Barriers to patient, provider, and caregiver adoption and use of electronic personal health records in chronic care: a systematic review

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Abstract

**Background** Electronic personal health records (ePHRs) are defined as electronic applications through which individuals can access, manage, and share health information in a private, secure, and confidential environment. Existing evidence shows their benefits in improving outcomes, especially for chronic disease patients. However, their use has not been as widespread as expected partly due to barriers faced in their adoption and use. We aimed to identify the types of barriers to a patient, provider, and caregiver adoption/use of ePHRs and to analyze their extent in chronic disease care.

**Methods** A systematic search in Medline, PubMed, Science Direct, Cumulative Index to Nursing and Allied Health Literature (CINAHL), the Cochrane Central Register of Controlled Trials, and the Institute of Electrical and Electronics Engineers (IEEE) database was performed to find original studies assessing barriers to ePHR adoption/use in chronic care until the end of 2018. Two researchers independently screened and extracted data. We used the PHR adoption model and the Unified Theory of Acceptance and Use of Technology to analyze the results. The Mixed Methods Appraisal Tool (MMAT) version 2018 was used to assess the quality of evidence in the included studies.

**Results** Sixty publications met our inclusion criteria. Issues found hindering ePHR adoption/use in chronic disease care were associated with demographic factors (e.g., patient age and gender) along with key variables related to health status, computer literacy, preferences for direct communication, and patient’s strategy for coping with a chronic condition; as well as factors related to medical practice/environment (e.g., providers’ lack of interest or resistance to adopting ePHRs due to workload, lack of reimbursement, and lack of user training); technological (e.g., concerns over privacy and security, interoperability with electronic health record systems, and lack of customized features for chronic conditions); and chronic disease characteristics (e.g., multiplicities of co-morbid conditions, settings, and providers involved in chronic care).

**Conclusions** ePHRs can be meaningfully used in chronic disease care if they are implemented as a component of comprehensive care models specifically developed for this care. Our results provide insight into hurdles and barriers mitigating ePHR adoption/use in chronic disease care. A deeper understanding of the interplay between these barriers will provide opportunities that can lead to an enhanced ePHR adoption/use.

1. **Background**

Promoting self-care and patient engagement in care management has gradually become key features in efforts to improve health service delivery and care quality in chronic diseases (1, 2). Electronic personal health records (ePHRs) provide the tools to empower patients and promote self-care (3, 4). A systematic review found that self-monitoring through ePHR improves health outcomes in chronic conditions (5). Because of such potentials to enhance quality and patient engagement (6-8), the Health Information Technology for Economic and Clinical Health Act (HITECH) and meaningful use phase 2 and 3 have driven the adoption of ePHRs in parallel to Electronic Health Records (EHRs) (9).

Studies have shown that both patients and providers are interested in ePHRs especially as they find them as a means to increase patient empowerment (10-12). Yet, there are barriers to overcome and challenges to embrace when adopting ePHRs. Some of these barriers are related to the implementation of EHRs such as EHR products and capital and human resource issues. For example, from 2,674 general hospitals studied in the United States (US) in 2013, only 5.8 percent of hospitals met measures for stage 2 meaningful-use readiness and several other criteria, including sharing care summaries with other providers and providing patients with online access to their data, as necessary functions for a tethered PHR (13). Other barriers are more ePHR specific ones such as poorly aligned functionalities with patients’ expectations and self-management practices and concerns about privacy and confidentiality of patient information in ePHRs (14, 15). Even outside the US healthcare context, similar hurdles have also contributed to a lower adoption rate than what has been expected or hoped for (16). Such results continue to be reported after the implementation of many health information technologies (HIT) including ePHRs, which highlight a strong need to understand factors and challenges that influence the implementation outcomes (17). Overcoming these challenges and barriers in implementing and adopting ePHRs can result in increased efficiency and improved quality patient care (18). Therefore, recognizing and understanding the nature of such barriers is imperative to be well equipped to devise strategies to overcome the barriers and to achieve ePHR’s meaningful use.

There have been a few reviews published on the barriers to ePHR adoption and use. A review of the patient-level barriers categorized them into individual, demographic, capability, health-related, ePHR-related, or attitudinal factors (19). Another review with similar scope concluded that a lack of awareness of and sufficient training regarding portal use were the two main barriers (18). In the elderly population, the main barriers were limited technology access and no prior knowledge of the existence of a patient portal, and limited health literacy and motivation to use a patient portal (20). In rural areas of the US, provider resistance, privacy concerns, and the lack of EHRs, interoperability standards, and funding have emerged as the main barriers (21). However, these reviews have narrowly focused on patient-level barriers (18, 19), or were limited in terms of age ranges (20), time frame, or geographical location reviewed (21, 22). To our knowledge, there is a significant gap in the literature on the barriers in the patient, caregiver, and provider levels that may impact ePHR adoption and use in the context of chronic care. To address this gap, we aimed to identify and synthesize evidence on ePHR adoption and use barriers in chronic disease care.

More specifically, we were interested to identify the types of barriers and to analyze their extent in this care. The insights gained will inform efforts for effective design, implementation, and use of ePHRs for a patient population at the most need of these tools.

2. **Methods**

This review was conducted according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) (23).

2.1. **Search strategy**

We conducted a literature search in OVID versions of MEDLINE, PubMed, Science Direct, Cumulative Index to Nursing and Allied Health Literature (CINAHL), the Cochrane Central Register of Controlled Trials and the IEEE database for English-language, journal or congress proceedings’ full texts published January 1,
2005, till December 31, 2018. We used a Boolean search strategy using keywords and MeSH terms related to two areas of interest i.e., the intervention (e.g., Personal Health Record OR Personal Medical Record OR patient portal OR patient internet portal, etc.) AND the health condition (e.g., Chronic Disease OR Chronic Illness, OR Chronic Condition, etc.). The details of our search strategy are accessible in Appendix A. We also conducted a manual review of all reference lists of included studies and the pertinent ePHR reviews including (14, 15, 18-22, 24-29).

2.2. Inclusion and exclusion criteria

We included studies according to the following inclusion criteria: 1) the intervention was an ePHR/patient portal, 2) the targeted users were chronic disease patients, their caregivers and/or their healthcare professionals, 3) the study was an original research article, and 4) the study design was either quantitative, qualitative, or mixed methods.

We excluded ePHR/patient portals that were not aimed at chronic patients, paper-based ePHRs or educational websites, assistive living technologies, or mHealth tools, systematic reviews, proceedings abstracts, commentaries, editorials, and articles describing theoretical background or design reports without having an evaluation nature. The main reasons for exclusions in each phase of this review are accessible in Appendix B.

2.3. Review procedures and data extraction

After removing duplicates, our search identified 3088 unique records, which were screened for eligibility. Figure 1 shows the PRISMA flow diagram of our review. Two reviewers (ET and MCH) were trained on the screening and data extraction tool by ZN, who is an experienced researcher in conducting systematic reviews in the field. The reviewers reviewed a sample of references and compared extraction results to reach an excellent agreement (kappa= 0.77). Then, they screened titles and abstracts of the above-mentioned search result to find relevant studies based on our inclusion/exclusion criteria. In this phase, 143 potentially eligible publications were selected for the full-text review. Further articles were found through the manual review. All articles were independently reviewed in detail by ZN and either ET or MCH. Disagreements were solved by consensus. Endnote version XI was used to manage records.

We extracted the following main study characteristics in the full review phase: general information (e.g., the authors and publication year), study objectives, study design, patient population, system users, the intervention (e.g., the description of ePHRs and their integration with other systems), and the main study results.

2.4. The methodological quality of studies

We used the mixed methods appraisal tool (MMAT) version 2018 to assess the quality of evidence in included studies (30). This tool can be used to appraise the quality of empirical studies (i.e., primary research based on experiment, observation, or simulation) in three categories of study designs (i.e., qualitative, quantitative, and mixed methods).

2.5. Data synthesis

According to a widely used definition, an ePHR 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” (3). We used two well-known models as a theoretical background to analyze and categorize barriers to ePHR adoption/use faced by users. The first was the “Personal Health Records Adoption Model” (PHRAM), developed through integrating several relevant parent models/theories (31). This model was used to analyze the barriers faced by patients and caregivers in the context of chronic care. We also used the unified theory of acceptance and use of technology (UTAUT) to analyze barriers specifically experienced by care providers (32). Since conducting a meta-analysis became out of the scope of this study due to the lack of unified quantitative data in included studies, we only provide a narrative description of results based on the PHRAM and UTAUT.

