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Barriers to the use of personal health records by patients: A structured review

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Introduction:

An increasing focus on personal electronic health records (PHRs) offers healthcare benefits for patients, particularly those in undeserved and marginalised populations, who are at risk of receiving less effective healthcare, and may have worse health outcomes. However, PHRs are likely to favour text, technical and health literate users, and be less suitable for disadvantaged patients. These concerns have prompted this review of the literature, which seeks evidence about barriers to the adoption and continued use of PHRs, the nature of the evidence for those barriers, and the stage of PHR implementation where particular barriers apply.

Methods:

Searches in PubMed, Embase, CINAHL and ProQuest databases were used to retrieve articles published in English after 2003 in a refereed journal or presented in a refereed conference or scientific meeting. After screening to remove items which were out of scope, the phase of the PHR implementation, the type of investigation, and PHR barriers were categorised using thematic coding.

Results:

The search retrieved 439 items; screening identified 40 in-scope publications, which provided evidence of 21 identified barriers to patient adoption and continued use of PHRs, categorised here as Individual, Demographic, Capability, Health-related, PHR or Attitudinal factors. Barriers were identified in most phases of PHR implementation, and in most types of study. A secondary outcome identified that eleven of the publications may have introduced a bias by excluding participants who were less affluent, less capable, or marginalised.

Conclusions:

PHR barriers can interfere with the decision to start using a PHR, with the adoption process, and with continued use, and the impact of particular barriers may vary at different phases of PHR adoption. The complex interrelationships which exist between many of the barriers is suggested in some publications, and emerges more clearly from this review. Many PHR barriers appear to be related to low socioeconomic status. A better understanding is needed of how the effect of barriers is manifested, how that effect can be countered, and how planning and implementation of PHR initiatives can make allowance for patient level barriers to PHR adoption and use, with appropriate actions to mitigate the effect of those barriers for more disadvantaged patients.
Barriers to meaningful use of personal health records by patients: A structured review

Chris Showell

1eHealth Services Research Group, University of Tasmania

ABSTRACT

introduction: An increasing focus on personal electronic health records (PHRs) offers healthcare benefits for patients, particularly those in undeserved and marginalised populations, who are at risk of receiving less effective healthcare, and may have worse health outcomes. However, PHRs are likely to favour text, technical and health literate users, and be less suitable for disadvantaged patients. These concerns have prompted this review of the literature, which seeks evidence about barriers to the adoption and continued use of PHRs, the nature of the evidence for those barriers, and the stage of PHR implementation where particular barriers apply. Methods: Searches in PubMed, Embase, CINAHL and ProQuest databases were used to retrieve articles published in English after 2003 in a refereed journal or presented in a refereed conference or scientific meeting. After screening to remove items which were out of scope, the phase of the PHR implementation, the type of investigation, and PHR barriers were categorised using thematic coding. Results: The search retrieved 439 items; screening identified 40 in-scope publications, which provided evidence of 21 identified barriers to patient adoption and continued use of PHRs, categorised here as Individual, Demographic, Capability, Health-related, PHR or Attitudinal factors. Barriers were identified in most phases of PHR implementation, and in most types of study. A secondary outcome identified that eleven of the publications may have introduced a bias by excluding participants who were less affluent, less capable, or marginalised. Conclusions: PHR barriers can interfere with the decision to start using a PHR, with the adoption process, and with continued use, and the impact of particular barriers may vary at different phases of PHR adoption. The complex interrelationships which exist between many of the barriers is suggested in some publications, and emerges more clearly from this review. Many PHR barriers appear to be related to low socioeconomic status. A better understanding is needed of how the effect of barriers is manifested, how that effect can be countered, and how planning and implementation of PHR initiatives can make allowance for patient level barriers to PHR adoption and use, with appropriate actions to mitigate the effect of those barriers for more disadvantaged patients.

