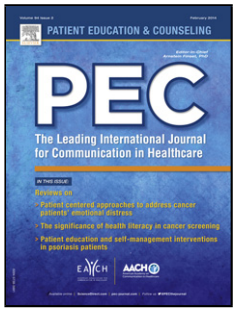
Accepted Manuscript



Title: The health literacy demands of electronic personal health records (e-PHRs): An integrative review to inform future inclusive research.

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PII: S0738-3991(17)30423-8
DOI: http://dx.doi.org/doi:10.1016/j.pec.2017.07.010
Reference: PEC 5741

To appear in: *Patient Education and Counseling*

Received date: 6-2-2017
Revised date: 26-6-2017
Accepted date: 8-7-2017

Please cite this article as: Hemsley Bronwyn, Rollo Megan, Georgiou Andrew, Balandin Susan, Hill Sophie.The health literacy demands of electronic personal health records (e-PHRs): An integrative review to inform future inclusive research.*Patient Education and Counseling* http://dx.doi.org/10.1016/j.pec.2017.07.010

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The health literacy demands of electronic personal health records (e-PHRs): an integrative review to inform future inclusive research.

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Highlights

- There are many health literacy demands of ePHRs which affect user groups.
- The attitudes and beliefs of patients and providers impact on the use of e-PHRs.
- Most research on e-PHRs has focused on patients with chronic health conditions.
- Implementation research that is inclusive of diverse patient groups is needed.

Abstract

Objective: To integrate the findings of research on **electronic** personal health records (e-PHRs) for an understanding of their health literacy demands on both patients and providers.

Methods: We sought peer-reviewed primary research in English addressing the health literacy demands of **e-**PHRs **that are online and allow patients any degree of control or input to the record.** A synthesis of three **theoretical** models was used to frame the analysis of 24 studies.

Results: **e-**PHRs pose a wide range of health literacy demands on both patients and health service providers. Patient participation in **e-**PHRs relies not only on their level of education and computer literacy, **and attitudes to sharing health information,** but also upon their executive function, verbal expression, understanding of spoken and written language**.**

Conclusion: The **multiple** health literacy demands of **e-**PHRs must be considered when implementing population-wide initiatives for storing and sharing health information **using these systems.**

Practice Implications: The health literacy demands of **e-**PHRs are **high** and **could potentially** exclude **many** patients unless strategies are adopted to support their use of these systems. **Developing strategies for *all* patients to meet or reduce the high**

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health literacy demands of e-PHRs will be important in population-wide implementation.

Keywords: Personal health records, PHR, e-PHR, health literacy,communication skills, communication impairment, disability, health

The health literacy demands of electronic personal health records (e-PHRs): an integrative review to inform future inclusive research.

1. Background

1.1 Introduction to the research

The past two decades have seen much development in health **Information Communication Technology (ICT)** relating to electronic personal health record (**e**-PHR) systems developed to support the delivery and management across the care pathway in health systems [1]. **e**-PHRs are designed to enable some aspect of patient engagement with and/or management of health information that is accessed and shared using a web-based system [2]. National **e**-PHR systems are used by Governments and health services to improve the exchange of health information between patients and healthcare providers [1, 2, 3]. Improved patient-provider communication, and the improved exchange of information across health service providers, is central to increasing the quality and safety of health care [4], and to creating efficiencies in health systems facing increasing demands on resources with the ageing of the population.

Recent reviews of literature on PHR systems (e.g., [5,6,7,8]) provide details on the types and features of **e**-PHRs, including applications, benefits, and barriers associated with use, and their effect on patient or consumer health outcomes [1, 6, 7, 8]. However, there is scant discussion on the health literacy demands of **e**-PHRs

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which enable the patient some control in terms of the sharing of the information or the upload of information. This may be due in part to these systems being relatively new and evolving with **digital** health **innovation;** a paucity of rigorous research on the outcomes and benefits of using **e-**PHRs in the general population**;** and research to date having a focus on people's views**,** rates of uptake and use**,** and barriers and facilitators for adoption**,** rather than on e-health literacy or health literacy demands of the systems.

In 2011, Archer et al., [7] reviewed 130 papers on PHRs in Canada and USA (92 of which reported on research) to describe their "design, functionality, implementations, applications, outcomes, and perceived and real benefits" (p. 515). Archer et al., predicted that adoption rates of PHR would be low "except for the disabled, chronically ill, or caregivers for the elderly" (p. 515). The impact of electronic patient portals on patient care has also been systematically reviewed [6]. From 1,306 references, with just five papers from four studies meeting the criteria for inclusion (including patients in general, or patients with diabetes mellitus, congestive heart failure, or in-vitro fertilisation), Ammenworth et al., [6] concluded that the number of controlled trials on the outcomes of **'**patient portals**' (one type of e-PHR)** was low and there was insufficient evidence to support the assumption that use of patient portals empowers patients. Price et al., [8] systematically reviewed research evaluating **e-**PHRs to determine which people with specific health conditions were sensitive to benefit from **e-**PHRs, and included 23 papers, 7 of which were randomized controlled trials. The authors identified 10 conditions represented across study participants (asthma, cancer, diabetes, fertility, glaucoma, HIV, hypertension, idiopathic thrombocytopenic purpura, lipids, multiple sclerosis), with PHR use benefitting populations with asthma, diabetes, fertility, glaucoma, HIV,

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hyperlipidemia, or hypertension. The authors [8] concluded that people with health conditions and evidence of benefit from PHRs tended to have "chronic conditions with a feedback loop" (p. 15), that is, where monitoring functions in the PHR were used with self-management of the health condition.

1. 2 Gaps in PHR Research: Under-researched Populations

Despite **a growing body of evidence** on PHRs, **particularly relating to populations with chronic health conditions (e.g., diabetes, cancer)** there is as yet little research examining how **other patient groups with long-term conditions** (e.g., people with disability and multiple health conditions) might benefit from use of PHRs to communicate their health information [9, 10**].** In 2013, Showell and Turner [11] searched for evidence on the design, implementation and evaluation of PHRs and from 73 full text articles and 29 abstracts found only 7 articles and 1 abstract mentioning patients in 'disempowered, disengaged and disconnected' groups, noting that these disadvantaged patients were frequently excluded from the design process for PHRs or discouraged from access owing to lower socioeconomic status. They concluded **that** "health informatics professionals rarely consider the needs of all users when designing, implementing, or evaluating PHRs" [11, p. 1037] and that consequently solutions for advancement of healthcare could "increase the extent of disadvantage and exclusion experienced by this high-risk high needs group." [11, p.1037]. **Although PHR adoption is expected to be higher among the disabled [7] little is known about how patients with disability (e.g., cerebral palsy, intellectual disability, stroke, autism)** are engaging with **PHR** systems [2, 11].

In a historical review of PHR research in PubMed, Kim et al., [5] located 229 PHR studies, **and noted** a rapid increase in publications from **the year** 2000 onwards, attributed to the increased use of internet and communication technologies

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and advancements in functionality of PHRs. The majority of studies reviewed related to health management and promotion, and the diseases diabetes mellitus and heart disease. Only six of the studies reviewed (2.6%) included participants with disability. Similarly, in examining literature to guide future research on the **e-PHR '**My Health Record**'** in Australia [9]**,** Hemsley et al., noted that people with disability are at risk of exclusion from **the** system where (a) no disability-specific information on how to use the system is provided, and (b) there is low awareness in the community on the roles of authorized and nominated representatives for people with little or no speech or intellectual disability [9, 12]. It is possible that the health literacy demands of e-PHRs pose a barrier to use by **many people** owing to the critical importance of communication **and cognition to** health literacy [13]. As such, while people **with disability who are vulnerable to communication difficulties** might benefit greatly by use of PHRs, they might also require additional supports to manage the health literacy demands **of these systems.**

1. 3 Gaps in the Research: Demands of e-PHRs on Health Literacy

While it is evident that the number of studies pertaining to PHRs is rapidly increasing (see [5]), research to date does not yet answer contemporary research questions about the demands of national e-health systems on the health literacy of patients, providers, and health systems for successful implementation and health benefit. **Previous research about the uptake and use of PHRs could provide important insights on the health literacy demands of these systems. In this study, we adopted a definition of health literacy which includes a focus not only on individuals but on health systems [14] as follows: "Health literacy means people can obtain, understand and use the health information and services they need to make appropriate health decisions. Healthcare providers and the health system**

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should provide information and improve interaction with individuals, communities and each other to respond to and improve health literacy." [14, p. 3].