3. Results

3.1. Characteristics of included studies

Our review identified 60 ePHR studies (5, 12, 33-90), among which 24 were qualitative, 22 quantitative, and 14 mixed methods studies. Table 1 provides the details of the included studies. These studies were conducted between 2006 and 2018, nine of them in the single year of 2015. Forty-six studies were from the US, followed by five studies in Canada, two studies in the Netherlands, two in the United Kingdom, and the remaining five in Denmark, Sweden, Germany, New Zealand, and Argentina (one study from each country). A majority of studies included older patient populations (compared with younger patients) and diabetics (compared to other chronic patients) in their evaluations. Ten studies had a target population of pediatrics (37-39, 43, 44, 60, 72, 73, 79, 86). The results are provided here according to the personal, environmental/medical practice, technological, and chronic disease factors on the bases of the PHRAM and UTAUT.

3.2. Personal factors

In one study involving survivors of pediatric cancers, referring to the issue of age, cancer survivors >18 years old were significantly more likely to use an ePHR compared to those <18 (86). While a high proportion of patients with age 50 and older had higher frequency and intensity of ePHR use (67), patients over the age of 65 were less likely to intend to use an ePHR (49), and patients aged over 70 were associated with a lack of use (71). In four studies, more men than women had access to computers or the internet, expressed confidence in using ePHRs, or used it (55, 68, 75, 85), while females were the dominant users in three studies (48, 67, 90).
People with minority race/ethnicity (including African-American, Latino, and Filipino) reported more negative attitudes towards ePHRs, were less likely to use ePHRs and experienced more obstacles compared to Whites and Caucasians (34, 47, 48, 56, 58, 62, 66, 67, 70, 71, 75, 76, 86). Having a paid job or higher income and living in a higher socioeconomic neighborhood, and being insured were associated with higher use (reported in studies from the US and the Netherlands) (42, 62, 67, 68, 76, 85); while, having a lower income and being below the poverty level were linked to non-use (34, 48).

Patients with lower educational attainments were less likely to intend to use or use an ePHR (34, 42, 48, 49, 62, 66, 68, 70, 71, 75, 76). Patients with limited health literacy were less likely to use ePHR or use it ineffectively (5, 34, 41, 46, 55, 66, 70, 75, 77, 78, 88). The level of knowledge, self-efficacy, and confidence in technology use was associated with ePHR adoption/use (53, 55, 57, 68, 84).

Negative attitudes toward the disease and health care experiences in general, and ePHRs in particular, prevented patients from using ePHRs (40, 44, 47, 49, 60, 72). Patients were concerned about the reliability of ePHRs to facilitate timely and productive communication with providers (37, 43, 66, 82). In one study, patients commonly expressed negative attitudes partly because of their experience of confusion and misunderstanding (40).

Fourteen studies highlighted the critical role of computer/technology literacy and skills to effectively use ePHRs (5, 41, 42, 45, 50, 53, 57, 66, 69, 77, 83, 84, 87, 88). Computer literacy barriers included, but were not limited to, the lack of basic computer skills, inexperience in using search bars or uniform resource locators, difficulty while navigating the portal, and negative experiences with online security breaches/viruses. Three studies noted that computer anxiety negatively affected patients' behavioral intention to adopt ePHRs (5, 34, 87).

Challenges related to communication preferences were brought up in several studies with a majority pointing out the value of in-person, or telephone contacts between patients and providers (37-40, 44, 47, 48, 50, 53, 59, 60, 65, 66, 77, 79-81, 83, 87). The main reasons for such a preference were getting anxious when seeing results online and concerns over technology replacing their providers. The preference for in-person communications was also shared by providers in certain circumstances (65, 81).

### 3.3. Environmental/medical practice factors

#### 3.3.1. Social influence

The impact of the social influence of "important others" (i.e., family members and care providers) on patients was evident (12, 55, 56). It was shown that living alone and being not currently married were associated with non-adoption and lesser ePHR use (34, 42, 68). Moreover, studies pointed out the role of providers’ willingness to use portals, their communication about it, and their level of use in patients’ initial portal use (47, 60, 82, 85). While patients wanted their physicians to get more involved in ePHRs (80), physicians viewed them as more of a patient, receptionist, or nurse tool (69, 80).

#### 3.3.2. Facilitating/impending conditions

Our review identified the existence or otherwise lack of the following organizational and/or technical infrastructures to support or impede ePHR use: being in an organization's priority list, integration into the EHRs, patients ready access to resources such as computers, the Internet, and ePHRs, adequate technical support, and proper training on ePHR use (5, 12, 34, 42, 46, 49, 51-53, 57, 61, 65, 66, 77, 85, 89).

Due to its impacts on physician’s time management and workload, “physician resistance” was mentioned as “the greatest barrier to ePHR implementation” (12). There were also concerns about the impacts on providers’ available time for care, lack of reimbursement, or professional liability issues (36, 65, 69). Physicians voiced their concerns about excess time and efforts to handle issues related to the ePHRs due to lack of integration with EHRs (80, 81).

#### 3.3.3. Incentive motivation

Tangible incentives and cost compensations, or otherwise lack thereof, were also an important factor (12, 55, 65, 66). For example, it was important to be certain about how ePHR-related services would be paid for, who would pay, and under what circumstances (41). The cost of services was also mentioned as a barrier by patients (77, 84, 89).

### 3.4. Technology factors

This section provides the results related to the perceived usefulness of ePHRs, perception of external control, compatibility, and perceived complexity.

#### 3.4.1. Perceived usefulness

Perceived usefulness featured as a key driving factor for the intention to use ePHRs (49, 50, 60, 66, 80, 81). For example, non-users mostly expressed concerns about simply not seeing the value of using a portal to manage their health or lack of personalization in using this technology (66).

#### 3.4.2. Perception of external control

Preserving general privacy, confidentiality, and security of health records was one of the most common concerns regarding ePHR use (e.g., confidentially of a stigmatized or sensitive condition, or confidentiality and security of information easily accessible to researchers and industry members, and misuse of information by insurance companies to deny coverage) (45-47, 49, 53, 59, 66, 69, 73, 77, 79, 88, 89). Patients voiced their concerns about caregiver’s access to their information and requested appropriate access limitation (53, 54, 69). Clinicians’ attitudes towards caregiver involvement in ePHR use were controversial in one study: while 28.3% favored it, 32.1% disagreed because it impaired patients’ privacy (81).
Moreover, patients reported frustration at several instances in which their profile, medication list, lab results or medical history were incorrect or missing in the ePHR but they were unable to correct them (46, 51, 65).

3.4.3. Compatibility

The degree to which an ePHR was perceived as being consistent with the existing values, past experiences, and needs of its potential adopters i.e., chronic patients and their caregivers and providers were mentioned as an important factor for adoption in some studies (36, 40, 44, 65, 91). When comparing with the traditional chronic care, users asked for much easier navigation through ePHRs, access to additional information (e.g., progress notes, outside test results, personalized medication information, and a structure to track the course of treatment) or a customized ePHR based on their specific chronic illness (36, 39, 41, 44, 46, 51, 61, 63, 79, 81).

3.4.4. Perceived complexity

The difficulty of understanding or navigating an ePHR was one of the most common barriers referred to in the included studies. Use of problematic medical jargon, confusing information display, and unclear presentation of information based on patients’ knowledge (e.g., unclear numeral values and unfamiliar medical terms) were only some of the barriers that prevented effective ePHR use (33, 35, 38-41, 46, 50, 51, 60, 61, 69, 77, 79, 80, 83).

3.5. Characteristics of chronic disease

3.5.1. Attitudes on negotiated collaboration and preferences for self-regulation

On the one hand, the feeling of having more control over the disease was a reason for limited portal use by patients (34, 60, 80). Providers also doubted whether patients who were proficient at monitoring their disease were the right group to benefit from ePHRs (80). On the other hand, being an active healthcare consumer and having a worse or higher proportion of co-morbid conditions and taking more prescribed medications were linked to ePHR use (34, 45, 55, 67, 85, 90). It was also noted that patients’ willingness to take responsibility for their health through ePHR depended on their coping style and perceived competence and autonomy (72). In a study, patients who “felt too confronted when monitoring the course of their illness” dropped out of an ePHR (81).

3.5.2. The perceived complexity of care

Based on the task-technology-fit model, a study found instances of mismatches between user mental models and the technology, which manifested primarily as vocabulary misunderstandings, as portal functionality that did not perform as the patient expected, and as requests for clarification and help (33). They did not have a very concrete understanding of how health information management tasks and processes underlying the ePHR worked.

