurprisingly, physical limitations impede the ability to effectively use a PHR. Only a small percentage of articles screened for inclusion measured or discussed levels of physical functioning, indicating that there is a dearth of research in this area.

The second study examined the usability of the McMaster PHR by a sample of older adults with at least one chronic condition. This usability evaluation used the "Think Aloud" Method of cognitive interviewing, identifying several common usability issues with the PHR interface and content, and exploring participant's attitudes and perceptions towards use. Overall, participants expressed interest in using a PHR to manage their health, and had access to computers and the Internet to do so. However, many were unsure of the functions of the PHR and were inexperienced in its use. This thesis made methodological, theoretical, and substantive contributions to this area of research. The thesis applied the “Think Aloud” technique of usability evaluation to collect more information about the use of, and perceptions toward use of PHRs among older adults. The thesis used an existing theory of technology adoption as a framework to identify factors affecting use in this particular context. Few other studies have looked at usability of a PHR from a patient’s perspective, particularly among older adults specifically. This thesis explored use of the McMaster PHR by older adults to self-monitor their physical functioning. Physical functioning was highlighted as an important factor affecting use in this population.

Physical Functioning Conclusions

Collectively, both studies concluded that physical functioning was an important factor influencing effective use of a PHR. In the "Think Aloud" study, three participants had physical limitations that limited their ability to use the PHR independently. For instance, one participant had recently suffered a stroke. Due to residual effects of the stroke, including deteriorating eyesight and headaches, they had difficulty using the computer to complete the tasks. It is important to consider how changes in physical functioning experienced by older adults may alter their ability to use technology such as a PHR. Physical limitations, when combined with other barriers, such as lack of computer experience, low health literacy, high computer anxiety, and lack of perceived benefit [1], could explain a low participation rate in PHR programs. In order to achieve the proposed benefits of PHR use, the usability of such systems should be optimized for older adults, with particular concern for the unique physical challenges faced by this population. Recommendations for the design of online screens for older adults, such as increased font size, and simplicity of navigation exist, but are not often followed [2]. Strategies to increase participation rate should be enacted and should address all these barriers to use.

Training

Training has consistently been identified as an essential component of successful use of health information technologies among older adults [3]. Successful training programs can increase "intention to use" [4], which is predictive of "actual use" [5]. These training programs should be tailored for the older adult, progressing in a logical manner, and at the participant's pace

[4]. Older adults experience more stress when using a technology, and need more practice time and support in use [6]. Training might be more effective if delivered by someone closer in age to the older adult that they can relate to and who understands the difficulties they face when using a new technology [4]. Training should build computer confidence and self-efficacy for use [4]. Within the "Think Aloud" study, participants were quite satisfied overall with the initial training they received. They also found it helpful to be provided with the phone number of the research coordinator, whom they could contact for assistance. Some commented though that they had forgotten how to use the system in the gap from the training received at baseline assessment to the six-month assessment. Providing "refresher" instructions or a follow-up training session might help participants relearn how to use the system.

Classifying Technology Expertise

There are multiple ways to categorize the experience of technology users [7], including frequency and breadth of use. It is important to know the baseline level of expertise in order to determine if a particular technology is appropriate for the individual and their abilities, and if so, to gauge how much training will be required for proficient use [8]. From a research perspective, it is also important to classify participants in a usability study based on their computer experience, in order to sample a range of expertise levels [7; 9].

Categories of technology expertise from Taylor et al. (2013) were used to classify participants in Study Two. During their in-person visit baseline assessment in the primary study, the OT or PT classified patients as a "non-user", "beginner user", or "familiar user". During the interview session, participants were asked for self-reported expertise using computers and the Internet. In all but one case, the participant's response matched the therapist's rating (one participant self-rated as "familiar" but was rated as "beginner" by the clinician). Past research has found that self-appraisal of computer expertise tends to be more lenient [8]. Within the systematic review, five articles (out of the thirteen identified articles) reported the participant's experience with computer and Internet use, and there was no consistent level of classification. For example, one study asked participants to rate their expertise as “beginner” or “competent”, while in another researchers decided if participants had “sufficient” or “insufficient” expertise.

It would be helpful to have a more descriptive and consistent method of classifying technology expertise in the future. Knowing a patient’s level of computer expertise would help develop an appropriate training program for the individual, and to determine how much ongoing technological support the individual might require. Having a consistent measure of classification would allow researchers to compare the use of PHRs by participants with similar levels of technology expertise.

A measure of computer expertise that was more illustrative of individual's ability to use an interactive health care information technology would assist with research and with clinical implementation of PHRs This comprehensive definition of "expertise" should consider the domain for which the technology is being used, as well as expertise with the technology itself [7]. For example, in evaluating the use of an information technology for health purposes, including a measure of health literacy could prove useful. Over sixty per cent of persons aged ≥16 years in Canada have low health literacy [11]. These individuals are less likely to adhere to self-management programs, and for these self-management programs to prove effective [11]. Three studies included in the systematic review identified health literacy as an important barrier to effective use of a PHR among older adults [12; 13; 14]. The eHEALS (ehealth literacy scale) has been proposed as a comprehensive measure able to evaluate whether an individual is properly equipped to effectively use an electronic health information technology, and whether they have the ability to benefit from its use [15]. The eHEALS is composed of six important forms of literacy: traditional, health, information, scientific, media, and computer. It gauges whether individuals can use a computer and whether they can read and understand the health information provided on it [15]. Future work is needed with this measure to validate its use in clinical settings, and with different populations, such as older adults [15], but a measure such as this could prove useful in future work.

Limitations

The study of health information technologies is a rapidly expanding area of research. This topic draws from a variety of fields, giving a large degree of heterogeneity of study questions and methods, making it difficult to generalize findings. Eighty-one of 240 articles screened at the full-text stage were excluded from the systematic review because they did not report the results of older adults specifically. Some of these excluded articles may have included older adults in their sample, but potentially relevant results could not be separated from the paper's overall findings. Conclusions of the second study are specific to that group of participants using the McMaster PHR for the specific purpose of the self-monitoring study. Participants who are more comfortable and enthusiastic about using technology for health may have selectively enrolled in this study.

Future Research

Fifteen to twenty participants per group are needed in order to perform inferential statistics using usability methods [7]. A larger sample size would allow an analysis of differences between persons with differing levels of computer expertise, and to evaluate usability differences between different ages of older adults. Future usability research could also evaluate PHR use in more naturalistic settings, such as the patient's home. Future studies could aim for a larger sample size of older adults to complete the UTAUT questionnaire, in order to be able to conduct inferential statistics. The goal of this larger survey would be to identify the predictors of successful PHR use among this population. Personalization, tailoring, and feedback have been identified as critical for improvement of health outcomes using consumer health informatics technologies [16]. Future interventions could explore how self-monitoring programs can most effectively incorporate personalization (making the intervention specific to the individual), tailoring (individualization of content and context based on the patient's characteristics) and behavioural feedback (updates to an individual on their status or progress in the intervention) [16]. Canadians are interested in the use of mobile technologies (such as iPads and cell phones) for health self-management- for example, using an application on their mobile phone to self-monitor diabetic symptoms [11]. As the use of mobile devices become increasingly common, it will be important to consider how the use of such technologies could best be incorporated into health care delivery. As privacy and security concerns are often cited as detractors to PHR use [4], these issues should be addressed in future PHRs. Lastly, it will be essential to evaluate whether the use of PHR technologies are providing added value beyond existing practice [1], and contributing to improved health outcomes.

References

1. Young, R., Willis, E., Cameron, G., Geana, M. 2013. "Willing but Unwilling": Attitudinal barriers to adoption of home-based health information technology among older adults. Health Informatics Journal

2. Becker, S. A. (2004). A study of web usability for older adults seeking online health resources. *ACM Transactions on Computer-Human Interaction (TOCHI), 11*(4), 387-406.

3. Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K. A., & Straus, S. E. (2011). Personal health records: A scoping review. *Journal of the American Medical Informatics Association, 18*(4), 515-522. doi:10.1136/amiajnl-2011-000105

4. Chen, K., & Chan, A. H. (2013). Use or Non-Use of Gerontechnology-A Qualitative Study *Journal of Environmental Research and Public Health, 10*(10), 4645-4666. doi:10.3390/ijerph10104645

5. Venkatesh, V., Morris, M. G., David, G. B., & Davis, F. D. (2003). User acceptance of Information Technology: Toward a unified view. *MIS Quarterly, 27*(3), 425-478.

6. Czaha, S. J., Sharit, J., Lee, C. C., Nair, S. N., Hernandez, M. A., Arana, N., et al. (2013). Factors influencing use of an e-health website in a community sample of older adults. *J Am Med Inform Assoc, 20*, 277-284.

7. Kushniruk AW, Patel VL. (2004). Cognitive and usability engineering methods for the evaluation of clinical information systems. *J.Biomed.Inform*, 37(1):56-76.

8. Van Vliet, P.J.A., Kletke, M.G., Chakraborty, G. (1994). The measurement of computer literacy: a comparison of self-appraisal and objective tests, *International Journal of Human-Computer Studies,* 40(5), 35-857, ISSN 1071-5819, http://dx.doi.org/10.1006/ijhc.1994.1040. (http://www.sciencedirect.com/science/article/pii/S1071581984710408)

9. Jaspers, M. W. (2009). A comparison of usability methods for testing interactive health technologies: methodological aspects and empirical evidence. *International journal of medical informatics, 78*(5), 340-353.

10 Taylor, M.J., et al., Website design: Technical, social and medical issues for self-reporting by elderly patients. *Health informatics journal*, 2013.

11. Health Council of Canada. (2012). Self-management support for Canadians with chronic health conditions: A focus for primary health care. http://healthcouncilcanada.ca/rpt_det.php?id=372#sthash.fzLgQwSq.dpuf

12. Or C, et al. Factors affecting home care patients' acceptance of a web-based interactive self-management technolog*y*. J Am Med Inform Assoc., 2011. 18(1): p. 51-9.

13. Kim, E., Stolyar, A., Lober, W. B., Herbaugh, A. L., Shinstrom, S. E., Zierler, B. K., et al. , *Challenges to using an electronic personal health record by a low-income elderly population.* Journal of Medical Internet Research, 2009. **11**(4): p. 1-9.

14. Lober, W.B., et al., Barriers to the use of a personal health record by an elderly population. *AMIA Annu Symp Proc*;, 2006. 1: p. 514-518

15. Norman, C. D., & Skinner, H. A. (2006). eHEALS: the eHealth literacy scale. *Journal of medical Internet research*, *8*(4).

16. Gibbons, M. C., Wilson, R. F., Samal, L., Lehmann, C. U., Dickersin, K., Lehmann, H. P., ... & Bass, E. B. (2009). Impact of consumer health informatics applications. *Evidence Reports/Technology Assessments, 108*(09(10)-E019)