National **e**-health record systems enable patient/consumer involvement or control over sharing of that information in a variety of ways [14]. An important element of such **shared e**-PHR systems is that the patient and the provider each use these systems for sharing of health information across healthcare providers. The use of **e**-PHRs **that enable patients to interact with the information potentially** affect the patient-provider care relationship [15]. **In effect, e**-PHRs represent a disruption in the moral order of healthcare **through giving patients more control over their own health information** [2, 16]. Tang, Ash, Bates, Overhage and Sands [2] contended that patients must know their roles and responsibilities in managing their own health, and that both patients and providers will be challenged in implementing PHRs that promote shared access to patients' health information. Tang et al., [2, p. 125] **predicted that e**-PHRs **will**:

> **…** threaten the control, autonomy, and authority of some healthcare providers, based on traditional provider-patient roles. Providers and patients will need to develop different mindsets and levels of trust. Providers must learn to encourage patients to enter the information accurately and to trust that information appropriately. Consumers must trust that providers will only use the information for the individual's benefit.

It is important to determine how the health literacy demands of **e**-PHR systems impact on the implementation of national e-PHR systems, that are inclusive of **a wide range of patients and inclusive of** those with communication **difficulties** who might benefit substantially [9, 10] but who are at risk of exclusion through **also**

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being "disempowered, disengaged and disconnected" [11, p. 4]**.** Considering that 'disempowered, disengaged and disconnected' groups are also at risk of low health literacy, it is important to determine how health **systems** might support engagement of all patients in **population-wide e**-PHR systems [14, **17, 18, 19**].

1.4 Aim

The aim of this review is to examine peer-reviewed research on e-PHRs, **that are online and enable the patient any degree of control or input to the record, for findings on the** health literacy demands of these **systems**. Such information could inform policies and practices surrounding the implementation of **e**-PHRs to maximize consumer participation, and ensure that ***all*** patients have access to **the** potential benefits offered by use of these systems. The findings could also **inform updates to the** design elements of **e**-PHR systems**, strategies for implementation that are inclusive of more patient groups, and** directions for future research.

2. Methods

The integrative review method [20] was selected for its strength in considering both qualitative and quantitative research in an emergent field of e-PHR research. A framework for extracting and analyzing data from included studies was developed through a synthesis of a **model on the adoption of e-PHRs [21] with two well established** health literacy models [13, 22]. **These three models, summarized in Table 1, were selected as causal models [23] considering not only** the patient, **but also the** carer/supporter, healthcare provider, health information system, as well as government, society, and technology. **Logue and Effken's model on the adoption of PHRs [21] was selected for its focus on e-PHRs, congruence with the two models of health literacy, and inclusion of technological aspects of direct relevance to e-PHR adoption.** The synthesis of the three models provided

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categories of factors affecting health literacy and this synthesis was used to extract data from the studies for analysis in this review (see Table 2).

Insert Table 1 and Table 2 about here

2.1 Review Methods

2.1.1 Sources and search terms. Four scientific databases (Medline, Web of Science, CINAHL, and PsychInfo) were searched using a combination of the following key concepts and terms: (i) Concept: 'health literacy' (several domains for this) AND**;** (ii) Usability: usability OR knowledge OR experience OR skills OR access OR attitude AND**;** (iii) Setting: "electronic health record" OR "electronic medical record" OR "personal health record" OR "personally controlled electronic health record" OR "patient portal" OR "personally controlled health record" OR "**M**y **H**ealth **R**ecord".

2.1.2 Inclusion criteria. We sought full papers reporting original research in peer-reviewed journals in English, meeting all three criteria: (a) relating to the patient/ consumer/ healthcare recipient (adults or children), and (b) e-**PHRs** of any type or name (patient portal, personally controlled electronic health record, personal health record) that enable sharing online (i.e., between providers/patients), and (c) having an aim or a result relating to health literacy (as defined by Hill [14]). Studies were excluded if they were not in English, not a full paper, not original research, not relating to patients/consumers, or not relating to **e-PHRs** that are accessed, kept, stored, or shared online or did not enable any degree of patient participation in the record.

2.1.3 Search strategy. In October 2015, the second author ran the search in the databases and exported the titles and abstracts to an Endnote library for processing, read through the titles retrieved, and made a decision to exclude if clearly

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not relevant to the review. The first and second authors then separately read the remaining titles **and abstracts** to exclude on the basis of the abstract, and discussed any **papers** where there was a disagreement to come to consensus about its exclusion or continued inclusion to full text review. Any uncertainties progressed to full text review. Three papers not found in the search, that the second author knew also fulfilled inclusion criteria, were added to the set. Full texts were retrieved, read, and judged against the inclusion criteria by two raters, and a third rater brought in if there was a disagreement on exclusion. Included studies were then subject to data extraction on (a) the characteristics of studies (i.e., author, year, title, aim, method, participants, definition of health literacy used, type of electronic health record, type of health condition at focus), (b) features of the studies relating to our framework of analysis using a combination of models of health literacy, and (c) directions for future research contained within the reports. Data was extracted by a research associate and checked by the first author against all included studies.

3. Results

3.1 Tabulated Search Results

The number of studies located in the search, **considered for inclusion or exclusion** (N = 122), and **ultimately included in the study** (*n* = 24) [9, 12, 21, 24 – 44) is outlined in Figure 1. The characteristics of the included studies are presented in Table 3, **including** design/methodology, methods/tools, and study participants (type, consumer, provider, organisation); **e-**PHR type, and geographic location of the study by country. The content in each study pertaining to the synthesis of health literacy models is presented in a matrix format in Table 4 (health condition, activities, environment) and Table 5 (personal factors). Quotes illustrating the personal factors

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are outlined in Table 6. Directions for future research extracted from included studies are summarized in Table 7.

Insert Table 3 about here

Insert Figure 1 Here

3.2 Health condition-related demands of e-PHRs

As shown in Table 4, 12 of the 24 studies reported including patients with specific health conditions, and these included: Attention Deficit Hyperactivity Disorder (ADHD), chronic obstructive pulmonary disease, cancer, cerebral palsy, diabetes, fibromyalgia, heart disease, HIV/Aids, intellectual disability, mental health conditions, neurological condition, rheumatic condition, stroke, and traumatic brain injury, and a range of other diseases [see 21, 24, 31, 32, 38]. **However, the** studies included very little information on how the health condition itself (i.e., signs, symptoms, features, or impairments associated with the health condition) had impacted directly on the person's health literacy or use or benefit of PHR.