INTRODUCTION

There is an increasing focus on personal electronic health records (PHRs) as a part of the implementation of ehealth services to support improvements in healthcare. PHRs have been defined as “...a private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers.” (Jones et al., 2010) Most publications about personal health record systems now focus on electronic versions providing online access for patients, which may be through provider portals. PHRs offer a number of benefits including better access to data and information, improved communication between patients and providers, the empowerment of patients, and opportunities for health self-management (Tang and Lansky, 2005; Pagliari et al., 2007). These benefits are certainly worthwhile, particularly for disadvantaged patients, who face challenges in receiving safe effective healthcare (Adler and Newman, 2002), and are likely to have worse health outcomes than more privileged patients (Olsansky et al., 2012). However, the benefits which result from the use of a PHR cannot be guaranteed. The use of specialised medical language within a PHR can marginalise non-specialist users (Showell et al., 2010), and in Australia, patients have largely been left
out of discussions about policies affecting national PHR developments (Showell, 2011).

However, information about demonstrated benefits to patients is limited, with most evidence of benefit applying to technically competent patients (Green et al., 2008; Ralston et al., 2009), and few details about how beneficial outcomes can be provided for other types of patients and patient groups. Concerns have been expressed previously about a risk that the development of PHRs may be skewed in favour of users with good levels of text, technical and health literacy, which as a result makes them less suitable for users who are at a socioeconomic disadvantage (Showell and Turner, 2013b,a). Low levels of text, technical and health literacy can act as barriers to the effective use of technology (Wilson et al., 2003), including personal health records (Angaran, 2011; Newman et al., 2012), and a number of other barriers have been identified (Sarkar et al., 2011).

1 OBJECTIVES

The concerns outlined above suggest that there are significant barriers to the adoption and continued use of PHRs by patients, particularly for those among disadvantaged and underserved populations. This literature review seeks information about those barriers, and the nature of the available evidence, as a way to inform the management and maintenance of equity in the development and implementation of PHRs. The review is designed to address three specific questions:

• What patient level barriers to the adoption and continued use of PHRs have been identified?

• What is the nature of the evidence for each of those barriers?

• At what stage of PHR adoption and use are those barriers most likely to apply?

The review also considers the type of study reported, the number of participants in the study, and whether any aspects of the methodology in each case would make the identification of barriers less likely.

2 METHODS

2.1 Eligibility criteria

The literature search identified publications providing evidence about barriers which might interfere with a patient’s decision to adopt a personal health record, or discourage continued use. Publications were included if they considered any stage of patient involvement with a PHR, from their willingness or ability to use the Internet or health information technology in the context of PHR use, through to long term use of a PHR as a part of their healthcare.

Papers in English, published after 2003 in a refereed journal, or presented in a refereed conference or scientific meeting were considered for inclusion. Publications were excluded if they focused on barriers affecting healthcare providers or organisations rather than patients, or if the description of barriers was not based on objective evidence, for example white papers, opinion pieces or editorials.

The types of publication which were retrieved included:

• Comparative trials involving multiple participating sites;

• Evaluations which involved the collection of data from patients about PHR barriers (using focus groups, interviews, surveys or questionnaires);

• Observational studies;

• Details of the attitudes and opinions of patients about possible future PHR use;

• Observations from health professionals about patient use of PHRs; and

• Literature reviews about barriers to PHR use.
2.2 Study selection and data extraction

The review process followed published guidelines on Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). (Liberati et al., 2009) Full literature searches were conducted in PubMed, Embase, CINAHL and ProQuest databases between January and April 2014, with additional searches conducted in May 2014. Details were retrieved for all publications in English from January 2004 to the date of the search.

As an example, a search conducted in PubMed used the terms [personal health record OR personal electronic health records OR patient portal] AND [barrier OR barriers], retrieved 51 citations. Searches were also conducted in Embase, CINAHL and ProQuest using comparable search terms. Additional items were retrieved by tracking citations within publications, and from a small number of other sources.