3.5.3. Characteristics of healthcare settings, providers, and chronic illnesses

In one study, patients in rural settings were less likely to use ePHRs compared with those in urban settings (34). However, if patients received care at multiple sites, they were more likely to use ePHRs. Patients acknowledged the need to consolidate data produced by multiple providers and scattered in different locations through ePHRs (33). A lack of interoperability between ePHRs and EHRs in provider offices was noted in three studies resulting in excess workload and frustration (46, 51, 92). In a survey of patients from 29 states across the US, with at least 38 different types of portals, 51% reported having two or more portal accounts creating frustration when it came to patients remembering their names, and managing different portals from different providers (57). This was a concern in another study, too (66).

Another problem was confusion over who should receive and reply to messages on the provider team i.e., a physician, a nurse, the office staff, or the entire care team; because this would impact the content of patient messages (37, 46, 87). In another study, patients had unsatisfactory communications with the care team through a portal; for example, they failed to track their health issues in a coherent way (43). Physicians were concerned about clarity about responsibilities (and potential liabilities) related to responding to patient-added information or commentaries seen by several different clinicians (36). For the sake of clarity, Table 2 provides a summary of provider-specific barriers.

[Table 2]

3.6. The methodological quality of the included studies

Appendix C provides the results of the quality check for included studies. There were some quality issues mainly about data collection and interpretation in four studies (5, 88-90). Because the MMAT discourages excluding studies based on methodological quality, we did include all 60 identified studies in our analysis and report.

4. Discussion

Understanding barriers that prevent realizing the ePHR’s full benefits is a prerequisite to future work aimed at its optimal use. Our comprehensive review identified 60 relevant studies, which reported barriers to ePHR adoption/use associated with the interacting factors of personal, environmental/medical practice, technology, and chronic disease condition. Our findings expand on those of earlier reviews (18, 19) and point out that our knowledge base for this topic is still limited (and one dimensional), with most of the research predominantly focusing on facilitators than barriers and also on barriers at the patient level than those existed beyond the patient level in chronic disease care.

Differences among users of health information technology (HIT) and the implication of their needs and requirements for design and development have recently gained further attention (93-96). ePHRs are aiming to empower patients and/or caregivers and engage them in collaborative and productive chronic
Most of the healthcare systems have important constraints in terms of human resources shortages, inadequate infrastructure, and insufficient finances, which require mindful management to operate and maximize efficiency (99). ePHRs have the potentials to do so by facilitating self-care and virtual visits. However, in the context of ePHR use, the responsibilities of patients and providers are changed in many ways. For example, they need to make sure that the data available in different locations are accurate, integrated, and updated (3). This is important particularly because data about chronic care is scattered throughout different EHRs that do not speak together, and then, the task of data integration is informally delegated to patients. ePHRs can be used meaningfully if they are implemented as a component (i.e., a tool for self-management) of comprehensive care models developed for chronic care (such as the Wagner’s Chronic Care Model (100)). If such models are implemented and proper links are made among their components (i.e., self-management, clinical information systems, disease registries, and decision support systems), patients are freed from extra responsibilities and can focus on productive “self-management” through an ongoing collaborative process with their providers via ePHRs. Therefore, as the adoption of ePHRs are very related to the adoption of EHRs, the barriers related to EHRs in the first place and then the interoperability between these two should adequately be addressed (17, 21, 27). For example, providers should consider ePHRs’ potentials and their fit within the information infrastructure of their practice when they commence investing in EHRs and choosing their vendors. This becomes especially important after changes that the outbreak of the novel coronavirus disease has brought up to the current and future practice in terms of managing virtual visits. Unfortunately, discussion on such issues has been underrepresented in the identified studies, which should be taken into account in future research.

Our review shows that the barriers related to the providers and the organization of chronic care have not fully been studied despite their importance (studied by only 8 studies). The lack of provider interest and even their resistance to adopting ePHRs are important (3, 12, 21, 101). Provider concerns about the impacts on workload, professional/legal liabilities, relationships with patients, and the lack of reimbursements should be fully addressed (15, 21, 102, 103). Moreover, their involvement in ePHR use has not been given full attention as it deserves. In a review of 19 ePHRs, only half had enabled user actions taken by physicians (17). Providers can act as an effective catalyst in this regard by practicing their social influence on patients (104). Scholars have highlighted that without involving providers in ePHR’s design, implementation, and application and without addressing their barriers, efforts for widespread ePHR adoption/use would be in vain (3, 105, 106). Therefore, it will be insightful if future studies explore in more depth provider issues and how they can further be engaged with this emerging technology in chronic care.

Functionalities of ePHRs that provide solutions for personalized needs and requirements of chronic patients have important implications for their adoption and use, as also emerged in our review (17, 19, 74, 91, 107). One review suggested that features such as access to personal health data and general health information, communicating with providers and support groups, and receiving personal decision support were linked to empirical evidence of benefits from ePHR-enabled self-management (19). Yet, no ePHR in that review described a platform for all those features. Furthermore, the necessity for measures to ensure the privacy and confidentiality in record transactions and communication through ePHRs was a serious concern voiced by clinical directors and health information technology leaders, besides patients (12, 45, 47, 49, 53, 59, 66, 69, 73, 77, 79, 81). The relevancy of this concern has also been highlighted elsewhere (20, 21, 27, 97, 108). Reviewing privacy policies of 24 ePHRs showed that such concerns are very relevant and that compliance with privacy standards and regulations were generally low (14). It has been recommended that institutions should assemble governance groups to develop policies regarding security, privacy, and confidentiality of records to assure ePHR users on preserving their rights (12).

4.1. Strengths and weaknesses of our review

To our knowledge, no study to date has analyzed ePHR studies exclusively concerning barriers to its adoption and use in chronic care. Nevertheless, our review has several limitations. First of all, we only included studies published in English. Second, facilitators and barriers to the adoption of technology is a complex concept without an agreed-upon research methodology. It is plausible that many of the discussions about these core concepts have appeared only in non-peer-reviewed or research publications such as white papers, perspectives, editorials, etc. The findings of our systematic review are confined by the content of included articles, and hence may not well reflect a proper balance of what is known on the topic. Such reviews, however, point out the gaps and direct future studies. Third, ePHRs are an evolving technology with new features and functionalities and so is their position in chronic care. Therefore, the barriers identified in this review are possibly not generalizable to all patient populations or different implementation strategies and healthcare systems. For example, a majority of studies are from the US and therefore a Western viewpoint is predominant here. Therefore, it should be born in mind that the barriers faced by users might be different in different healthcare contexts.

5. Conclusion
If we are to reap the full benefits of ePHRs in chronic care, we ought to understand the unique characteristics of this type of care and the barriers and challenges that ePHR users face in adoption and sustained use, in the first place. This knowledge should be used to make ePHR functionalities that fit in these unique characteristics well. Future research must aim at identifying the barriers experienced especially by younger chronic patients and their requirements and expectations, and also those barriers faced by care providers all beyond the patient level. A deeper understanding of these barriers will reveal opportunities that if addressed in the design, development, and implementation can lead to the enhanced use of ePHRs.

Abbreviations

- electronic Personal Health Records (ePHRs)
- Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- Institute of Electrical and Electronics Engineers (IEEE)
- Health Information Technology for Economic and Clinical Health Act (HITECH)
- Electronic Health Records (EHRs)
- The United States (US)
- Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA)
- Mixed Methods Appraisal Tool (MMAT)
- Personal Health Records Adoption Model (PHRAM)
- Unified Theory of Acceptance and Use of Technology (UTAUT)
- Health Information Technology (HIT)
- Urmia University of Medical Sciences (UUMS)

Declarations

Ethics approval and consent to participate

According to our institution’s research ethics policies, a review study did not require an ethics approval or any consent for participation in the study.

Consent to publish

This study does not include any confidential information. Then, consent for publication is not applicable.

Availability of data and materials

All data generated or analyzed during this systematic review are included in this published article [and its supplementary information files].

Competing interests

None

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Authors’ contributions

ZN, ET, MCK and HP designed the study and the search strategy. ET conducted the systematic search. ZN, ET and MCK screened the titles and abstracts and reviewed full texts of articles and extracted data. ZN wrote the early version and revised it according to ET, MCK, AG and HP’ comments. ET, MCK, AG and HP contributed in the interpretation of the results. HP conducted the quality check of the included studies. ZN, ET, MCK, AG and HP read and approved the final version.