Insert Table 4 about here

Insert Table 5 about here

Insert Table 6 about here

Czaja et al., [26] outlined some of the sensory and perceptual demands of PHRs, along with cognitive (e.g., selective attention) and task response demands (e.g., fine motor skills), associated with tasks involved in using PHRs. The authors did not make note of any 'hearing' demands, however vision and perceptual recognition featured in *locating information* and *recognition of information* (e.g., in relation to medications information, recognizing a normal result). Czaja et al., [26] noted that using a PHR places demands on the user's *selective attention* and *long-term memory*. Three other studies mentioned but provided little detail on the role of *cognition* in the

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use of PHRs. Taha et al., [40] examined the cognitive abilities impacting the performance of older adults, who were English- speaking non-cognitively impaired and in good to excellent health, and reported that cognitive abilities predicted overall performance in using the PHR, and "verbal ability was the most influential … followed by reasoning… and then executive functioning." [40, p. 1131]. **However, only** one study included any adults with cognitive impairments [12] and one included adults with cerebral palsy, aphasia, or traumatic brain injury [9]. Both van Dooren et al., [12] and Hemsley et al., [9] discussed the potential impact of cognitive and communication impairments on the use of the Australian 'My Health Record' but did not present evidence **on patients'** experiences using the system.

No studies in this review addressed impairments of fluency, voice, or physical impairments or functions (e.g., mobility, range, rate, control of body movements) in relation to the uptake or use of PHRs. No studies specifically investigated health literacy demands of PHRs in relation to people who are deaf/hearing impaired, or blind/visually impaired, and some actively excluded individuals with hearing, vision, or cognitive impairment [see 37, 38, 40]. **Furthermore, the a**ccessibility of PHRs to people with impairments of sensory function was not discussed in any of the studies.

3.3 Activity and environment demands of e-PHRs

The use of e-PHRs inherently involves a range of activities and the use of technology in the environment (i.e., tools and equipment) and other environmental supports (e.g., the service provider supporting use of the e-PHR, support from other people to use the technology) so these findings are reported together.

3.3.1 Knowledge of health and e-health technology. Included studies covered a wide range of activities associated with using PHRs, including using the Internet, not

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only to seek health information online but to "communicate with provider or view health information" [26, p. 500]. Although health literacy is impacted by knowledge, including prior knowledge (e.g., illness experience, and knowledge and familiarity with health care systems) [22], few studies focused on patients use of PHRs specifically to acquire *new* knowledge about their health condition or its management. Part of that new knowledge might relate to terminology and vocabulary, as participants reported that medical terms were unfamiliar [24] and "explaining medical terms was the most highly cited wish" [24, p. 234] for future improvements to PHRs. Some activities related to operational competence, with some participants struggling to use PHRs through "not knowing how to register and initiate the authentication process… not being able to locate the link… not fully understanding the circumstances and situations in which they should use the Secure Messaging tool" [33, p. 6]). Thus, patients may be impeded from the activity of using PHRs by the design of the systems not being matched to their knowledge of health-related terms or PHR related instructions [39]. Attempts to use PHR being unsuccessful were also associated with preferring more familiar methods for communicating information with their healthcare providers [29]. A web portal was viewed as "too cumbersome and that communicating with their health care providers through the phone system was still easier and faster." [29, p. 826]. Only one study investigated how participants might integrate use of their e-PHR with their existing paper-based health information at home. Although no participants were yet using e-PHRs, results reflected that the different formats of paper and digital health information storage may be associated with different challenges to organisation and access. Using a computer and the Internet afforded one young adult, with severe disability and no functional speech, independent access to personal health information but this was not well organized

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(i.e., information was stored 'loosely' in the documents folder and on emails); whereas storage boxes for paper files impeded her independent access to her own health information, removing her right to privacy by reliance on another person to retrieve, search, and open paper files in the boxes [9]. It is not known how far these results would apply to wider populations of individuals who already store health information at home in either storage boxes, computer files, or attached to emails.

3.3.2 Education and learning of health and technology. Use of PHR was reported as "generally associated with higher education levels" [42, p. 11]; educated patients were consistently more likely to use some functions of PHR than less educated patients [38], and performance in PHR was affected by "low health literacy, less than high school education, and low computer experience" [39, p. 9]. Czaha et al., [26] who included 54 participants ranging in age from 22-62 years with (52%) and without (48%) high school education, noted that:

> Information on the usability of these systems for diverse user groups is essential to the design and deployment of useful and usable PHR systems. This consideration is essential to ensuring meaningful adoption of these systems and decreasing the potential for health disparities among vulnerable populations, such as older adults or those with low health literacy or education. [26, p. 504].

Taha and colleagues [40] also reported education, internet experience, cognition, literacy, numeracy and age affected performance on PHRs. However, level of formal education did not always predict performance in simple or complex tasks of PHR, until internet experience was also taken into account [41]. This suggests that e-PHRs might be difficult even for patients with relatively high levels of education, if they do not also have experience in using the internet. Some patients were "anxious to learn about and embrace technology" [44, p. 6] and there was a "need for increasing

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awareness, education and instruction" [33, p. 8] in using PHRs. The included studies provide substantial information relating to the use of PHRs for seeking, finding, and obtaining personal health information, with a lesser focus on filtering, judging, appraising or applying that information (see Table 4). Indeed, patients might overestimate their ability to apply information found online. Older adults, who expressed confidence in their ability to undertake the activities of the PHR, were reported to have overestimated their abilities: "many of the participants in this study tended to overestimate their numeracy ability, which implies that…(they) may believe that they can comprehend and use numeric information provided in their PHR correctly when, in fact, they may not." [41, p. 1133].

3.3.3 Receptive language skills and understanding. The emphasis across the studies on receptive language skills involved in understanding health information acknowledges that patients' receptive language must be considered in the design and use of PHRs. However, the studies did not provide detailed information on how the communicative functions (i.e., receptive and expressive language) could be enacted in activities in using PHR such as taking part in conversations about PHR, or communicating healthcare results through use of PHR online sharing facilities. Hemsley et al., [9] noted that patients with communication impairments and limitations in function might benefit greatly by the provision of PHRs to share health information online with multiple healthcare providers. However, no studies in this review considered how participation in healthcare decisions use could be made more accessible to people with communication impairments (e.g., lack of speech, cognitive, sensory, or communication impairments or limitations).

3.3.4 Support for using e-PHRs. As noted previously, most studies related to hypothetical use, and did not evaluate the actual use or impact of PHRs. As only three

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studies took a sociotechnical approach [9, 32, 37], there is little reported in the studies about the ways that people could engage in activities surrounding PHR use with or without the support of family, community, or health professionals in relation to PHRs. Degree of independence or need for assistive technologies to participate in the activities was considered only in some studies. Only 1.5% of low-income elderly participants [34] could participate in activities related to using the PHR independently, whereas in one case, an adult with cerebral palsy "accessed the computer and Internet independently using assistive technologies" [9, p. 102]. There were no studies examining how engagement in PHRs could be a social or group-related activity whereby people could learn from family (i.e., a private group) or peers or other patients (i.e., public groups) about filtering, appraising or applying information from test results in regards to health behaviours, and no studies mentioned the use of social media in relation to PHRs. The concept of using PHRs impacting on health behaviours (e.g., nutrition and diet) or other activities (e.g., walking) at home or at work was not explored, despite many of the studies including a focus on chronic health conditions (e.g., diabetes mellitus).

3.4 Personal demands of e-PHRs

Several of the included studies reflected that both the prospect of and using PHRs could have a range of personal demands on both patients and healthcare providers (e.g., fear, worry, competitiveness, skepticism, incompetence or lack of confidence) (see Table 5 for personal factors appearing in studies and Table 6 for illustrative quotes). While it is not known how far these findings apply beyond the included studies, it is possible that the attitudes and beliefs of both healthcare providers and healthcare recipients could influence how different patient groups and their healthcare providers approach or use PHRs. The included studies did not provide much insight

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into how personal factors such as these, along with beliefs, attitudes, emotions, and thoughts influence the strategies taken by patients or providers towards either avoidance or use of PHRs, nor whether providing information or training on PHRs will address these personal factors. It is also not known how such personal factors could be leveraged to increase meaningful use of PHRs (e.g., engaging skeptical patients and clinicians in research exploring the benefits and risks of PHRs; providing opportunities for coaching or practice in use of PHRs to address lack of confidence and competence in PHRs; displaying usage statistics over time if competitiveness or self-improvement is a motivator).