All publications were initially screened to remove items which were considered to be out of scope, for example where the reference to PHRs was incidental, (Bonacina and Pinciroli, 2010; Abimbola et al., 2012) where the barriers identified were exclusively those affecting healthcare providers and organisations (Hart, 2009; Gaskin et al., 2011), or where the focus was on PHR infrastructure issues (Hammond, 2005; Tejero and de la Torre, 2012). The screening process also removed items which made only incidental mention of PHRs (Stead et al., 2005) or barriers (Burke et al., 2010). Publications were included if they provided specific evidence about barriers which might influence the intended or actual adoption of PHRs by patients or their continued use. Literature reviews were removed if they included only publications which had already been retrieved for this review and added no helpful additional commentary.

Data from the publications which remained after screening were extracted using an iterative process of reviewing full text publications. The data variables which were recorded included the phase of PHR implementation, the type of investigation undertaken, barriers which were identified, the location of the study and the PHR system in use. Where relevant, details were also recorded of the number of individuals in the population being studied, and the number included in the study. For studies which obtained information or participation from individuals, aspects of the methodology which might discourage or exclude low capability subjects from seeking to enrol in the study, or reduce the likelihood of their selection as participants were noted. Following an initial review of the data from all in-scope publications, frameworks were developed for the phase of PHR implementation studied, the type of investigation and, and the evidence it provided about barriers.

2.2.1 Implementation phase

For each publication, the authors’ description of the phase of PHR implementation under investigation was reviewed, and thematic coding used to establish a schema describing each phase of implementation. This schema was then used to categorise all publications. The majority were focused on a single phase of implementation, with three (Atreja et al., 2005; Cho et al., 2010; Luque et al., 2013) addressing two phases.

2.2.2 Investigation type

For each publication, descriptions of the type of study were reviewed, and used to develop a categorisation by type of investigation. Publications were assigned to a category of investigation type, with the majority of publications using a single type of investigation, and three (Nijland et al., 2011; Gordon et al., 2012; Butler et al., 2013) spanning two types.

2.2.3 Barriers

Each of the publications was reviewed to identify evidence about barriers which might inhibit patients’ adoption or continued use of a PHR, as well as barriers to Internet use more generally (in the context of PHR use). An iterative process of thematic coding was used to classify barriers, with each included publication reviewed at least three times to ensure that meanings were not misinterpreted, and that the thematic structure remained consistent.

3 RESULTS

3.1 Summary

Searches in PubMed, Embase, CINAHL and ProQuest retrieved a total of 439 publications. Another 36 items were identified from citation tracking and other sources, giving a total of 475 publications. After removing 81 duplicates, 395 publications remained for initial screening. This resulted in the exclusion of 256 records, leaving 138 full text articles to be evaluated for eligibility. This evaluation removed 98
articles which provided no direct evidence about PHR barriers or did not address patient barriers to PHR adoption and use, and literature reviews whose content duplicate other retrieved publications. This left 40 articles for the synthesis of evidence. This process is outlined in Figure 1 below:

![PRISMA flowchart](image)

**Figure 1.** PRISMA flowchart.

Each of the included publications was coded in order to identify the particular phase of the PHR implementation which was being evaluated, the type of investigation conducted, and the barriers which were identified.

### 3.2 Key features of selected studies

Details of the included publications, including method, size of target population and number of participants is shown in Table 1 below, categorised by Investigation type.

**Table 1.** Summary of included publications.

<table>
<thead>
<tr>
<th>First author(yr)</th>
<th>Investigation type</th>
<th>Population</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>A: Collection of data from PHR users, or non-participants</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continued on next page</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 1 – continued from previous page