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Tables

Table 1. Studies providing information on barriers to PHR adoption and use in chronic care
| Authors (year of publication) | Study objective | Research method | Country | Features of PHRs (if any) | Integration with EMR/EHR | PHR’s target chronic patient population | Study participants | Main or related objective current: |
|------------------------------|-----------------|-----------------|---------|---------------------------|------------------------|-----------------------------------------|-------------------|----------------------------------|
| Lober et al. (2006) (1)      | To evaluate the barriers faced by a low income, elderly population in creating and using a personal health record. | Qualitative     | The USA | A Personal Health Information Management System (PHIMS), allows viewing personal demographics, past surgeries and immunization records, environmental factors and foods, medications and allergies to medications, also with capabilities of messaging with provider, sharing printed version of information with providers or family | Untethered       | Adults elderly patients           | 38 elderly residents of a nursing home, many had chronic disease | - Health literacy: - Physical cognitive of elderly - Problem access to computer owning a and acces assistant system (e available or social) |
| Hess et al. (2007) (2)       | To explore challenges to office-based implementation of a patient portal and initial patient reaction to the technology in the context of diabetes care | Qualitative     | The USA | University of Pittsburgh Medical Center (UPMC) HealthTrak (a patient portal) allowing to view test results, medication and problem lists, and health reminders, secure, electronic communication with the physician’s office, to view and schedule appointments, and disease-specific tools and information plus self-management tools for weight and blood pressure monitoring | Tethered         | Adults diabetic patients          | Diabetic patients | - Patient inefficiency - missing lab results - radiology inaccurate data - inconsistent responses from physician nurse. - Barriers including unknown and pass unware of features (HealthTrak) possible to of patient not just the care physician lack of computer |
| Zickmund et al. (2008) (3)   | To discern the impact of the provider–patient relationship on interest in using a web-based patient portal | Qualitative     | The USA | - “HealthTrak”, a patient portal originally offered online information, laboratory results, and an encrypted and secure method for e-mailing messages. The enhanced version for diabetes patients allowed them to track glucose, blood pressure, and physical activity records online entered by them | Tethered         | Adults diabetes patients          | Patients with diabetes | - Diabetes use was limited patient satisfaction with the provider - so as part of a satisfyn patient re appeared of the patient - Barriers the system - lower computer literacy required - Fear of personal communication with their primary physician - sending emails (o) portal fun - Concern the office reading the messages the patient that the patient the the email through the portal |
| Britto et al. (2009) (4)     | To evaluated the usability of “MyCare Connection” portal for parents of children with cystic fibrosis, diabetes or arthritis. | Mixed           | The USA | Web-based secured web application allowing to view demographic and contact information; laboratory, radiology and pathology reports; inpatient and outpatient encounters; | Tethered         | Children with cystic fibrosis, diabetes or arthritis | Parents of children with cystic fibrosis, diabetes or arthritis | - Clarity of issues included - children comprehension messages - least in that satisfactory - A number of problems issues inc |
| Source | Objective | Design | Country | Setting | Participant Characteristics | Technology Description |
|--------|-----------|--------|---------|---------|-----------------------------|------------------------|
| Kim et al. (2009) | To assess the use and utility of PHRs in a low-income, elderly population | Quantitative | The USA | Untethered | Adults elderly chronic patients | A stand alone, individually controlled, Web-based repository of personal health information allowing users to enter, update, or delete structured information in nine different categories. It provides summary pages that list all the information entered into the system by the user. A hardcopy and/or electronic copy can be shared with health care providers or family members. |
| Sarkar et al. (2010) | To examine use of an internet-based patient portal among a well characterized cohort of English-speaking adult patients with diabetes differed between those who report limited health literacy versus those who do not. | Quantitative | The USA | Tethered | Adults diabetes patients | An internet based patient portal allows viewing laboratory test results, sending email to providers, requesting medication refills, and making medical appointments. |
| Weppner et al. (2010) | To evaluate use of a web-based shared medical record (SMR) between older patients with diabetes and providers. | Quantitative | The USA | Tethered | Adults diabetes patients | A web-based shared medical record allowing a secure messaging with health care providers, request medication refills and in-person appointments; and view test results, after-visit summaries, medical problem lists, allergies, and immunizations. |
| Wagner et al. (2010) | To examine patient perspectives on ePHR use and functionality as part of the development process of an existing ePHR | Qualitative | The USA | Untethered | Adult patients with hypertension | My HealthLink, an ePHR enabled consumers to store personal health information with core functions of secure messaging; access to educational materials; medication interaction checking; recording and monitoring health measures, for example, blood pressure; and goal setting and health diaries. |

*Note: * Overload: systems were not comprehensive or easy to use; informatics requiring interpretation; explainatiks help optimal holder an catching s instructio needed. Most system us while assi graduate students stafer was the reside.
| Study (Year) | Design | Country | Description | Sample Size / Characteristics |
|-------------|--------|---------|-------------|-------------------------------|
| Nordfeldt et al. (2010) (9) | Qualitative | Sweden | A Patient portal called “Diabit” containing specific diabetes-related information and social networking functions such as message boards and blogs and allowing medical prescription renewal, making appointments, sending questions, viewing questions and answers, contact information, photos of staff, and other general information about the local diabetes teams and their services. Used by patients, parents and providers. | 16 mothers and 3 fathers of sick children, and 5 young patients (11-18 years old) |
| Goel et al. (2011) (10) | Quantitative | The USA | MyChart, a patient portal allowing a patient to log-on to a secure portal to access personalized health information, including laboratory results and a medication list and sending secure electronic messages to physicians. | 16 mothers and 3 fathers of sick children, and 5 young patients (11-18 years old) |

- Desire to those patients’ and parents’ attitudes toward a local Web 2.0 portal tailored to young patients with type 1 diabetes and their parents and opportunities and obstacles to the application of the system.
- To explore patients’ and parents’ attitudes toward a local Web 2.0 portal tailored to young patients with type 1 diabetes and their parents and opportunities and obstacles to the application of the system.
- To identify patients’ and parents’ attitudes toward a local Web 2.0 portal tailored to young patients with type 1 diabetes and their parents and opportunities and obstacles to the application of the system.

- The experiential control of secure websites as a treatment period of reason for use of the portal.
- Previous contact with practitioners regarding sufficient experience with diabetes management and perceived success related to the portal.
- Various user experiences as few hits specific to seeing the portal had been little to none and up-to-date of the portal. Creating the portal that the patients were not "toes".
- Issues with password.
- Users with particular feelings about disease and care experience might not go through procedures on a different portal.

- Reasons for enrolling: remembering the patients’ and parents’ attitudes toward the portal.
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- Reasons for enrolling: remembering the patients’ and parents’ attitudes toward the portal.
| Reference | Study Objective | Study Design | Setting | Population | Sample Size |
|-----------|-----------------|--------------|---------|------------|-------------|
| Tenforde et al. (2011) (11) | To measure the association between use of an advanced electronic medical record-linked PHR and diabetes quality measures in adults with diabetes mellitus (DM). | Quantitative | The USA | MyChart, the Cleveland Clinic’s electronic medical record (EMR)-linked PHR, allowing to access patient’s’ diagnoses and co-morbidities, laboratory and other test results, along with secure messaging through the PHR with their provider. Patients can also access glucometer readings, a set of diabetes-related health and wellness links, and diabetes specific health reminders (including recommended glycated hemoglobin, urine albumin, and cholesterol testing due dates, recommendation for pneumococcal vaccination, and due dates for diabetic foot and dilated retinal eye exams). | Tethered | Adult diabetes patients | 4,036 diabetes patients |
| Sarkar et al. (2011) (12) | To examine patient use patterns of an innovative internet-based patient portal within a well-characterized large, diverse cohort of adult medically insured patients with diabetes | Quantitative | The USA | An internet-based patient portal allowing to view laboratory test results, email physicians or care team, request medication refills, and make appointments. | Tethered | Adult diabetes patients | 5671 diabetes patients |

- There was no significant difference for not attending presence disease (1 in 5 patients was cited chronic disease in 71% with disease).
- Addition for not attending they prefer providers discuss health rather than communicating electronic nearly 25% they did not internet is not communicating sensitive information.

- Compare users, PH younger, lower incomes education attainment likely to be Caucasian better adjusted diabetes quality profiles.
Nielsen et al. (2012) (13) To evaluate the use of a secure internet portal in an academic Multiple Sclerosis (MS) Center

Quantitative The USA “PatientSite”, a patient internet portal allowing individuals to manage their clinic appointments (making, canceling, or rescheduling with department administrators), request prescription refills and referrals directly to their physician’s office, view their medical records including labs, pathology, and radiology study results, and communicate directly with their provider regarding non-urgent issues through a secure electronic message system. In addition, PatientSite provided web links to helpful health-related information, an account statement for patient medical bills, and technological support to portal users.