4. Discussion and Conclusions

4.1 Clinical implications

As using e-PHRs demands verbal ability, reasoning, and executive functioning [26] it is important for health service providers to consider ways to support **the use of e-**PHRs by people who have impairments of these functions. In the absence of large-scale research including individuals with health conditions impacting on verbal ability, reasoning and executive functioning (e.g., stroke, traumatic brain injury, cerebral palsy, or intellectual disability), it is important to engage directly with these patient groups in designing appropriate modifications and supports for using **e-**PHRs and to consider the important role of family members or paid support workers in relation to using **these systems**. **The use of Participatory Action Research designs in public health research [see 45] is appropriate as technologies evolve and patients and their supports inevitably encounter more e-health technologies, and in the absence of research including heterogeneous populations. Research including measures of e-health literacy of health providers is lacking, and considering that they are integral to the patient's use of e-PHRs this represents a**

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substantial gap in knowledge. Involving both patients and providers in participatory research about e-PHR systems has the advantage of enabling user-centred design and input into the implementation of e-PHRs at the development stage; and increased engagement with the community affected by both the e-PHR and the research.

The findings relating to knowledge and education suggest that all people, regardless of level of education, will need instruction and information supports on medical jargon and terms used in **e-**PHRs as this can be difficult to understand. Therefore, information about **e-**PHRs needs to be pitched at early levels of education and readability [21, 24, 42] and needs to be inclusive of all potential groups who might benefit by using **these systems** to share their health information with multiple healthcare providers. Efforts need to be taken to reduce jargon without removing meaning in information pertaining to privacy and security of **e-**PHRs. However, information supports are not going to be sufficient for some people with communication physical, cognitive, or sensory impairments, who might also need direct support from assistants or assistive technologies to access online PHRs [9, 12]. No studies in this review directly measured reading grade or 'readability' of e-PHRs, even if comments about readability were made in the discussion of the results. Research on electronic PHRs to date has largely ignored physical access demands, in not including participants with chronic disabling health conditions that impact on mobility (e.g., cerebral palsy, spinal cord injury, multiple sclerosis, spina bifida). Future studies need to report on participants' physical, cognitive, or language impairments and not limit reporting to languages spoken or presence or absence of sensory (hearing/vision) impairments.

4.2 Implications for participation and inclusion

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Reflecting the well-recognized inequities in health service provision for people with a disability and high risk of exclusion from health research [46], the results of this review suggest that people with **disability and people with communication** impairments are more likely to be excluded from research on electronic PHRs, than to be included in studies or **be the** focus of **the** studies. Their absence from e-health record research is of great concern, considering their higher risk for health conditions, significantly higher healthcare service utilisation and hospitalisation costs, and significantly increased risk for multiple preventable and harmful adverse events [47]. Their inclusion in **e-health record** research is vital to inform policy and practice on the adaptations or supports needed to ensure their inclusion in these important new digital health innovations and online health services.

Health literacy models to date have focused substantively on 'activities' associated with using **e**-PHRs. Taking part in activities relating to use of **e-**PHRs might facilitate more equitable engagement in sharing health information with patients who have previously not had access to this information by verbal means. **Norman [48] proposed a descriptive model of e-health literacy that highlighted one personal factor of "confidence"; and Norgaard et al., [49]'s relatively recent descriptive model also featured "confidence" along with a small number of other personal factors, namely a "wish to prioritize" "sense of control" "empowerment" and "motivation" [49, p. 280-530] as influencing e-health literacy.** This review shows that attention to **a substantial number of** 'personal factors' **is** important and needs to be considered in future theory development in the area of e-health literacy.

The results of this review demonstrate that e-PHRs pose a wide range of health literacy demands upon individuals who would potentially benefit by having

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greater participation in their health information exchange across multiple health providers. Not all of these demands have received sufficient attention in the literature as to determine their impact for different populations with impairments impacting cognition or communication function. **In drawing upon established health literacy models, and outlining the health literacy demands of e-PHRs, this review could help in designing health literacy interventions that translate into more inclusive e-PHR systems that include adaptations for the needs of different populations.** The apparent cognitive and communication-related health literacy demands of PHRs mean that patients with health conditions associated with communication impairments **in particular** may be at risk of exclusion from local and national **e**-PHR initiatives. Furthermore, the support needs of healthcare recipients who have physical, intellectual, or sensory impairments have not been well researched and there is little information on the uptake and use of **e-**PHRs across different populations with a range of health conditions associated with communication disability (e.g., stroke, cerebral palsy, traumatic brain injury). Including participants with a range of communication impairments in **future e-PHR** research will be important if findings are to be used to support these individuals to participate in local and national PHR initiatives. Findings across the literature relating to personal attitudes, beliefs, and values of both patients and healthcare providers affecting **e-**PHR use could inform future social marketing of **e-**PHRs and a person-centred approach to implementation that takes values, beliefs and attitudes into account. The future research directions **synthesized** across a substantive body of research to date could inform an inclusive research agenda aiming to improve the information accessibility features of **e-**PHRs to benefit all healthcare recipients, including those with communication **or cognitive** impairments.

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4.3 Limitations and directions for future research

This review only included original research up to February 2015 and was limited by its focus only on peer-reviewed studies in English. The pragmatic decision to use 'and' in the search methods (i.e., 'health literacy' and 'personal health records') in the initial step of searching scientific databases was made to find only the most relevant studies. It is possible that some of the excluded studies included a minor focus on health literacy by virtue of focusing on PHRs. A scan of the same databases using the same search terms in February 2017 revealed that there are recent reports of primary research supporting the findings of this review (e.g., [50, 51]). However, we did not locate any new studies aimed at determining the health literacy demands of **e**-PHRs **for patients with health conditions placing them at increased risk of communication impairments.**

The directions for future research garnered from the included studies (see Table 7) reflect the importance of user-centred approaches to research and studies that specifically aim to include minority populations in examining the health literacy demands and needs associated with use of PHRs. Table 7 outlines a range of categories for attention in future research.

Insert Table 7 about here

Increased diversity in larger participant groups, the fields of research explored, and the research designs used must embrace user-centred and inclusive research approaches. There is a further need for intervention studies focusing on implementation of **e**-PHRs in the community and ways to modify or adapt PHRs for ease of use across populations. Given that there are so many communication skills evident in health literacy demands of PHRs, future research on designing PHRs for full digital **health** inclusion needs to target all populations who struggle to get their

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message across using spoken language [52]. **The results of this review highlight the importance of recognizing both the complexity of e-PHRs and potential relationships across the major categories in the directions for future research (e.g., intervention studies on the user-centred design elements; increasing diversity in health services research on e-PHRs). Collaborative consultation across the disciplines and with both patients and providers will be important for setting research priorities and strategic direction in e-PHR research. Considering the rate of development and evolution of e-PHR systems, a research priority setting exercise is urgently needed to inform the implementation of e-PHRs across populations.**

Acknowledgements

This review was funded by the National Health and Medical Research Council of Australia G1058094.