<table>
<thead>
<tr>
<th>First author(yr)</th>
<th>Investigation type</th>
<th>Population</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderson (2004)</td>
<td>Telephone interview survey</td>
<td>3,000</td>
<td>186</td>
</tr>
<tr>
<td>Atreja (2005)</td>
<td>Focus groups/interviews with clinic staff; observation</td>
<td>-</td>
<td>15</td>
</tr>
<tr>
<td>Cho (2010)</td>
<td>Postal survey questionnaire</td>
<td>-</td>
<td>201</td>
</tr>
<tr>
<td>Chrischilles (2014)</td>
<td>Mixed methods: UCD with evaluation; questionnaire</td>
<td>15,000</td>
<td>1,075</td>
</tr>
<tr>
<td>Crabb (2011)</td>
<td>Interview survey</td>
<td>75</td>
<td>50</td>
</tr>
<tr>
<td>Emani (2012)</td>
<td>Postal survey questionnaire</td>
<td>1,500</td>
<td>760</td>
</tr>
<tr>
<td>Fuji (2014)</td>
<td>Interviews with trained users</td>
<td>59</td>
<td>23</td>
</tr>
<tr>
<td>Goel/Cooper (2011)</td>
<td>Telephone interviews with non adopters</td>
<td></td>
<td>159</td>
</tr>
<tr>
<td>Hall (2014)</td>
<td>Trial of result communication via PHR</td>
<td>66</td>
<td>49</td>
</tr>
<tr>
<td>Hilton (2012)</td>
<td>Online survey (within supported PHR use)</td>
<td>2,871</td>
<td>338</td>
</tr>
<tr>
<td>Kruse (2012)</td>
<td>Interviews about Internet use</td>
<td>713</td>
<td>638</td>
</tr>
<tr>
<td>Lober (2006)</td>
<td>Analysis of data about PHR use</td>
<td>170</td>
<td>41</td>
</tr>
<tr>
<td>McCleary-Jones (2013)</td>
<td>Interviews</td>
<td>350</td>
<td>88</td>
</tr>
<tr>
<td>Mishuris (2014)</td>
<td>Semistructured interviews with patients</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Roblin (2009)</td>
<td>Paper survey with online option (non-adopters)</td>
<td>5,309</td>
<td>1,777</td>
</tr>
<tr>
<td>Taha (2013)</td>
<td>Lab usability test of a simulated PHR</td>
<td></td>
<td>107</td>
</tr>
<tr>
<td>Weitzman (2009)</td>
<td>Focus groups, usability testing, email</td>
<td></td>
<td>302</td>
</tr>
</tbody>
</table>

B: Observational studies

<table>
<thead>
<tr>
<th>First author(yr)</th>
<th>Investigation type</th>
<th>Population</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Byczkowski (2011)</td>
<td>Retrospective observational study</td>
<td>1,900</td>
<td>498</td>
</tr>
<tr>
<td>Goel/Hasnain(2011)</td>
<td>Retrospective data analysis with adopters</td>
<td>7,088</td>
<td>4,891</td>
</tr>
<tr>
<td>Nielsen (2012)</td>
<td>Retrospective chart review</td>
<td>240</td>
<td>154</td>
</tr>
<tr>
<td>Sarkar (2010)</td>
<td>Telephone, web and written survey</td>
<td>14,102</td>
<td>5,671</td>
</tr>
<tr>
<td>Sarkar (2011)</td>
<td>Telephone, web and written survey</td>
<td>141,02</td>
<td>5,671</td>
</tr>
<tr>
<td>Yamin (2011)</td>
<td>Data analysis comparing adopters and non-adopters</td>
<td>75,056</td>
<td>32,274</td>
</tr>
</tbody>
</table>

C: Patient attitudes and opinions

<table>
<thead>
<tr>
<th>First author(yr)</th>
<th>Investigation type</th>
<th>Population</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Logue (2012)</td>
<td>Survey questionnaire</td>
<td></td>
<td>38</td>
</tr>
<tr>
<td>Luque (2013)</td>
<td>Mixed methods: Written questionnaire/Focus group</td>
<td>120/8</td>
<td>90/8</td>
</tr>
<tr>
<td>Noblin (2012)</td>
<td>Paper survey on health literacy and PHR usage intention</td>
<td></td>
<td>562</td>
</tr>
<tr>
<td>Patel (2011)</td>
<td>Telephone survey</td>
<td></td>
<td>200</td>
</tr>
<tr>
<td>Patel (2012)</td>
<td>Paper survey of support for HIE and PHR</td>
<td></td>
<td>117</td>
</tr>
<tr>
<td>Zarcadoolas (2013)</td>
<td>Focus groups</td>
<td></td>
<td>28</td>
</tr>
</tbody>
</table>

Multiple types

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Table 1 – continued from previous page

<table>
<thead>
<tr>
<th>First author(yr)</th>
<th>Investigation type</th>
<th>Population</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Butler (2013)</td>
<td>Mixed methods: Semistructured interviews with staff/Telephone interviews with patients (A, D)</td>
<td>9/404</td>
<td>39</td>
</tr>
<tr>
<td>Gordon (2012)</td>
<td>Mixed methods: Surveys, database analysis, usage logs (A, C)</td>
<td>8,249</td>
<td>509</td>
</tr>
<tr>
<td>Nijland (2011)</td>
<td>Mixed methods: Survey; interviews; log files; usability assessment (A, B)</td>
<td>350</td>
<td>50</td>
</tr>
</tbody>
</table>

**Literature reviews**

Archer (2011)  
Goldzweig (2012)  
Jimison (2008)  
McInnes (2013)  
Or (2009)  
Urowitz (2012)  

The publications retrieved for this review displayed a distinct geographic bias, with 38 out of a total of 40 studies describing PHR implementations in the USA (with one each from the United Kingdom and the Netherlands). Three particular PHR systems – My HealtheVet, kp.org and MyChart – accounted for nine of the publications (with three each). Data about a possible bias in the selection of participants was retrieved during the data extraction, and evaluated as a secondary outcome.

### 3.3 Implementation phase

For the purposes of categorising publications, the following schema was adopted in order to identify which phase of PHR readiness, adoption and use was being considered.

1. Readiness to use a PHR, including evaluations of Internet use:
   1.1 – Patient use of technology, including the Internet;  
   1.2 – PHR usage intentions; or  
   1.3 – Design of PHRs, with User Centred Design (UCD), or usability studies.
2. Initial registration for an account within a PHR system;  
3. Initial use of a PHR; publications which studied any use of a PHR at an unspecified time after registration were included in this category;  
4. Continued use of a PHR, including long term use; or  
5. PHR benefits affecting the patient’s health and wellbeing.

### 3.4 Investigation type

Publications were categorised according to the investigation types, with publications categorised as either a literature review, or one of:

A An evaluation involving the collection of data about barriers about from PHR users, or participants who did not initiate or continue PHR use (using focus groups, interviews, surveys or questionnaires);  
B An observational study providing a qualitative or quantitative evaluation of demographic data and records of users and non-users;  
C Details of attitudes and opinions of patients about barriers to possible future PHR use, and the demographic characteristics of those with particular usage intentions; or D Observations from health professionals about patient use of PHRs.

### 3.5 Barriers

Each of the included publications provided statements about barriers to patient adoption and continued use of a PHR. This evidence was either: described by potential users in advance or anticipation of PHR use; reported by potential users as a reason for not commencing use of a PHR, or not continuing that use; inferred from demographic differences between users and non-users; or identified in a literature review. Thematic analysis was used to identify barriers and categorise barrier types. This process involved a degree of simplification for some of the barrier concepts described in publications. For example, while ‘Age’ could be applied as a straightforward description for a barrier, the term ‘Health literacy’ was
applied to a number of terms, including “Patient comprehension of medical terminology and health-related information...” (Urowitz et al., 2012) and ‘Lack of motivation’ was assigned to descriptions such as “Participants did not perceive the PHR as having added value for managing their existing self-care behaviors...” (Fuji et al., 2014).