Tethered Adult multiple sclerosis patients 240 multiple sclerosis patients

Wagner et al. (2012) (14) To examine the impact of a PHR in patients with hypertension measured by changes in biological outcomes, patient empowerment, patient perception of quality of care, and use of medical services.

Quantitative The USA My HealthLink, which provided a secure, comprehensive, electronic record that enables consumers to store PHI. This PHR is “allowing to view problem lists and information on medications, allergies, and immunizations Core functions also include: secure messaging; access to educational materials; medication interaction checking; recording and monitoring of health measures, for example, BP; and some goal setting and health diaries.

Tethered Adult patients with hypertension 443 hypertensive patients

Day and Gu (2012) (15) To find out: what factors influence PHR use? Do perception of ease of use influence patient’s engagement with the software? What is about available software that is considered useful by patients?

Qualitative New Zealand PHR linked to their doctor’s Practice Management System (PMS) allows viewing laboratory results, diagnosis, immunizations and medications list Capabilities: interaction patients with their GP, singing patients to system via internet at home and accept electronic invitations

Tethered Adults chronic patients (not specified) Chronic patients (not specified)

Emani et al. (2012) (16) To apply a theoretical model, the diffusion of innovation model, to the study of PHRs and conduct an exploratory empirical study on the

Quantitative The USA Patient Gateway, allowing requests for appointments, prescription refills and referrals, access to certain components of

Tethered Adult asthma, CHF, hypertension, or diabetes patients Asthma, CHF, hypertension, or diabetes patients

Emani et al. (2012) (16) To apply a theoretical model, the diffusion of innovation model, to the study of PHRs and conduct an exploratory empirical study on the

Quantitative The USA Patient Gateway, allowing requests for appointments, prescription refills and referrals, access to certain components of

Tethered Adult asthma, CHF, hypertension, or diabetes patients Asthma, CHF, hypertension, or diabetes patients

Table 1. Description of the studies included in the systematic review.

| Study | Objective | Design | Setting | PHR Type | Tethered | Number of Patients | Key Findings |
|-------|-----------|--------|---------|----------|----------|--------------------|-------------|
| Nielsen et al. (2012) | To evaluate the use of a secure internet portal in an academic MS Center | Quantitative | The USA | “PatientSite” | Tethered | Adult multiple sclerosis patients (240) | ...
| Wagner et al. (2012) | To examine the impact of a PHR in patients with hypertension | Quantitative | The USA | My HealthLink | Tethered | Adult patients with hypertension (443) | ...
| Day and Gu (2012) | To find out: what factors influence PHR use? | Qualitative | New Zealand | PHR linked to Practice Management System (PMS) | Tethered | Adults chronic patients (not specified) | ...
| Emani et al. (2012) | To apply a theoretical model, the diffusion of innovation model, to the study of PHRs and conduct an exploratory empirical study | Quantitative | The USA | Patient Gateway | Tethered | Adult asthma, CHF, hypertension, or diabetes patients | ...
| Tom et al. (2012) (17) | To examine integrated personal health record use patterns among parents of children with chronic disease and compare ratings of care experiences between integrated PHR users and nonusers. | Quantitative | The USA | In "MyGroupHealth" parents access their child's account as a proxy through their own account. Users can viewing: immunizations, test results, after-visit summaries, allergies, medical conditions, health assessments, health plan benefits and medication management. Capabilities: secured messaging and appointment management. | Tethered | Children with chronic disease (types not specified) | Non-adopters reported: on person innovative informatic technology:
- Innovate younger t users and adopters
- Only 50% adopters year colle more cor: 76% of th 71% of la 69% of ot = 0.001).
- Only 41% adopters household $75,000 o compared laggards, innovator other use 0.001).
- Non-ado differ from innovator laggards: status (47 < 0.001).
- In terms health sta adopters lower rati health co innovator laggards, users and reported i health sta innovator also repo: smaller n comorbidi: 2.8) than rejecters, adopters 3.7). The grea relative a ease of us trialability the more value the communic their doct - More po perceptio and secur informati are assoc greater p value of ti.
| Study | Objective | Study Design | Country | Description | Sample Size | Group | PHR Use | Notes |
|-------|-----------|--------------|---------|-------------|-------------|-------|---------|-------|
| Urowitz et al. (2012) | To evaluate the experience of patients and providers using an online diabetes management portal for patients. | Qualitative | Canada | A Patient portal which provides access to “Health Library” for diabetes education material (for both patient and providers) and providers access to “Personal Health Records” for allowing patients to consolidate their personal health information including medical and family history, medication details, lifestyle choices, and test results | Tethered | Adults patients with diabetes | Patients with diabetes and their providers i.e., general practitioners (GPs), nurses, nurse practitioners (NPs), dieticians, diabetes educators (DECs), and other clinical staff | - Technical regarding discovery access to difficult d and diffic items | - Some pa that they controllin diabetes that their measures been fair | - The need | - Informat | - Requires duplicate efforts to | - PHR use | - Those in | - A tool for | - Other care | - Provider | - PHR use | - Place of My | - PHR use | - Patient Mission a | - PHR use | - The organ mission a | - Priori | - Coordina |
| Gordon et al. (2012) | To describe the process and outcome of developing and implementing a personal health record for people living with HIV/AIDS | Mixed | The USA | My health profile allowing to access most recent medication lists, test results, information on healthcare providers and payers, viewing an integrated audit log, and enabling the development a continuity of care document. | Tethered | Adult | Patients living with HIV | - Potential use of My Profile in functional computer | - Privacy and confidential concerns, reluctance to technolog cognitive (e.g., rem password) | - PHR im | - Place of My Profile mission a | - Priori to coordina |
| Logue et al. (2012) | To describe the results of an exploratory study that provided an initial test of a theoretical framework to understand an elderly’s decision to participate in self-directed care. | Quantitative | The USA | Without a PHR | Not applicable | Adult chronic condition | Senior adults with chronic conditions | - Older se reported | - Confidenc ability to | - Based PH not perce | - Place of My Profile mission a | - Priori to coordina |
interested in the use of PHRs. - Those who more about health resources were available online were likely to be motivated by incentives offered with PHRs. - Older adults were less confident in their ability to use the internet, but once they did not report having a computer, they were less likely to give them this ability. Those who reported being able to care about their needs and how to use PHRs more like to express their ability to communicate via written and self-help tools. - Easier access to well-correlated believing offer an advantage over alternative methods, were com current health needs and were likely to give them that they would choose. - Of the respondents who disagreed with the three indicators (16) reporting having access to computer = 17) reporting having access to internet. - Indicate that access is a prerequisite knowing how to use internet and how to use PHRs. - More females than males reported being interested in using a based PHR instead of discussing the likelihood that they would choose a doctor or provider.
| Study & Authors (Year) | Objective | Population | Setting | Approach | Findings |
|------------------------|-----------|------------|---------|----------|----------|
| Britto et al. (2013) (21) | To examine parents' perceptions of the benefits and / or drawbacks of a patient portal for managing their child's chronic illness. | Mixed | The USA | Qualitative | - Many more (28%) were about privacy compared (10%) - Those who work on their healthcare team were likely to be more motivated to share things, knowing health resources available, internet, using an internet-based PHR for them to use PHRs, providers to access them, things that fit between their health needs and interests one - Positive were also seen between the perceived illness reported and more illness reported more like a health-related PHR. The multiple health providers who preferred their own were consistent within the beliefs that they were coming to their current healthcare provider if they were interested in it. |
| Osborn et al. (2013) (22) | To (1) understand who uses an existing patient portal and reasons for use and nonuse, (2) understand how portal users are using a portal to manage their medications, and (3) explore participants' ideas for improving portal functionality | Mixed | The USA | Tethered | Tethered | Parents of children with cystic fibrosis, diabetes mellitus, or juvenile idiopathic arthritis: - A potential on the loss of interpersonal communication with providers - Some parents preferred a provider who was more like the health-based PHR. |
| Study | Design | Country | Patient Portal Features | Tethered | Diabetic Patients | Diabetic Patients of Age | Findings |
|-------|--------|---------|--------------------------|----------|------------------|------------------------|---------|
| Ronda et al. (2013) (23) | Quantitative | The Netherlands | A patient portal allowing users to access their medical records, including the information provided by their healthcare provider during medical consultation, such as physical examination, laboratory results, problem lists, and treatment goals. It also provides access to general diabetes information and an overview of all examinations and diabetes visits that are needed according to guidelines. Patients can upload the glucose levels measured at home and seek contact with their care provider through secured electronic messaging | Tethered | Adults diabetic patients types 1 and 2 | Diabetic patients of 18–85 years old | - Reasons included about having access computer family members as an online tool |
| Wade-Vuturo et al. (2013) (24) | Mixed | The USA | A patient portal which called “MyHealthAtVanderbilt (MHAV)”. Users can view EHR data, use secure messaging to communicate with providers, manage medical appointments and bills, and perform other tasks. | Tethered | Adult diabetes patients type 2 | Patients with type 2 diabetes | - The part of login was significant compared without. C participants login, 63.1% male compared without login, 56.5% of diabetic patients were younger. Type 1 patients were you a higher ϵ level. Follow guidelines for diabetes treated by a general practitioner. Type 2 diabetic patients had been treated with diabetes longer time. Insulin was frequently used more compared without a login. Patients with a login sign perceived diabetes distress and with login less self-<sup>-</sup> less lower diabetes knowledge. With increased patients education patients Dutch flu patients were job, where decreased treated by care phys internist) alone. |
| Source                        | Objective                                                                 | Research Design | Setting                          | Primary Population | Population Characteristics                                                                 | Relevant Findings                                                                                                                                 |
|-------------------------------|---------------------------------------------------------------------------|-----------------|----------------------------------|--------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|
| Lyles et al. (2013) (25)      | To examine the associations between patient ratings of provider communication or trust with portal use in diabetes patients. | Quantitative    | The USA                          | Tethered           | Adults diabetics patients                                                                     | Diabetes patients - There was a significant adjusted association between patient/provider trust and registered portal use. - Among patients over 5 years of age, there was a significant association between trust and portal registration. - After adjustment, there was a significant association between patient trust in the provider and overall secure message usage. |
| Pai et al. (2013) (26)        | To determine the experience of, and feedback from, prostate cancer patients using a PHR, while receiving care from a provincial cancer agency. | Mixed           | Canada                           | Tethered           | Adult patients with prostate cancer                                                             | Male patients with prostate cancer - Mixed recall of clients should be performed. PHR use was lower among patients under 50. Besides other options, patients felt that the government should fund the PHR. - Several difficulties arose. *Provider* was an integrated system to store and access the medical records of patients. With access to laboratory, pathology, imaging, operative, and procedure reports, scheduling and appointment information, secure messaging patient-provider and etc. |
| Martinez et al. (2013) (27)   | To identify the characteristics of PHR users versus non-users              | Quantitative    | Argentina                        | Tethered           | Adult chronic patients                                                                         | Chronic patients with hypertension, diabetes, dyslipidemia, cerebral vascular disease, coronary artery disease, chronic heart failure, chronic renal failure, peripheral vascular disease, and smokers - PHR use was lower among patients under 50. Besides other options, patients felt that the government should fund the PHR. - The main barrier was lack of computer access. |
| Luque et al. (2013) (28)      | To assess barriers and facilitators to use of online PHRs among patients   | Mixed           | The USA                          | Tethered           | Adult patients living with human immunodeficiency virus                                       | - Lack of broadband also affected secure messaging. - Patients living with human immunodeficiency virus were less likely to use the PHR. |
| Study | Research Question | Study Design | Setting | Intervention | Sample Size | Key Findings |
|-------|-------------------|--------------|---------|-------------|-------------|--------------|
| Byczkowski et al. (2014) | To assess parents understanding of the importance of PHR, their concerns for using web-based portals for their children's diseases | Mixed | The USA | Tethered | 16/90,18 | Barriers to use (5/|
| Fiks et al. (2014) | To design a portal to facilitate shared decision making between families of children with asthma and primary care clinicians based on user-identified criteria and integrated within the EMR | Qualitative | The USA | Tethered | Children with asthma | 7 parents of children with asthma and 51 care providers |
| Sharp et al. (2014) | To characterize the knowledge, interest, and attitudes of childhood cancer survivors and their caregivers towards ePHRs. | Qualitative | The USA | Tethered | Children with cancers | Caregivers of survivors who were <14 years old and also survivors ≥14 years old along with their caregivers when present |
| Odlum et al. (2014) | To assess the ease of use and usefulness of My Health Profile (MHP) and to identify the actual information needs of MHP-users and perceived information needs of MHP-users and MHP non-users before MHP-plus roll out. | Mixed | The USA | Untethered | Adults people living with HIV | People living with HIV |
| Barron et al. (2014) | To explore whether older adults with chronic conditions and/or their caregivers demonstrate capacity to use a patient portal, and their perspectives on the experience | Qualitative | The USA | Tethered | Adult chronic obstructive pulmonary disease or congestive heart failure | 14 patients and 19 caregivers |
| Study                  | Research Question                                                                 | Study Design | Country     | PHR Type | Participant Characteristics                                                                                       | Findings                                                                                                                                                                                                                                                                                                                                 |
|------------------------|----------------------------------------------------------------------------------|--------------|-------------|----------|--------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Baudendistel et al. (2015) | To explore needs and requirements of potential users with regard to the content and function of a patient-controlled personal electronic health record | Qualitative  | Germany     | Without a PHR | Adult patients with colorectal cancer, health care providers, clinicians, clinical staff in an umbrella company | - Needs a requirements structure facilitate course of treatment for both patients and patients important information or a prior current is a basic dr relevant i that would for every in the patient care with volume of - The pre informatics in a patient assessable accessible comprehe - Given th several pl from different care setting have PHR physician concerns uncertain negative conseqe professio for reacti added inf comments |
| Gartrell et al. (2015)  | To examine factors associated with ePHR use by nurses for their own health management | Quantitative | The USA     | Different PHRs | Adults chronic patients 664 sick nurses with chronic conditions in 12 hospitals                                  | - A larger ePHR use chronic m condition taking a prescription medicatio compared (65%) (P< - A large | PHR user Internet f (several times compared non-users - A larger ePHR use more aware technology nearly 80% compared approxim nonusers their prior providers used an E (p<0.01) - More ePHR (72%) was concerns general p security o informatics compared (64%, p<1) - Factors with ePHI an active consumer chronic bs condition prescribe medicatio having a l provider i for care,  |
| Gee et al. (2015)       | To learn from chronically ill engaged and educated                                 | Qualitative  | The USA     | Different PHRs (Core functions were not) | Adults chronic patients 18 chronic patients                                                                 | - Health a literacy is |
To understand perceptions of CKD patients about ePHRs, and describe characteristics associated with their expressed intent to use an ePHR.

| Study | Design | Country | PHR Access | Intent to Use | ePHR Benefits |
|-------|--------|---------|------------|---------------|---------------|
| Harrison et al. (2015) | Quantitative | Canada | Without a PHR | Not applicable | Adults patients with non-dialysis-dependent CKD | Patients with non-dialysis-dependent CKD |
|        |        |         |            |               |               | - Patients of 65 who intended to use ePHR |
|        |        |         |            |               |               | - No association between self-perceived importance of ePHR and intension to use ePHR |
|        |        |         |            |               |               | - Those with secondary and tertiary care were more likely to express an intent to use an ePHR |
|        |        |         |            |               |               | - 69.8% of patients in the ePHR group agreed that the ePHR report was a significant benefit of health care |
|        |        |         |            |               |               | - The perceived benefits of ePHR include personalized health care, health management, and lab results |

(e-patient) adults how and why they use PHRs for self-management support and productive patient-provider interactions.
| Reference          | Design Method | Country | Platform/Record | Use | Study Population | Linked to: |
|--------------------|---------------|---------|----------------|-----|------------------|------------|
| Nippak et al. (2015) (38) | Mixed         | Canada  | MyChart: a secure and private web-based platform that offers self-management tools that are entirely accessed and controlled by patients such as diaries to record their health history, symptoms, and medications, emergency contact information as well it provides access to health education sites and appointment scheduling features | Not documented | Adults elderly chronic patients | - Privacy, confident security of electronic record information - The knowledge gap underlining informatics fearing of values - Issues re. use of MyChart - Fears on exchange members workload on comm. between patients |
| Tieu et al. (2015) (39) | Qualitative  | The USA | Patient portals in general/without a specific PHR | Not applicable | Adult chronic patients | 11 patients with chronic illness including diabetes and 5 caregivers |
| Wells et al. (2015) (40) | Mixed         | The USA | Different PHRs across the country | Not applicable | Adult chronic patients in general | - The greater perceived physician workload due to con. to patient's productivity, and diminish interferin ongoing comm. with their |
Latulipe et al. (2015) (41) To investigating facilitators and barriers to adoption of patient portals among low-income, older adults in rural and urban populations older adults in rural and urban populations Qualitative The USA A patient portal in general/Without a specific patient portal Not applicable Adults chronic patients 36 chronic patients and 16 caregivers (chosen from low-income, older adult populations across the country)

- Lack of i
reimburs
interaction
- Not applicable

Smith et al. (2015) (42) To document disparities in registration and use of an online patient portal among older adults. Quantitative The USA A patient portal allowing three main options (message a provider, request a prescription reauthorization, and view test results) with additional options including personal health records (monitoring vital statistics [e.g. height, weight, body mass index, body surface area, blood pressure, heart rate, breathing rate, temperature], previous conditions, and current conditions), previous or upcoming appointments, sent and received messages, personal profile, and a help page.

- White pa
gender, co
graduates
with mar
adequate
literacy w
likely to h
registered
patient po
its option

Eschler et al. (2016) (43) How do individuals characterize their experiences of and expectations for using asynchronous communication strategies to coordinate health care with clinicians? Qualitative The USA A patient portal allowing to view medical test results, visit summaries, immunization lists, allergy lists, medical condition lists, exchanging secure messaging with providers, ordering medication refills, scheduling an in-person appointment

- Failing t
issues fol
secure co
with care
such as a
status ind
unresolve
exposing inco
munication patterns: either a c
written ne
confuses lea
lapses in managem

Schneider et al. (2016) (44) To understand patients' lived experience with a patient-controlled electronic health record (PCEHR) and how the Qualitative The UK A patient-controlled electronic health record, called Patients Know Best It allowed patients and clinicians alike to

- Patients
to take pa
responsibil
health thr

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| Authors | Study Objective | Study Design | Setting | Sample Size | Challenges and Insights |
|---------|-----------------|--------------|---------|-------------|------------------------|
| Hazara and Bhandari (2016) (45) | To evaluate the characteristics and experiences of those patients who have registered for renal patient view but were inactive in using it. | Mixed | The UK | 69 chronic renal patients | - Main reason being in-a mention difficult to use computer password followed by perception not to add anything. - Other reasons were too busy, anxious, or website not working. - No need to use website due to satisfaction with routine care from the renal team. |
| Graetz et al. (2016) (46) | To understand whether socio-demographic differences in patient portal use for secure messaging can be explained by differences in internet access and care preferences. | Quantitative | The USA | 69 chronic renal patients | 1041 patients aged 18 or older who had at least one of the following chronic conditions: asthma, coronary artery disease, congestive heart failure, diabetes, or hypertension. |
| Ryan et al. (2016) (47) | To explore the feelings, ideas and expectations of patients and primary care providers concerning both the implementation and the use of patient portals. | Qualitative | Canada | Without a patient portal/patient portal in general | Not applicable | Adult patients with diabetes, hypertension, asthma, obesity, COPD, thyroid condition, hyperlipidemia and cancer. | 7 patients and 4 providers (i.e., two family physicians, one nurse practitioner and one family practice nurse) | - Challenges related to accessibility of portals, cost, and trust entered into provider-patient relationships. | }

| Arcury et al. (2017) (48) | To determine potentially modifiable factors affecting patient portal utilization by older adults who receive care at clinics that serve low income and ethnically diverse communities. | Quantitative | The USA | The patient portal systems of the urban and rural clinics differed, but included viewing test results, sending a message to doctors or nurses, refilling prescriptions, making or changing an appointment, requesting a referral, finding information about a health issue, and other | Tethered | Adult patients with diabetes, hypertension, dyslipidemia, or cardiovascular disease | 100 patients with diabetes, hypertension, dyslipidemia, or cardiovascular disease | - Patient portal utilization differs by age and gender. | 

- Poverty associates with patient portal utilization those below 150% of the FPL and 53.1% above 200% poverty level utilized the portal.
- Those with greater than a high school education odds of portal utilization.
- Those with current less than portal utilization.
- Receiving urban clinic increased patient portal utilization.
- Those with health utilization.
- More minority participation than white (62.5%) have utilized the portal.
- Lesser electronic health records in their homes vs 1.2%.
- Internet access a day (47% and who experience stress with computer use).
| Authors          | Methodology | Country | System Description                                                                 | Setting Description                                                                 |Patient Characteristics                                                                 |
|------------------|-------------|---------|-------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| Sieck et al.     | Qualitative | The USA | MyChart, an interactive patient portal allowed viewing demographics and test and lab results, schedule appointments, request refills and send secure messages to providers. | Tethered Adult patients with at least one cardiopulmonary condition                  | 13 Family Medicine providers in the department of Family Medicine and 29 of their patients who had at least one chronic condition. |
| Cerdan et al.    | Qualitative | Denmark | The Digital patient booklet, a patient portal for rehabilitation with supportive information and exercise programs for self-management activities. | Not documented Adults patients with heart disease, lymphedema and chronic pulmonary obstructive disease | Patients with heart disease, lymphedema and chronic pulmonary obstructive disease |
| Tieu et al.      | Mixed       | The USA | Web-based PHR with links to online health education library; allows viewing visit summaries, prescribed health education, test results and looking up general health information | Tethered Adult patients with diabetes, hypertension, asthma or COPD, heart disease, heart failure or chronic kidney disease | Patients with diabetes, hypertension, asthma or COPD, heart disease, heart failure or chronic kidney disease and their caregivers and 2 care providers |
| Williamson et al. | Quantitative | The USA | SurvivorLink, a web-based PHR allowing users to upload and store important health documents and electronically share these documents with their providers independent of institutional or practice specific electronic medical records systems. | Stand alone Pediatric cancer patients | Patients with cancer and their parents |
| Peremislov       | Qualitative | The USA | A patient portal allowing patient-provider e-communication (e-mail) | Tethered Adult type 2 diabetes | Patients with type 2 diabetes |

- Concern imposing physician of provide reimburse interaction
- Uncertainty by both patient and provider with messaging
- Patients positive toward use of messaging
- Negative towards technical support for patient and provider
- Negative towards patient and provider
- Negative towards treatment and communication
- Inadequate messaging with patient and provider
- Inappropriateness of messaging topics
- Inadequate messaging with patient and provider
- Inadequate messaging with patient and provider
- Basic difficulty understanding non-health medical terms
- Black PH registrant significance to use the SurvivorLink
- Young adult registrant old or the transition of observants were similar more like SurvivorLink
- Compared 18 (with t parent as
- Of 71 e-communication
communication or e-message encounter) between patients with type 2 diabetes and their providers within the patient portal.

| Price-Haywood et al. (2017) (54) | To examined the relationship between health literacy, portal use status, and interest in using websites or smartphone applications for tracking health information and to identify specific facilitators and barriers to use the portal. | Quantitative | The USA | Tethered Adult patients with hypertension and/or diabetes | 247 patients with hypertension and/or diabetes |
|---|---|---|---|---|---|

- The patient portal of Epic systems called “MyOchsner” allowing patients to securely schedule/cancel non-urgent appointments, request medication refills, send and receive secure messages, view/download their health records, and access medical tools (e.g., wireless or patient-entered flow sheet data)

- The odds of being interested in websites/apps increases total e-health and decreases black patients’ odds of being interested in websites/apps compared nonusers, proportion rated portal use useful.
- e-health positively with high and negative association. The odds usage increases total e-health and decreases black patients’ odds of being interested in websites/apps.

- Portal mostly excellent concerns security of information personalization using technical resources skills. support in computer Internet. not seeing for or value the portal their health
- There were among us computer cumbersome logging in accounts remember password accounts in the same households technical variations availability appointment scheduling response medical
- Patient Advisory identified clear tang incentives for the portal suppleme traditions
| Author          | Primary Objective                                                                                       | Study Design | Setting                  | Type          | Population                                      | Findings                                                                                                                                                                                                                                                                                                                                 |
|-----------------|--------------------------------------------------------------------------------------------------------|--------------|--------------------------|---------------|-------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Price-Haywood et al. (2018) (55) | To examine whether the intensity of bidirectional secure portal messaging is associated with improved clinical outcomes. | Quantitative | The USA                  | Tethered     | Adult patients with hypertension or diabetes    | A higher proportion of patients aged 50 years or older, female non-Hispanic co-morbid and hypertensive, higher frequency of advice to nonusers, were younger, and were from lower zip codes. Among patients, there were proportional non-Hispanic and lower Charlson scores. |
| Ali et al. (2018) (56) | To identify task-technology fit problems and usability challenges in the novel portal, recommend solutions, and to evaluate whether the recommended design changes improved usability. | Mixed        | The USA                  | Tethered     | Adults chronic patients                          | A number of barriers (to use, insufficient guidance portal) - Mismatch of users, technology of a very understated health management - Problem of consolidating medical and scattered multiple sharing. |
| van den Heuvel et al. (2018) (57) | Primary objectives: To test the feasibility of a PHR for bipolar patients To evaluate the user experiences of persons with bipolar disorders (BD) involving informal caregivers, and clinicians. The secondary objective: To examine changes in quality of life, empowerment, symptom reduction, changes in mood and activity, and illness burden and severity. | Quantitative | The Netherlands          | Untethered   | Adult bipolar disorder patients                  | Over a large number of clinicians direct telephone contact in communication through a PHR-BD work, the perceived value, we and felt to be part of the process. Participating clinicians perceived the PHR due to increased privacy of might be and might communic. |
| Study                          | Objective                                                                 | Methodology   | Location     | Patient Portal Characteristics                                      | Sample Size/Characteristics                                 | Findings/Concerns                                                                 |
|-------------------------------|---------------------------------------------------------------------------|---------------|--------------|---------------------------------------------------------------------|-----------------------------------------------------------------|--------------------------------------------------------------------------------|
| Latulipe et al. (2018) (58)   | To examine how older adult patients perceive the benefits and risks of proxy patient portal access by their caregivers. | Qualitative   | The USA      | A patient portal (no details available)                             | Not documented                                                  | Adult patients with diabetes, hypertension, dyslipidemia, or cardiovascular disease  |
|                               |                                                                           |               |              |                                                                     |                                                                  | 10 patients with diabetes, hypertension, dyslipidemia, or cardiovascular disease | - Concerns about the premature adoption of technology and the lack of compatibility with existing health information systems. |
| Nahm et al. (2018) (59)       | To examine the current state of older chronic patients’ patient portal use and their experiences with patient portal training. | Mixed         | The USA      | At least 38 different patient portals across the country            | Not applicable                                                  | Adult patients with at least one chronic disease including hypertension, arthritis, depression, and others |
|                               |                                                                           |               |              |                                                                     |                                                                  | Patient with at least one chronic disease including hypertension, arthritis, depression, and others | - Patient knowledge and efficacy of Portal use was relatively average (5.2 ± 1 mean self PP use of portals) |
|                               |                                                                           |               |              |                                                                     |                                                                  | - Having trouble remembering one’s login credentials.           |
|                               |                                                                           |               |              |                                                                     |                                                                  | - Participants perceived the portal as useful if their health data was low, mean of 28.7. |
| Powell and Myers (2018) (60)  | To explore how patients are introduced to and learn about portals and how patients and providers perceive the usefulness of a portal in the context of chronic illness self-management. | Qualitative   | The USA      | Web based electronic patient portals in general                    | Not applicable                                                  | Adult patients with multiple chronic conditions (diabetes, hypertension, heart disease, or coronary artery disease) |
|                               |                                                                           |               |              |                                                                     |                                                                  | 9 patients and 7 healthcare providers                            | - Difficulty identifying the portal password or server. |
|                               |                                                                           |               |              |                                                                     |                                                                  | - Multiple specific problems identified by both patients and providers. |
|                               |                                                                           |               |              |                                                                     |                                                                  | - Unavailability such as connection errors in changing pharmacy |
|                               |                                                                           |               |              |                                                                     |                                                                  | - Many patients preferred interacting with a human person rather than the portal. |
|                               |                                                                           |               |              |                                                                     |                                                                  | - A number of specific issues related to financial concerns, regulatory, and payment providers. |

Abbreviations: personal health records (PHR), electronic medical record (EMR), electronic health record (EHR), chronic kidney disease (CKD), Odd Ratio (OR) chronic obstructive pulmonary disease (COPD), bipolar disorders (BD), human immunodeficiency virus (HIV), my health profile (MGP), the United States of America (the USA), the United Kingdom (the UK).
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[1] In the chronological order of publication year

Table 2. Barriers to the adoption and use of care providers on the basis of the UTAUT
| Factors | Citations |
|---------|-----------|
| Healthcare provider characteristics |  |
| IT experience and knowledge, years in practice, role, age, gender, race |  |
| Medical practice characteristics |  |
| Practice size, teaching status, location, single-multispecialty, practice level, types of third party payers, patient age range |  |
| Voluntariness of use |  |
| Perceived voluntariness |  |
| Performance expectancy |  |
| Perceived usefulness and needs | Physician resistance due to concerns about the impact on their patients (2) Need to meet provider requirements for example by a structure to facilitate tracking the course of illness and treatment over time; highlight important or new information with color or a priority for current issues; include a basic dataset of relevant information that would be crucial for everyone involved in the patients’ health care with manageable volume of information (3) |
| Relative advantage |  |
| Job-fit | Provider concern on overreliance of patients on portals when exacerbations in their condition occur (4); provider belief that patients should view PHRs as access to care for chronic condition and not for an acute flare in their condition (5); uncertainty about how the patient should use the messaging function of PHR to communicate with providers (6) |
| Reimbursement and financial incentives | Concerns about lack of provider reimbursement for provider interactions via the portal and discussions around how to better reimburse for interactions (1,5,7) |
| Effort expectancy |  |
| Perceived ease of use | Concerns on system interface that need to be simple and the content be clear (5); provider concerns on the ability of patients to understand and interpret the content of portals (7) |
| Ease of use |  |
| Complexity |  |
| Social influence |  |
| Subjective norms competition, supportive organizational culture for change, friendship networks, |  |
| Facilitating or inhibiting conditions |  |
| Computer self-efficacy |  |
| Computer anxiety |  |
| Legal concern | Physician concern and uncertainty regarding negative consequences on professionals’ liability for reacting to patient-added information or commentaries when several physicians from different healthcare settings would have PHR access (3) |
| Financial constraints |  |
| Availability of ICT infrastructure | Difficulty accessing the portal due to computer or server problems (8) |
| Time cost | Impact on provider workload and the required provider duplicate time and efforts to handle issues related to the PHR use parallel to those in the office time (1,3,5,6,7) |
| Interoperability | A lack of compatibility with existing hospital electronic medical record systems (9) |
| IT support |  |
| eHealth and business process alignment | A number of regulatory barriers causing provider frustration for example by the amount of data required to be monitored for insurance services, as well as by being told how to practice (6) |
| End user involvement |  |
| Management commitment and support for change |  |
| Uncertainty about IT vendor |  |
| Professional autonomy | Honesty and trust of providers on the data entered by patients (7) |
| Interference with healthcare provider-patient relationship | The primacy of (and preference for) direct patient-provider relationship particularly in special circumstances (6,7,8) |
| Patient privacy concerns | Provider concerns on the privacy and confidentiality of patient information (6,8) |

Note: Only 9 out of 60 identified studies involved care providers as study participants to evaluate PHR adoption barriers faced specifically by providers.

a the degree of a healthcare provider’s perception of uncertainty over return on monetary investment (according to Li et al. Interactive journal of medical research 2013;2;1/e7)

b the degree of a healthcare provider’s perception of high monetary cost for adopting eHealth system (i.e., start-up costs and ongoing maintenance costs, and the availability of financial resources to cover the cost (according to Li et al. Interactive journal of medical research 2013;2;1/e7)

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[1] For details on the definition of factors, please refer to 1. Venkatesh V, Morris MG, Davis GB, Davis FD. User Acceptance of Information Technology: Toward a Unified View. MIS Quarterly. 2003;27(3):425-78

**Additional Materials**

Supplementary material_appendix A: The search strategy in the electronic databases used in our study

Supplementary material_appendix B: The main reasons for exclusion of articles

Supplementary material_appendix C: Quality of included studies by the MMAT tool

**Summary table:**

- Barriers to ePHR adoption/use, with special focus in chronic care has not been well described and understood
- Addressing barriers for ePHR adoption/use in chronic care should cross the boundary of patient level barriers
- Barriers at the provider and healthcare organization levels should be understood and addressed, thoroughly
- ePHRs should fit in the structure of “chronic care models” developed for improving chronic care

**Figures**

![Figure 1](image-url)
Flow diagram of study selection (literature search January 1, 2005 till December 31, 2018)

**Supplementary Files**

This is a list of supplementary files associated with this preprint. Click to download.

- SupplementaryfileAppendixA.docx
- SupplementaryfileAppendixB.docx
- PRISMA2009checklist.doc
- SupplementaryfileAppendixC.docx