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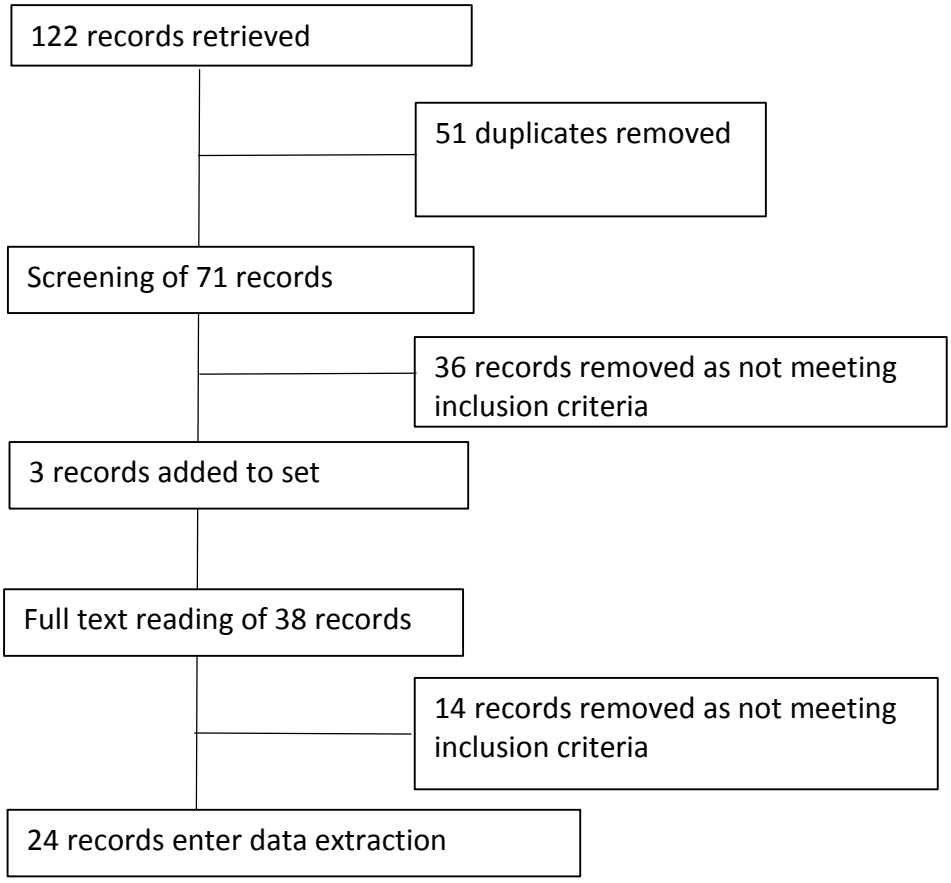
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Figure 1

Flowchart of records retrieved, reviewed, removed, added, and included



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Table 1

Three models informing the framework of analysis in this review

Model Name	Model elements
The Health Literacy Skills Framework [13]	Factors that impact on health literacy skills include demographics, individual resources, capabilities and prior knowledge. These factors shape the health literacy skills of: print literacy, communication and information seeking and e-health. These skills allow the individual to comprehend health stimuli - however there are a number of mediating factors including attitudes and emotions that determine how people retain, retrieve and use health information. These mediators can also feedback and effect health literacy skills. The stimuli being understood can lead to health-related behaviors and outcomes. These outcomes can also further impact upon health literacy skills as well as the factors the influence the development and use of health literacy skills. Health literacy skills are directly linked to health literacy demands. Lastly, the health literacy process is influenced by ecological influences such as culture, community resources and family.
Personal Health Record Adoption Model [21]	Model of the adoption of e-PHRs: integrates five factors: environmental, personal, technology, chronic disease and behavior that interact to affect the intent to use and the actual use of e-PHRs.
Integrated Model of Health Literacy [22]	The individual's health literacy skills are determined by knowledge, competence and motivation to access, understand, appraise and apply health information. Through this process the individual gains knowledge, allowing them to navigate through health care, disease prevention, and health promotion information. This information may be presented to the individual themselves and the general population as a whole. Situational, personal and social/environmental determinants impact on the interpretation of the information. Other factors including health service use, health behavior, participation, equity, health costs, health outcomes, empowerment and sustainability also impact on the above determinants. The individual continues to move through this process of engagement with health information throughout their life.

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Table 2

The synthesis of a model of adoption of PHRs [13] with two health literacy models [21,22].

Health condition	Cognition and sensory	Activities and Participation	Environment	Personal Factors
Health status Illness experience Disease prevention Number of chronic illnesses Chronic disease factors Perceived complexity of condition Self-regulation of chronic disease factors Self-management (tasks the individual must complete to live with the chronic condition) Health outcomes (e.g., mortality, disease state, health care service utilisation)	Cognitive capabilities Sensory capabilities (vision, hearing)	Education (in general, in health, and in becoming more resourceful) Employment Knowledge (including prior knowledge, illness experience, knowledge and familiarity with health care system and vocabulary) Updating oneself on social determinants of health in social and physical environment, regularly Learning what to do and how to do it. Accessing health information (seek, find and obtain) Accessing health information depends on understanding, timing and trustworthiness of the information Understanding (comprehending health information / comprehend the stimuli / understanding pictorial/graphic comprehension) Processing and appraisal of information depends on complexity, jargon and partial understanding of the information. Appraising (filtering and judging) Interpreting health information. Applying (communicating and using information to make health decisions and improve health Behaving (the intent to act and the act itself) / Health-related behaviours	*The individual in society* Media / media use Family Peers Income Socio-economic status Culture / cultural differences *Society* Societal attitudes Community / Community resources Equity Health determinants in the social and physical environment Politics Social support Societal language Societal system Social influence Sustainability *The healthcare service / providers* Health care provider Perceived complexity of treatment, access to care, number of healthcare settings, number of healthcare providers Healthcare demands Health care systems Health promotion	Demographic situation Age Life-course Gender Ethnicity Person's cultural competence Person's attitudes (including on negotiated collaboration) Beliefs (does the individual believe organizational and technological infrastructure support their use of the system) Thoughts Expectations Motivation Empowerment Self-efficacy Autonomy Perceptions of utility and interpretation of causalities Affective variables / emotions Preferences (for communication; for self-

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	Reading/Writing literacy (reading/writing) (e.g., to process written information from brochures, booklets, websites) Navigating e-Health and navigating internet search engines e-health literacy (also referred to as Internet health literacy) Calculating / Interpreting numbers, scores, results (numeracy) Communicating (listening, speaking) Communicating to give and receive important information Health literate individuals can participate in public and private dialogues about health Health literacy impacts on participation (benefits a range of activities including activities at home and work)	Health care service utilisation Health costs Incentive motivation *The information* The messenger of the information The health literacy demands of a text/health related stimuli: [characteristics of the text; communication channel (interpersonal or mediated channel), message content (type of language used and orientation of text) and message source (who provides the message)]. Development and modification of health material for varying levels of health literacy Storage of health information affects message comprehension and the individual's ability to incorporate new information into their current knowledge base *The technology* Technology factors: "cost, perceived usefulness, perception of external control, relative advantage, compatibility, complexity, trialability and observability." (Logue & Effken, p. 359). Making the task less demanding	regulation; to control and manage themselves)

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Table 3
Characteristics of included studies: study number, aim, design, methods, population/participants, e-PHR type, location