The analysis identified 21 distinct barriers, which are listed by barrier category in Table 2. Age, sex, and race or ethnicity are innate characteristics of an individual user, not amenable to change, and were grouped together as Individual factors. Income, socioeconomic status, level of education and Internet and computer access were categorised as Demographic factors related to an individual’s circumstances. Functional or text literacy, numeracy, health literacy, and technical literacy and skills were categorised as Capability factors. Health related factors included the individual’s health and wellbeing (including the presence of a chronic disease), disability generally, and specific physical, cognitive or visual limitations. Barriers associated with the usability of a PHR, the costs associated with access or lack of information about the PHR were categorised as PHR factors. The remaining barriers – discomfort with computer use, concerns about privacy security and confidentiality, and lack of motivation were grouped as Attitudinal factors.

### 3.6 Primary outcome: PHR barriers

Most barriers were identified in most phases of PHR implementation, and in most types of study. The number of references to each barrier by phase of PHR implementation and type of study are shown in Table 2, together with the number of publications in which each barrier was identified; barriers which are likely to be associated with socioeconomic disadvantage are flagged. It should be noted that failure to identify a barrier within a particular publication does not provide evidence that the barrier was absent in the population studied, merely that it was not identified. Also note that some of the publications report multiple phases or investigation types, and totals by Type and Phase for some barriers may exceed the number of occurrences.

#### Table 2. PHR barriers by implementation phase and investigation type.

<table>
<thead>
<tr>
<th>Implementation phase</th>
<th>Investigation type</th>
<th>Literature review</th>
<th>Number of occurrences</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1.1</td>
<td>1.2</td>
<td>1.3</td>
</tr>
<tr>
<td><strong>Individual factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>4</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Sex</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income, socioeconomic statusa</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Education</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Internet and computer access</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td><strong>Capability factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Text literacya</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Numerica</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Health literacya</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Technical literacy, skillsa</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health, chronic disease disability (general) Physical disability</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Implementation phase</th>
<th>PHR factors</th>
<th>Attitudinal factors</th>
<th>Literature review</th>
<th>Number of occurrences</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 PHR readiness - use of technology</td>
<td>Cognitive disability</td>
<td>Usability</td>
<td>A Collection of data from PHR users, or non-participants</td>
<td>a Barrier associated with socioeconomic disadvantage</td>
</tr>
<tr>
<td>1.2 PHR readiness - usage intentions.</td>
<td>Visual disability</td>
<td>Cost</td>
<td>B An observational study using demographic data and records of users and non-users;</td>
<td></td>
</tr>
<tr>
<td>1.3 PHR readiness - participation in design of PHRs, 2 Initial registration</td>
<td>PHR factors</td>
<td>Lack of information</td>
<td>C Attitudes and opinions of patients about barriers</td>
<td></td>
</tr>
<tr>
<td>3 Initial use</td>
<td>PHR factors</td>
<td>Discomfort with computer use</td>
<td>D Observations by health professionals.</td>
<td></td>
</tr>
<tr>
<td>4 Continued use</td>
<td>PHR factors</td>
<td>Privacy concerns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 PHR benefits</td>
<td>PHR factors</td>
<td>Lack of motivation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Key: Implementation phase**

- 1.1 PHR readiness - use of technology
- 1.2 PHR readiness - usage intentions.
- 1.3 PHR readiness - participation in design of PHRs,

**Key: Investigation type:**

- A Collection of data from PHR users, or non-participants
- B An observational study using demographic data and records of users and non-users;
- C Attitudes and opinions of patients about barriers
- D Observations by health professionals.

**3.7 Individual characteristics**

The characteristics of each barrier, and salient details of the evidence are outlined below.

**3.7.1 Age**

A total of 15 of the included studies and two literature reviews identified patient age as a barrier which has an impact on the adoption and continued use of PHRs. However, the effect was not clearly delineated. A literature review by Or and Karsh (Or and Karsh, 2009) noted that “[a]ge was examined in 39 studies and did not show a consistent effect. Among those 39 studies, 26 (67%) found significant relationships and 13 did not. Among the 26 studies with significant relationships, only one showed that higher age was associated with increased acceptance, 19 found that age was negatively associated with acceptance, and six found a nonlinear relationship.” (Or and Karsh, 2009, p. 553) It is likely that age has a variable impact on ability, usage intention and the motivation to continue using a PHR after enrolment. Internet use was more common for younger patients, with use declining with increasing age(Kruse et al., 2012) and PHR ‘innovators’ were younger than other other users and ‘non-adopters’ (Emani et al., 2012), with older patients less likely to enrol for a PHR (Goel et al., 2011b), although one study found that, once receiving a password, older patients were more likely to log on to the system (Sarkar et al., 2011).

**3.7.2 Sex**

The sex of participants was noted as a barrier in statistical analyses, but the effect was generally modest, and inconsistent between publications. Studies found that found that men were more likely to find computer use enjoyable and be confident about using the Internet and online PHR (Logue and Effken,
more likely to go online (Cho et al., 2010), and more likely to be higher users of PHRs, and more engaged (Chrischilles et al., 2014). However, one study found that women were 15% more likely to adopt a PHR (OR 1.15, CI 1.08-1.21) (Yamin et al., 2011).

### 3.7.3 Race and ethnicity

Race and ethnicity were identified as a barrier in nine studies and two literature reviews, either inhibiting the adoption of a PHR (Kim et al., 2009; Roblin et al., 2009; Goel et al., 2011b; Emani et al., 2012), or making its continued use less likely (Yamin et al., 2011; Byczkowski et al., 2011; Sarkar et al., 2011). Publications did not always clarify the extent to which this tendency was associated with related barriers such as education, income and socioeconomic status, literacy or computer and Internet access.

### 3.8 Demographic factors

#### 3.8.1 Income, socioeconomic status

PHR barriers for those with lower income and lower socioeconomic status were identified in nine studies and two literature reviews. PHR adoption was less likely in groups with lower socioeconomic status (Yamin et al., 2011) and those without private health insurance (Byczkowski et al., 2011), although for those who did adopt a PHR, level of income did not appear to affect the degree of use (Yamin et al., 2011).

#### 3.8.2 Level of education

Level of education was identified as a barrier in seven studies and three literature reviews, associated with both computer and Internet access and use (Kruse et al., 2012) and with the adoption and use of a PHR (Roblin et al., 2009; Emani et al., 2012), although the association with continued use of a PHR following enrolment appeared less pronounced (Sarkar et al., 2011).

#### 3.8.3 Internet and computer access

Lack of Internet and computer access were identified as barriers in 11 studies and four literature reviews. Problems with access did not appear to have a marked effect on PHR usage intention (Goel et al., 2011a), although they did affect actual use of a PHR (Lober et al., 2006; Nijland et al., 2011; Kruse et al., 2012).

### 3.9 Capabilities

#### 3.9.1 Text literacy/functional literacy

Only two studies and two literature reviews specifically identified low levels of text literacy or functional literacy as a barrier to the use of a PHR, with functional literacy identified as a potential barrier by a focus group discussion (Taha et al., 2013). This limited evidence was despite the obvious limitation that an inability to read would impose on a potential PHR user.

#### 3.9.2 Numeracy

Numeracy was identified as barrier in only one study, and in one literature review. The study authors found that poor numeracy skills accounted for 4-5% of users’ failures with overall task performance and the performance of complex tasks in a simulated PHR (Taha et al., 2013). It should be remembered, however, that an element of numeracy is often included as a contributor to overall health literacy.

#### 3.9.3 Health literacy

Low health literacy was identified as a barrier in seven studies and three literature reviews, and was noted as having an impact on both adoption (Sarkar et al., 2011; Noblin et al., 2012) and continued use (Lober et al., 2006; Kim et al., 2009). Greenhalgh et al Greenhalgh et al. (2010) found that many subjects who described their attitude to portal use as “...’not bothered’ or ‘don’t care’...” were also judged by the researchers to have low levels of health literacy.

#### 3.9.4 Technical literacy and skills

A lack of technical literacy and computer or Internet skills were the most frequently identified barrier, with 19 publications identifying this as a barrier to either technology use (Olshansky et al., 2012) or the use of a PHR (Lober et al., 2006; