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Systematic review

Lack of diversity in personal health record evaluations with older adult participants: a systematic review of literature

Laura Kneale
Department of Biomedical Informatics and Medical Education, University of Washington, Seattle, USA

George Demiris
Department of Biomedical Informatics and Medical Education, University of Washington, Seattle, USA, and School of Nursing, University of Washington, Seattle, USA

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Author address for correspondence:
Laura Kneale
Biomedical and Health Informatics
Department of Biomedical Informatics and Medical Education, University of Washington,
USA.
E-mail: lkneale@uw.edu

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ABSTRACT

Background Older adults are not adopting personal health records (PHRs) at the same rates as other adult populations. Disparities in adoption rates are also reported in older adult subgroups. The variability in adoption may be because PHRs are not designed to meet older adult users.

Objective We analyzed PHR evaluation studies to examine the characteristics and perspectives of older adult study participants to identify their self-reported needs.

Method We searched Medline, CINAHL, PsycINFO and Embase for PHR evaluation studies that involved older adult participants.

Results 1017 abstracts were identified, and 179 publications went through full text review. Ten publications met inclusion criteria. These publications described studies conducted in three countries, and evaluated seven PHRs. Homogeneity was found in the study populations and participant opinions of the systems.

Discussion Many PHR evaluations do not include diverse older adult participants. This may lead to consistency in outcomes, but it also may create gaps in identifying user needs. Additional studies, specifically targeting diverse older adult participants, are needed to gain a more comprehensive understanding of the opinions of older adults on PHRs and how these systems could benefit older adult healthcare consumers.

Conclusion The body of research shows that older adults are highly satisfied using PHRs. These outcomes may not be generalizable because most PHR evaluation studies do not include diverse older adult participants. This lack of participant diversity may be contributing to the disparities observed in PHR adoption rates.

Keywords: Aged, biomedical, health records, personal, review, technology assessment

BACKGROUND

The consumer health movement has placed increased significance on the concept of patient activation, described as an individual's ability to 'take independent actions to manage their health and care'.[1] Activated healthcare consumers have better health outcomes, increased patient satisfaction and lower healthcare expenditures.[1–3] Older adults may benefit from increased activation due to their higher medical complexity. A 2014 survey of older adults from 11 countries found that between 33% and 68% of older adults had two or more chronic conditions, between 29% and 53% took four of more medications, and many older adults reported challenges with care coordination.[4]

Personal health records (PHRs) are tools that have been designed to support patient activation by allowing consumers to access, manage and share their personal health information.[5] To support increased activation, recent governmental efforts such as the Affordable Care Act (United States (US)) and the Digital Agenda for Europe (European Union) have sought to increase adoption of PHRs among healthcare consumers.[6] These efforts have led to a rise in PHR adoption rates,[7,8] but recent studies have found that older adults are less likely to adopt PHRs than younger or middle-aged adults.[9–11] Disparities are even more pronounced in older adult minority populations, and with older adults with lower levels of education attainment.[10,11] One reason for these disparities may be that the PHRs have not been designed to truly meet older adult needs.[12,13] This hypothesis is consistent with other research that suggests older adults adopt health information technology for different reasons than younger adults.[14]

Performing end-user evaluations of health information systems is important for obtaining information on how to encourage and sustain adoption of technologies.[15] Therefore, in order to better understand older adult perspectives on PHRs and to identify their self-reported needs, our study systematically examined publications that included older adult participants in PHR evaluations. In our review, we explore the characteristics of the older adult study participants, and we describe their views on the systems. Our findings highlight several gaps in literature and call for future studies to engage diverse older adults to better understand their PHR requirements.

Materials and Methods

Study selection

We generated search terms in collaboration with a biomedical librarian. For 'personal health record', we used: 'personal health record', 'personal medical record', 'personal electronic health record', 'patient health record', 'patient medical record', 'patient web portal', 'shared electronic health record', 'shared electronic medical record', 'patient internet portal' and 'personally controlled health record.' For 'older adult', we used: 'older adult', 'elder', 'older people', 'aged', 'aging', 'geriatric' and 'senior.' We also used indexing terms unique to the databases where appropriate. Search terms for 'evaluation' were not generated after careful analysis of existing literature. This concept is not described uniformly across biomedical literature, and we wanted to ensure that we captured the greatest number of relevant articles.

To identify the publications, we systematically searched Medline (via PubMed), CINAHL (via EBSCO), PsycINFO (via EBSCO), and Embase (via Ovid). After yields from each search were merged and duplicate citations were removed, citations were uploaded into the Internet-based systematic review website Covidence[16] to track the screening processes. No date restrictions were placed on the search. The primary author (LK) conducted all searches on July 1, 2015.

LK screened all abstracts, and any publication that was clearly ineligible was excluded. GD randomly screened 10% of the abstracts (*n* = 80). Initial agreement between the authors was 90% (*n* = 72), and disagreements were resolved through consensus. After consensus, one abstract was added to the full-text review (*n* = 1, 1.25% of random abstracts screened).

Full-text reviews were performed on publications that met inclusion criteria or if the abstract did not provide adequate information to make the determination. LK screened all full-text articles. GD randomly screened 10% of rejected articles (*n* = 16) and all included articles (*n* = 10). Initial agreement was 88% and disagreements were resolved through consensus. After meeting, no additional articles were added to the final list of publications.

Inclusion and exclusion criteria

Full-text peer reviewed publications were included if the manuscript: (a) described a primary data analysis on a consumer evaluation, (b) analyzed study participants aged 60 and older separately from other adult populations and (c) evaluated a PHR that met our definition: a system that allows consumers to access, manage and share personal health information over the Internet. Some publications did not report the mean or median participant age, but reported age categories of participants. These manuscripts were included if the age categories of 60 and older included at least 50% of the total participants. In order to confirm that the PHR met our definition, LK asked the publication authors to describe the PHR functionality at the time of evaluation through email communications.

Publications were excluded if the manuscript described a study where: (a) participants were not exposed to a PHR (e.g. a focus group of non-PHR users), (b) participants were only exposed to a PHR during laboratory settings, or (c) if the full text was not available in English.

Abstraction

To provide context for the older adult opinions, we abstracted publication details including study design, patient population, study setting, and PHR features. To address the purpose of our review, we abstracted the participant demographics, evaluation outcome measures and results, and facilitators and barriers for PHR use among older adults.

Quality reporting was conducted using the three most important items from the condensed version of the Statement on Reporting of Evaluation Studies in Health Informatics (Stare-HI).[17] In addition, we added two additional criteria. These criteria help readers better understand the context of the evaluation study results and were: ‘provides a description of the PHR functionality under investigation’ and ‘describes how participants used the PHR functionality under investigation.’ Articles were ranked on a scale of 0 (worst) to 5 (best). Authors independently scored each included article, scores were merged, and disagreements were resolved through consensus.

RESULTS

Ten publications are included in the final analysis (5.59% of the full text publications).

Publication features

All publications were published between 2009 and 2014.[18–21] Publications described studies that were conducted in the US (*n* = 7, 70%),[18–24] Canada (*n* = 2, 20%),[25,26] or New Zealand (*n* = 1, 10%).[27] The publications describe ten evaluations of seven unique PHRs.

Seven publications (70%) described studies that evaluated the entire PHR,[18,19,23–27] and three publications (30%) evaluated specific components of an existing PHR. These publications evaluated a Blue Button feature – a US federal initiative that allows consumers to download their medical information,[20] a PHR tool to support consumer medication reconciliation[21] and the information sharing features of an existing PHR.[22] Table 1 displays the publication features, and the demographics of the PHRs were evaluated in each publication.

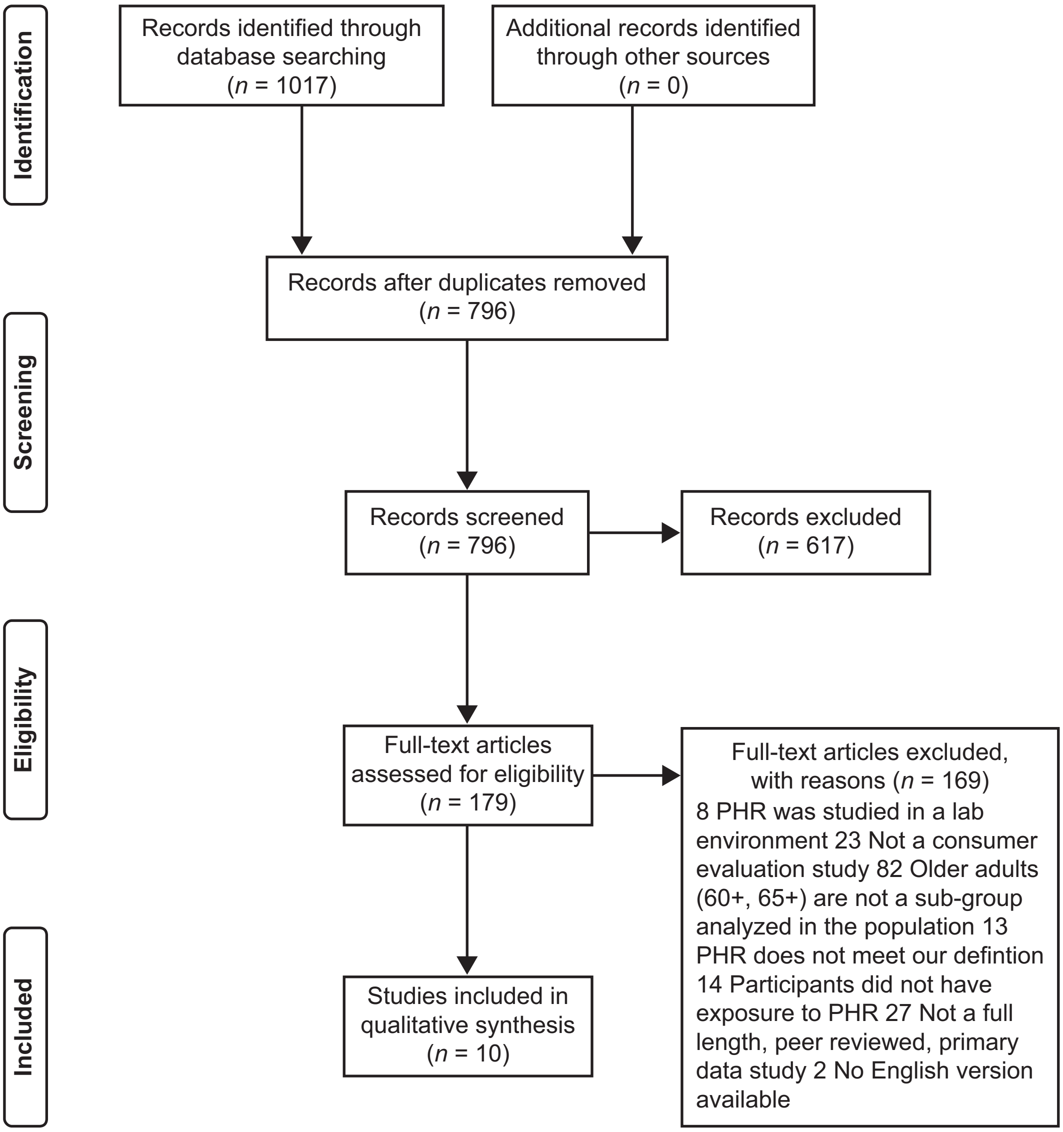

Figure 1 **Displays a PRISMA diagram for the screening process**

Table 1 Demographics of evaluation study participants

			Participant demographics as reported in publications (Intervention group)						
First author	**Year**	**PHR**	**% Female**	**Participant age**	**Racial and/or ethnicities**	**Educational attainment**	**Computer literacy**	**Medical complexity**	**Other**
Boland[19]	2014	Microsoft healthvault	55%	69.6	European: 37% African American: 58% Asian: 3% Hispanic: 3%	Less than HS: 19% High school: 51% College: 11% Post-college: 19%	Not reported	Health status: Excellent: 13% Good: 63% Fair: 24% MMSE median: 28	Income per 1000 population by zip code US$49,000
Gu[27]	2013	PHR*	30%	63.5	Not reported	Not reported	Computer skills: Basic: 40% Intermediate: 20% Advanced: 40%	Average of diagnoses: 2.8 Average of medications: 3.5	Occupation: Retired: 50% Electrician: 10% 'I work at airport': 10% Special effects designer: 10%
Heyworth[21]	2014	My healthevet	9%	61	Not Reported	Not reported	Not reported	5+ medications: 78% All participants had at least one chronic condition	70% private insurance or medicare
Kim[24]	2009	Personal health information management system*	71.40%	63	Not reported	Not reported	Not reported	Not reported	Primary language: English
Kogut[18]	2014	ER-Card	46.70%	65+: 76.7%	Not reported	Not reported	Not reported	Not reported	Not reported
Nazi[23]	2013	My healthevet	8%	61–70: 45% 71–80: 15% 81–90: 6%	Not Reported	Did not complete HS: 2% HS Graduate: 12% Some College/Vocational School: 42% Postgraduate: 8% Graduate or professional degree: 15%	Using the Internet: Beginner: 3% Intermediate: 33% Advanced: 64%	Self-disclosed impairments: Hearing: 8% Visual: 7% Dexterity: 6%	Not Reported

Pai[26]	2013	PROVIDER*	0%	64	Caucasian95.46%	75% completed post-secondary education	Used a computer more than 1 hour per week: 90.91% Used computers more than 5 hours per week: 55% Searched the Internet for health information: 82%	Not reported	71% married
Spencer[25]	2011	Geriatric myhealth passport*	Not reported	92.1	Not reported	Not reported	Not reported	Not reported	Not reported
Turvey[20]	2014	My healthevet	8.30%	60–69: 51.0% 70–79%: 15.8% 80+: 4.1%	Not reported	Not reported	Computer literacy: Beginner: 3% Intermediate: 28.4% Advanced: 68.6%	Self-related health fair/ poor: 22.9% Mean # of illnesses: 2.3	Not reported
Turvey[22]	2012	My healthevet	Wave one: 9% Wave two: 8%	Wave one: 60-69: 47% 70+: 22% Wave two: 60–69: 48% 70+: 21%	Not reported	Not reported	Wave one: How often do you visit the PHR: 5% Weekly: 24% Monthly: 50% Every 6 months: 6% Less than every 6 month: 3% First Time Visitor: 12% Wave Two: Daily: 5% Weekly: 25% Monthly: 47% Every 6 months: 3% Less than ever 6 months: 3% First time visitor: 14%	Wave one: Excellent: 5% Very good: 18% Good: 38% Fair: 29% Poor: 10% Wave two: Excellent: 4% Very good: 19% Good: 38% Fair: 29% Poor: 10%	Not reported

* denotes a proprietary system

Demographics

Gender

One study did not report the participants' gender.[25] Two publications (20%) reported somewhat equal representation between men and women,[18,19] one publication (10%) reported recruiting mostly female participants[24] and six evaluations (60%) reported recruiting mostly male participants.[20–23,26,27] Of these male dominated studies, five publications recruited less than 10% women participants.[20–23,26] Four of these studies were conducted with US veterans, and one study focused on participants diagnosed with prostate cancer.

Participant age

Eight (80%) publications reported a participant average age of 70 years or below, or included more than 70% of the participants in age ranges 70 years or below.[19–24,26,27] One publication (10%) reported a median age of 92.1 years old.[25]

Racial and/or ethnic identities

Eight (80%) publications did not report participants' race and/or ethnicity.[18,20–25,27] Of the two (20%) studies that did report this information, one reported that 95.45% of the participants identified as 'white'[26] and the other reported that 58% of the study participants identified as African American, 37% as Caucasian, 3% as Asian, and 3% as Hispanic.[19]

Educational attainment

Educational attainment was assessed in three publications (30%). Two studies reported that 75% or more of the older adult participants completed post-secondary studies, either through college/university or vocational and training programs.[23,26] The third study reported lower levels of education attainment, with 51% of participants completing high school and 30% completing post-secondary education.[19]

Computer literacy

Participant computer literacy was assessed in five publications (50%). Two studies found that 97% of the participants were intermediate or advanced computer users.[20,27] A third study reported that 60% of their participants considered themselves intermediate or advanced Internet users.[23]

The other two publications (20%) used self-reported usage as a proxy for computer literacy. In these studies, 82% of their participants had used the Internet to search for health information, 90.91% of the participants reported using a computer at least 1 h per week,[26] and at least 70% of participants used the PHR that was being evaluated at least one time per month.[22]

Medical complexity

Six publications (60%) reported medical complexity using one or more of the following measures: self-reporting scales of general wellness, assessing cognitive impairments, self-report number of chronic illnesses, counting the number of medications reported per user or self-reported prevalence of disabilities.

Three publications (30%) asked participants to rank their general health using a Likert Scale from 'excellent' to 'poor'. In these publications, more than 60% of their population rated their wellness as 'good' or better ('good', 'very good' and 'excellent').[19,20,22] Another study (10%) administered a mini-mental state exam (MMSE) and found the median score to be 28 (normal cognitive function).[19] Two publications (20%) reported the average number of medical conditions per participant as 2.3[20] and 2.8[27], respectively. Another publication (10%) reported that 100% of their participants had at least one chronic condition, but did not report an average number per participant.[21] Two additional publications (20%) reported an average of 3.5[27] and five medications[21] per participant. Finally, one study (10%) asked self-report impairments and found that 8% of the participants reported a hearing impairment, 7% reported a visual impairment and 6% reported a dexterity impairment.[23]

Other demographics

Participant primary language,[24] marital status,[26] average income,[19] insurance status[21] and current occupation[27] were each only reported in one publication.

Participant opinions

Participant satisfaction

Eight publications (80%) asked participants to evaluate their satisfaction with the PHRs.[19–21,23–27] Five publications collected the information through surveys:[19,20,23,24,26] using a Likert Scale,[19,23,26] a 1 to 10 satisfaction scale,[20] and an unspecified survey question.[19,23,26] a 1 to 10 satisfaction scale,[20] and an unspecified survey question.[24] Three publications collected satisfaction data through in-person[25,27] and telephone interviews.[21]

The majority of the participants were satisfied or highly satisfied with the PHRs. More specifically, participants stated that PHR use improved their ability to manage and understand their health information, their confidence in daily self-management routines, and confidence that their providers would be able to better handle their care.[20,23–25] Three publications reported that use of the PHRs improved participant relationships with their medical providers.[23,25,27]

One study captured the views of individuals who had never used the Blue Button feature (a US federal initiative that allows consumers to download their medical information) in the PHR. Never-users reported not using Blue Button because the participants were: not aware of the feature (61.3%), aware of the feature but did not know how to use it (34.4%) and were aware of the feature but did not know how to locate it (9.5%).[20]

Participants in four studies (40%) did report some dissatisfaction with the systems. Usability was the most common reason. Comments on the difficulty with printing and using information from the PHRs were present in all four studies.[20, 21,26,27] Surprisingly, one publication reported that 59% of participants would use the system again despite the fact that more than half of the participants reported trouble with navigating the system.[21]

Participant reported system use

Eight publications (80%) evaluated participant-reported PHR use. Five used surveys for collecting this measure,[20,22–24,26] and three collected this information through participant interviews.[18,25,27]

The long-term usage reported differed between the systems. Two publications reported difficulty sustaining long-term use. In one publication, only 30.3% of the participants were still using the PHR at follow-up, and a second study found that participants only used the system an average of three times in 6 months.[24] Two publications that evaluated that the My HealtheVet system did describe sustained use with over 75% of participants reporting that they used the system at least once per month.[22,23]

Three studies asked if participants used the PHRs to share data between care team members. In the Blue Button evaluation study, only 11.8% of the participants used Blue Button to share information with a family member, 9.7% used Blue Button to share information with out-of-network providers and 5.7% used Blue Button to share information with in-network providers. When participants did share their health information, most participants chose to share their laboratory results (79.2%) or medications (54.4%).[20] A second publication reported that 3 out of 11 (27%) participants had shared the PHR information with a healthcare provider,[25] and a third publication reported 37% (n = 7/19) participants reported sharing PHR data with others.[18]

Whether or not participants added their health data into the system depended on if the PHR was connected to their healthcare system or not. Participants that used PHRs connected to their healthcare system reported low use in functionalities that allowed them to enter and track in their health information, such as entering daily weight values.[22,23,27] An evaluation of a standalone system found that 79% of their participants were willing to enter medical data into the system at least once during the study period.[24]

Three publications (30%) evaluating tethered PHRs reported differences in participant usage of PHR features. Two studies reported high numbers of participants viewed medical records through the PHR (88%, 94%[23,26]). Accessing medical records, such as laboratory results, was the most frequently used PHR feature. Other commonly used PHR features across the three publications were administrative functions, such as renewing medications, viewing and scheduling appointments, and communicating with healthcare providers.[23,26,27]

PHR cost

A publication from Canada asked participants opinions on PHR costs. One (5.9%) participant strongly disagreed, eight (47.1%) were neutral, three (17.6%) agreed, and five (29.4%) strongly agreed with the statement: 'would be willing to pay user fee for use of personal health record system.' Additionally, the participants were asked: 'who should be responsible for paying for a PHR.' The answers included the government (federal and provincial), healthcare institutions, and private industry; however, all participants stated that the government should help fund PHRs.[26]

Quality review

The results from our quality review are displayed in Table 2. Because of our inclusion criteria, all manuscripts described whether the study were conducted in the laboratory, simulation, or field (simulations and laboratory studies were excluded). The total quality ratings ranged from 3 to 5. All articles met the three top Mini Stare-HI requirements. Descriptions of the PHR functionality under investigation and how the participants used the functionality were more varied. Although PHRs have many similar functions, informing the reader about what the system does and how participants used the system provides more context to how the system attempts to drive adoption. Future PHR evaluation studies should provide enough context about the system functionality evaluated to better understand the experiences of the end-users.

DISCUSSION

As described above, the majority of older adult participants expressed satisfaction and found that using the PHR was helpful to their care. Given this finding, it is interesting that PHR adoption among older adults remains lower and more inconsistent than in other populations.

We propose that adoption among older adult populations may be constrained because this body of literature does not fully understand the nuanced requirements of older adults. Firstly, this body of literature lacks overall diversity of older adult participants. Basic demographics such as age, gender or sex, and/or race and ethnicity are not consistently being reported in publications and when reported do not reflect the diversity of older adults. Secondly, the methods used to evaluate the systems do not lend themselves a deeper understanding of older adult requirements.

Demographics

Despite the variety in PHRs, countries, and research teams conducting these evaluations, we found that study participants were often younger older adults (average age 60–70 years old), white or Caucasian males who have high levels of education attainment and are comfortable using computers. The lack of diversity in older PHR evaluation participants will limit the generalizability of these publications' findings.

In the US, people aged 75 and older and people who identify with racial and ethnic minority populations are two of the fastest growing older adult subgroups.[28] Unfortunately, the PHR evaluations included in this review lacked diversity in these and other participant demographics. Although study constraints, such as recruiting older adults who have technical skills or patients with

Table 2 **Outcomes of the publication quality analysis**

		Quality reporting requirement					
First author	**Year**	**Interprets the data and gave an answer to the study question***	**Describes whether it is a laboratory, simulation or field study***	**Provides a description of the outcome measure/ evaluation criteria***	**Provides description of the PHR functionality under investigation**	**Describes how participants used the PHR functionality under investigation**	**Total quality rating**
Boland[19]	2014	1	1	1	0	**0**	**3**
Gu[27]	2013	1	1	1	1	**0**	**4**
Heyworth[21]	2014	1	1	1	1	**1**	**5**
Kim[24]	2009	1	1	1	1	**0**	**4**
Kogut[18]	2014	1	1	1	0	**0**	**3**
Nazi[23]	2013	1	1	1	1	**1**	**5**
Pai[26]	2013	1	1	1	1	**1**	**5**
Spencer[25]	2011	1	1	1	1	**1**	**5**
Turvey[20]	2014	1	1	1	1	**1**	**5**
Turvey[22]	2012	1	1	1	1	**1**	**5**
Total		**10**	**10**	**10**	**8**	**6**	

* denotes three most important criteria in the condensed version of the Statement on Reporting of Evaluation Studies in Health Informatics[20]

specific chronic diseases like prostate cancer, may have lead to unequal representation, we are missing the opportunity to identify the unique needs of these groups.

In addition to lacking diversity in the reported demographics, these evaluations also missed capturing some key participant characteristics. For example, although educational attainment was reported in three studies, a health literacy assessment was not described in any of these publications. Health literacy is not the same as education attainment as people at all levels of education attainment can have poor health literacy.[29] In addition, health literacy has been found to be a significant demographic difference between older adult PHR users and non-users.[13] To better understand the context and generalizability of the findings from older adult study participants, additional demographic measures, such as health literacy, should be assessed and reported in future PHR evaluation studies. Our findings call for future studies to specifically focus on PHR evaluations with underrepresented older adult groups to better understand the reasons why some older adults are adopting PHRs at faster rates than others.

Evaluation outcomes

Participant satisfaction was most often reported through survey questions. Studies that included participant interviews did not highlight specific areas that enable or discourage older adults from adopting personal health record systems.

Previous literature suggests that multi-method approaches to evaluation are essential for obtaining the breadth and depth of end-user opinions.[15] To add to this body of literature, more work is needed to highlight the exact perceptions of older adult users to inform PHR developers of system requirements of older adult users. Perhaps using qualitative methods that could explore the reasons for satisfaction and dissatisfaction among older adult participants will help us better understand why there is variability in adoption rates and how to encourage sustained use of these systems.

LIMITATIONS

Our review includes PHR evaluations with older adult subjects. Although our broad search methodology attempted to capture all publications describing PHR evaluation studies with older adults, it is possible that we excluded studies in which older adults were approached but not enrolled. In addition, our definition of a PHR was specific to an Internet-based system. Although this meets the current accepted definition of a PHR,[30] it is possible that another format would better fit the needs of older adults.

CONCLUSION

Our review suggests that older adults are willing, able, and highly satisfied using PHRs. In addition, older adults who perceive PHRs as useful are willing to overcome technical barriers to engage with these systems. Our review also suggests that there are gaps in the current evaluation literature. These gaps include the lack of diversity in the older adults' participation in PHR evaluations, and the lack of qualitative methods used to probe older adult requirements for PHR adoption. Without evaluating PHRs with diverse groups of older adults and understanding what their requirements are, we risk the potential of designing systems that only meet the needs of specific subgroups in the population. This may lead to continued disparities in PHR adoption rates. More evaluation studies are needed with diverse older adult participants in order to gain a broader perspective on PHR use, adoption and acceptance in older adult populations.

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