Ref	Aim relating to PHR	Design	Field/Methods	Population / Participants	PHR / Provider	Location
9	Barriers to and facilitators for PCEHR use by people with severe communication impairments and their service providers, and present directions for future research	Mixed	Sociotechnical case study; Online or face-to-face survey interview, focus groups.	1 adult with severe cerebral palsy in a case study; 12 adults with severe communication impairments in interviews; 2 focus groups of 9 direct support workers, and 5 allied health clinicians.	My Health Record / Australian Department of Health and Ageing	AUST
12	Facilitators and barriers to registering for an eHealth network for people with intellectual disability and those who support them; determine improvements to registration.	Qual	Interviews and focus groups	9 adults with mild, moderate, severe intellectual disability, 3 parents, 2 direct support workers.	My Health Record / Australian Department of Health and Ageing	AUST
21	A theoretical framework to help understand factors that influence the adoption of PHRs by older adults with chronic illness. (p3)	Quant	Survey: Demographics, e-Health literacy (using modified eHEALS modified General Self Efficacy (GSE) scale; two indicators for the concept of enjoyment, motivation based on Hung et al; Output quality, perception of external control, complexity, compatibility, trialability and observability.	Adults aged 65+ on Medicare (USA) with one or more chronic illnesses: 38 older adults, over 65 years of age, on Medicare and self-reporting one or more chronic illnesses.	Electronic PHR / Pts on Medicare in Arizona	USA
24	Feasibility of providing health info in patient portals for older adults and their carers.	Mixed	Simulated patient at John Hopkins Hospital (JHH) PHR. Brief training in portal, timed tests (6 tasks), interview; self-	7 older adults with chronic pulmonary disease or congestive heart failure, caregivers; “predominantly	Patient portal / JHH	USA

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			efficacy assessment; perceived social support.	white and well-educated." (p. 233)		
25	Diabetic veterans' access to and use of the Internet, interest in in using MyHealtheVet (MHV); computer literacy of veterans' and carers for using MHV	Quant	Survey on demographics; Internet use, access and attitudes; computer skills; awareness and attitudes towards the MyHealtheVet	Veterans: 201 Veterans with out of control diabetes (97% M; age 58.9±10.4 yrs).	Patient Portal: MyHealtheVet /Dept of Veterans' Affairs	USA
26	Demands associated with using electronic PHRs; and the ability of adults of lower socioeconomic status and low health literacy to use PHRs.	Mixed	Task analysis and health literacy load analysis, usability evaluation of 3 PHRs. Participants' perception of the potential value of using a PHR.	General population (underserved): 54 adults, aged 22-62, mean Newest Vital Sign score 2.48, 4% used the Internet to communicate with provider or view health info.	3 currently available PHRs / Providers in underserviced areas.	USA
27	Attitudes of underserved patients and those with HIV/AIDS towards online access to their medical records. including doctors' notes.	Mixed	Focus groups, content thematic analysis, questionnaire (demographics and pre-post self-assessment of knowledge of and interest in the topic).	4 focus groups (30 adults, considered "physically and mentally able to participate" p. 725) in general medicine (13) and HIV (17) clinics; 80% with chronic illness.	Patient portal to clinic EMRs / HIV, AIDS clinics.	USA
28	Health organisation attitudes to PHR adoption, flow of information to patients' PHR, readiness of organisation for PHR.	Qual	Interviews with health executives from five different organisations in one network in Indianapolis.	5 executive health staff of 5 organisations.	PHRs of the Pts' choosing to be integrated into HIE system of Indiana.	USA
29	Patient perspectives of challenges and barriers of access to the PHR.	Qual	Focus groups. Content thematic analysis.	Adults: 21 adults seen in two primary healthcare clinics in previous 3 months. About 10 had previously accessed a PHR.	PHR on web portal / Nurse practitioners.	USA
30	Ethical concerns of expert stakeholders about	Qual	Descriptive analysis of semi-structured interviews with	Expert informants in multiple disciplines: law,	My Health Record /	AUST

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	the new Australian electronic health record system.		expert informants (researchers, healthcare providers, policy, consumer advocacy groups).	psychiatry, privacy and research ethics, health informatics, philosophy bioethics, mental health, biochemistry, pharmacy, information technology, health service management, consumer advocacy, health policy.	Australian Department of Health and Ageing	
31	Views of patients and the public towards the Summary Care Record, and Healthspace	Qual	Interviews, focus groups; content thematic analysis within and across data sources.	103 patient interviews, in primary care centres (aged 16-78), 7 focus groups (67 participants).	HealthSpace / NHS, Dept of Health	UK
32	Policy-making process, implementation by NHS organisations, and Pts' and carers' experiences of efforts to introduce an Internet accessible personal electronic health record (HealthSpace) in a public sector healthcare system.	Mixed	Sociotechnical, multilevel case study. National statistics on invitations sent, HealthSpace accounts created; and Interviews and ethnographic observation of Pts and carers. Sociotechnical approach/ Critical discourse analysis. Data analysis considered macro and micro influences on both adoption and non-adoption of innovations.	Users of HealthSpace: 56 patients and carers; 160 policy makers, project managers and clinical staff.	Summary Care Record and HealthSpace / NHS, Department of Health	UK
33	Veterans' experiences using Secure Messaging in the My HealtheVet portal over 3 months, system usability; barriers to and facilitators of use; strategies to support use of Secure Messaging	Mixed	In-depth interviews, face-to-face testing, review of transmitted secure messages, telephone follow-up interviews. Assessed computer literacy; Content thematic analysis within and across sources.	33 Veterans who had access to and had previously used the Secure Message feature of My HealtheVet	Pt Portal: My HealtheVet / Department of Veterans' Affairs	USA

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34	Use and utility of PHRs in a low income, elderly population	Mixed	Assessed use and user satisfaction through system logs, questionnaire surveys, and user group meetings.	Residents of a housing complex of low income/elderly: 70 residents of a housing complex, reducing to 44 over the three years of the program.	PHR (Personal Health Information Management System PHIMS) / US Healthcare	USA
35	How usability methods can be extended to identify both usability and health literacy issues.	Qual	Qualitative heuristic evaluation of usability for four tasks in a PHR; Usability testing by one participant videoed while using the PHR for followed by brief post task interview.	Experts: 1 usability specialist (heuristics evaluation), 1 layperson	PHRs / Canadian health service providers are inferred.	CAN
36	Patients' feelings about their ability to find and appropriately use relevant health-related information on the Internet; characteristics of Pts who are or are not willing to adopt a PHR.	Quant	Pilot study, peer review, written survey based on eHEALS literacy scale, including demographic details and question re intention to use PHR	General practice stakeholders: Pilot study - 10 patients, full study survey 562 patients.	PHR / 1 Medicare practice in Florida	USA
37	Whether use of an Internet-based Pt portal among English-speaking adult patients with diabetes differed between those who report limited health literacy versus those who do not.	Mixed	Sociotechnical analysis of real-world Internet based Pt portal use data from provider of the portal, and self-reported health literacy survey. Lengthy survey of 184 questions in 52 pages.	Adults with diabetes: 14102 participants, aged 30+, 49% female, diagnosed with diabetes. 62% with any health literacy limitation.	KP.org Pt portal / Kaiser Permanente New York City, Diabetes Study	USA

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38	Whether socio-demographic factors and health literacy were associated with 1) registering for a patient portal account and 2) using the portal's functions (p2)	Quant	Secondary data analyses (LitCog cohort data linked to Pt portal usage data). Group differences in who was offered a Pt portal code, who subsequently registered; likelihood of using each of the available functions; analyses of outcomes prescription or test result.	534 patients aged 55-74 who had at least 2 clinic visits in the previous 18 mos. Over half of the patients had an adequate level of health literacy (59.6%), with 23.0% and 17.4% classified as marginal and limited, respectively.	Patient Portal HER (Epic Systems Corp) / Northwestern Medicine Electronic Data Warehouse	USA
39	An interface for parents of children with ADHD to enter disease-specific information with minimal task burden.	Mixed	ADHD-specific personal health App: needs analysis (focus groups with parents) and heuristic evaluation of pre-release version of PCHR; usability testing using "think aloud" protocol; performance testing of revised prototype; finalizing design. Time on task and both task burden and subject characteristics.	15 parents of school-aged child with ADHD. In focus groups: 4 Spanish-speaking parents with diverse health literacy, 4 English-speaking parents with lower health literacy, and 7 English-speaking parents with higher health literacy. 10 participants in 'walk through' usability testing, 7 participants in 'performance' usability testing.	PCHR / Boston Children's Hospital	USA
40	Ability of middle-aged and older adults to use a PHR to perform common health management tasks. Impact of individual factors.	Quant	Simulation, 2-day participation in learning task using a simulated PHR for a fictitious Pt. Tasks designed to span spectrum of health numeracy ability; Cognitive task analysis; establish elemental steps; determine the cognitive skills needed to perform.	107 middle-aged and older adults speaking English and non-cognitively impaired; were diverse in gender, ethnicity, education, and Internet experience.	Patient portal simulation based on 'MyChart' (Epic) / Miami area community centres.	USA
41	Impact of numeracy skills impact the ability	Mixed	Simulation of PHR: Telephone pre-screening, background	51 adults, all English-speaking and non-	Patient portal simulation based	USA

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	to perform health management tasks using a PHR, technology skills feelings about portals in general, problems using the numeric information.		questionnaire, technology experience questionnaire; health literacy (TOFHLA) and numeracy measures; Usability questionnaire. 15 tasks developed to test performance on use of a simulated portal.	cognitively impaired; mainly good to excellent health.	on MyChart (Epic) / Miami area community centres	
42	Consumer attitudes to PHRs and health care providers' use of Health Information Exchange (HIE); evaluate consumer use of the Internet for PHRs.	Quant	Secondary data statistical analysis of Health Information National Trends Study (HINTS, 2007) 3 survey questions: importance to Pts using PHRs; their providers sharing medical information electronically (HIE); Pt use of Internet to track PHRs.	5078 US civilian non-institutionalized adults who completed the HINTS survey indicating that they had access to the Internet.	PHR and HIE systems (National Cancer Institute) / health providers in general	USA
43	Family practice physician and staff views on benefits of, barriers to, and use of PHRs.	Qual	Focus groups (+ pilot focus group). Content thematic analysis.	29 healthcare providers (physicians, nurses, pharmacist)	PHRs / Iowa physicians	USA
44	Perceived utility and value of patient portals and their core features and functions.	Qual	Focus groups (plus scripted introduction to patient portals and technology experience survey - appointment setting, health proxy functions, medication management and lab test results). Content thematic analysis.	28 adults aged 21-63 years; education level of high school or less; low economic means; most were of an ethnic/racial minority group. Primary healthcare shortage area.	Patient portals and their functions / 3 New York City Medical Centres, health providers in general	USA

Notes: COPD = chronic obstructive airways disease; CHF = chronic heart failure; Pt(s) = patient(s);

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Table 4
Health conditions, activities, participation, and environment in the results of the included studies.

Ref	Includes people with specific health condition	Employment/ income	Learning	Knowledge	Education	Updating self	Accessing (seek, find, obtain)	Appraising / filter, judge	Apply / Behaviour	Literacy	Numeracy	Communication (receptive)	Communication (expressive)	Participating in health dialogue	Activities at home/work to benefit	Navigating the Internet / e-health literacy or technology
9	CP, Stroke, Traumatic brain injury			X			X					X	X	X		X
12	ID					X	X	X		X		X	X	X		X
21	Chronic *			X	X	X	X	X				X	X			X
24	Chronic **	X			X		X			X		X				X
25	Diabetes	X	X	X	X	X	X	X	X							X
26		X			X		X	X		X	X	X	X		X	X
27	HIV			X	X		X					X		X		X
28							X	X		X		X	X	X		X
29												X	X			X
30							X		X					X		X
31	Diabetes +	X	X	X	X	X	X	X	X	X		X	X	X	X	X
32	HIV/AIDS, MH, ID, #	X	X	X	X	X	X	X	X			X	X	X	X	X
33		X		X	X		X					X				X
34						X	X					X	X	X		X
35							X	X	X			X	X	X		X
36		X			X	X	X	X				X	X	X		X
37	Diabetes	X	X	X	X	X	X	X	X	X		X	X	X		X
38	Chronic ***				X				X			X	X	X		X
39	ADHD				X	X	X		X			X	X			X
40		X	X	X	X	X	X	X	X	X	X	X	X	X		X
41		X	X	X	X	X	X	X	X	X	X	X	X	X		X

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42	Cancer	X			X	X	X	X	X			X	X	X		X
43		X	X	X	X	X	X	X	X			X	X	X	X	X
44		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X

Note: Refer to Table 3 for study numbers.
Key:
* Participants with a mean of three chronic health conditions, not specified
**COPD/CHF; COPH/CHF = Chronic Obstructive Pulmonary Disease / Chronic Heart Failure;
*** arthritis, asthma, bronchitis or emphysema, cancer, coronary heart disease, depression, diabetes, heart failure, and hypertension.
MH = mental health; ADHD = Attention Deficit Hyperactivity Disorder; HIV = Human Immunodeficiency Virus; ID = Intellectual Disability.
+ = hypertension, heart disease, kidney disease, thyroid disease, chronic lung disease, arthritis, chronic disability from stroke, visual impairment.
# = drug recovery.

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Table 5
Personal factors in the results or discussion of included studies.

Ref	Demographic situation (SES)	Age	Life-course	Gender	Ethnicity	Person's Cultural Competence	Beliefs	Expectations	Motivation (or desire, interest)	Empowerment	Self-efficacy	Person's autonomy	Perceptions of utility	Interpretation of causalities	Affective variables	Preferences for communication	Preferences for self-regulation	Attitudes	Thoughts	Other
9		X	X	X		X							X			X			X	X
12		X		X				X					X		X	X		X	X	X
21	X	X	X	X	X	X		X	X		X	X	X		X		X	X	X	X
25	X	X		X	X	X			X			X	X					X		X
26	X	X		X	X	X								X				X		X
27	X	X		X	X			X	X	X		X	X	X	X	X	X	X	X	X
28								X	X			X	X		X	X		X		X
29	X	X			X	X			X	X		X	X			X				X
30				X		X		X	X	X		X	X	X	X	X		X	X	X
31		X	X	X	X			X	X	X	X	X	X			X				X
32	X	X	X	X	X		X	X	X	X	X	X	X							X
33	X	X	X	X	X	X		X	X	X	X	X	X		X	X	X	X	X	X
34		X	X	X	X	X				X			X		X	X		X	X	X
35									X				X							X
36	X	X	X	X		X			X		X	X						X		X
37	X	X	X	X	X	X			X											X
38		X	X	X	X	X			X									X		X
39	X		X		X	X		X					X			X		X		X
40		X	X			X					X								X	X
41		X	X	X	X										X					X
12																				X
42	X	X	X	X	X		X						X			X		X	X	X
43			X			X			X	X	X	X	X			X		X	X	X
44	X	X	X	X	X	X				X	X	X	X					X	X	X

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Table 6
Personal factors: examples from included studies

Personal factor	Example quote or paraphrase and source
Age	"the youngest group studied (aged 18 to 24) … were less likely to value the importance of HIE compared with respondents who were aged 35 and above." [42, p. 10] (HIE = health information exchange)
Gender	"men were more likely than women … to positively appraise the importance of HIE." [42, p. 10]
Ethnicity	"Hispanic populations were more likely to value the concept of electronic personal health records." [42, p. 10]
Cultural context	"the cultural setting, context, or back-ground of potential PCEHR owners will have an influence on system uptake and use, and therefore utility." [30, p. 34]
Values/Beliefs	"individual values, needs and perspectives affect usefulness and acceptance" [21, p. 165]
Empowerment and disempowerment	"46.7% (3586/7674) of the respondents surveyed reported that it was very important to have access to their medical records electronically." [42, p. 10] "I think patients should have total control of who gets access, but the information put in there should be from professionals like pharmac[ists] or doctors. Patients should not be able to enter any information without the doctor or someone else validating it. Otherwise that information is just subjective." [43 p. 12] "some of these patients were not aware that providers wrote notes after each clinic visit. In addition, many did not know of their legal right to access their medical records." [27, p. 730]
Patient self-efficacy	"Providing patients with such a tool is an important step in allowing patients to take ownership of their healthcare outcomes." [36, p. 5] "patients who are less educated may try to compensate by seeking health information through the PHR format." [36, p. 5].
Patient autonomy	Patients "had a strong desire to know everything about their medical and health conditions and wanted nothing hidden from them.: 'I want to see everything. *I want to know that nothing's being left out*." [27, p. 727] (Emphasis in original).
Patient worry or discomfort/ concerns	"Perceived benefits of online access were improved patient understanding of health and disease, convenience, empowerment and a stronger relationship with their provider. Concerns included threats to privacy, worries about being unable to understand their record, fear that the computer would replace direct provider contact and hesitancy about potential demands on a provider's time." [27, p. 724]
Patient or provider trust / lack of trust	"Statistically significant differences between respondents having home Internet access and those without included … trust in the Internet as a source for health-related information" [25, p. 598] "Increased age and lower levels of education, income, and experience with and trust of the Internet all be appear to be associated with lack of an Internet connection and home and lower interest in using an Internet-based tool to help improve control of their chronic illness." [25, p. 600].
Attitudes, thoughts: lack of confidence / uncertainty	"Older seniors reported less confidence in their ability to use internet-based PHRs and did not perceive that they had the resources in place to use them" [21, p. 155] "35 percent of patients who do want to view and use a PHR do not feel comfortable with their ability to use the information they are provided for health decisions" [36, p. 4]
Attitudes, thoughts: Provider skeptical	"Although some of the respondents were skeptical about a PHR's value for themselves, nearly all of them said they felt PHRs would be valuable for individuals with chronic illness and those caring for aging parents." [28, p. 21]

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Attitudes, thoughts: provider fear / competitiveness	"my gut reaction is how is the doctor going to cope with this workload? [...] To be honest, I fear for the other doctors in the practice if this was foisted on them!" [31, p. 8] "All three providers currently not using a PHR … felt that to stay competitive they would need to make one available in the future. However, none of the three had specific timetables for selection, implementation, or deployment." [28, p. 22]

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Table 7
Future research directions in included studies: theme categories, subcategories, and focus or type of research indicated

Theme category	Sub-category	Focus or type of research indicated	Examples
Increased diversity in rigorous person-centred and inclusive research	Participant diversity	Representative samples in surveys	[39]
		Larger more diverse groups	[12, 24, 26, 27, 28, 35, 40, 41, 42]
		Include vulnerable patients who have physical / intellectual / communication disability	[9, 12, 27, 34]
		Low income or elderly	[34, 40, 41]
		Underserved minorities	[12, 42]
		Provide research tools (e.g., surveys) in additional languages other than English, and Easy English explanations.	[12, 36]
		Research including different types of specialist doctors (e.g., paediatricians).	[32]
	Diverse fields of research and designs	Quantitative, qualitative and mixed methods studies.	[9, 12, 31, 33]
		Sociotechnical research.	[31]
		Focus on ethical concerns (e.g., consent, privacy, confidentiality, freedom to choose, autonomy, risks and benefits).	[9, 30, 32, 42, 43]
		Retrospective studies using PHR data.	[33]
		Health economics studies (e.g., cost/benefit).	[9, 32]
		Longitudinal studies (over 3 months).	[33, 36, 39]
		Sensitive measures of health literacy in relation to PHRs.	[41]
		Gender studies.	[42]
		Accessibility studies.	[9, 12, 28]
		Barriers, facilitators, and interventions to address solutions to the barriers (in Pt or clinical team) (ie., overcome barriers, promote solutions).	[9, 12, 21, 29, 33, 42]
	Person-centred research	Assess relationships between self-efficacy, Pt activation, social supports, and PHR use.	[9, 12, 24]
		Patient perspectives / attitudes / values / needs/	[9, 29, 30, 31, 33, 43]
		Patient self-management practices and information needs.	[32]
		Patient empowerment in knowing rights, responsibilities.	[42]

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		Patient engagement and motivation.	[31]
		Patient access and use of PHR data to improve health outcomes.	[36]
		Emancipation research, PHR to empower.	[43]
Health services and systems research	Health services and systems research	Articulation of PHR within wider health service/policies; disability service policies.	[9, 12, 29, 31, 35]
		Relationship between PHR use and patient engagement with health services and processes of care.	[37]
		Integration of PHRs into workflow.	[43, 44]
		Role clarity in implementation, roles of patient, caregiver, provider.	[9, 12, 43]
		Attitudes of patients and providers changing; impact on PHR.	[31, 42, 43, 44]
		Impact of PHR on attitudes and Pt-provider communication.	[9, 28, 44]
		Institutions providing targeted supports for vulnerable patients	[26, 38]
		Inequalities in access to PHR.	[28, 34, 35, 37, 38]
		Expand programs and services for men.	[42]
		Ways to strengthen health literacy, literacy, and numeracy.	[12, 25, 36, 40, 41]
		Computer skills and technological literacy as a barrier to adoption and use.	[42]
	Intervention studies and health outcomes research	Patient behavior as a result of using PHR.	[29]
		Relationships between PHR use, interventions, and health outcomes.	[29, 37]
		Interventions to increase usage and benefit to health outcomes.	[21]
		Ways to strengthen health literacy, literacy, and numeracy.	[12, 25, 36, 40]
		PHRs in management of chronic illness (e.g., diabetes, cancer).	[25, 42]
		Behaviour change as an outcome of using PHRs.	[44]
Design studies	Design of PHRs	Interoperability.	[28]
		Potential methods to improve PHRs.	[29]
		Designed to be tailored to individuals (e.g., socio-economic, literacy, numeracy, language).	[12, 40]
	Design for digital inclusion	Improving computer self-efficacy and addressing design issues that promote value of and intention to use PHRs.	[42]
		Digital inclusion, digital divide, Internet access and use.	[12, 25, 29, 37, 38, 40]

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	Potential of the Internet use of audio, graphic, video, and multiple languages on PHR systems.	[37, 44]
	Use of smart phone and multiple mobile devices with PHRs to increase inclusion.	[38]
	Address health literacy, numeracy, and cognitive demands of PHR.	[12, 26, 33, 37, 40, 44]
	Provide supports *within* the PHR for people with lower literacy and numeracy, and cognitive impairments.	[12, 40, 41, 44]
	Evaluating relationship between patient maintenance of PHR and ability to read and understand written health materials.	[36]
User-centred design	Designed and refined with the input of a diverse body of consumers.	[44]
	Cultural factors impact on design of PHRs in different ethnic groups	[42, 44]
	Testing usability / function / efficacy of PHRs.	[25, 35]
	Heuristic evaluation and heuristic violations.	[35]
	Performance testing in naturalistic rather than lab-based settings (i.e., at home).	[39]
	Human factors engineering studies.	[26]
	Collaborative design: developers, policy-makers, providers, and Pts working together to address challenges.	[28]
	Patients being included and at the centre of iterative design / re-design of PHRs.	[31, 35, 39]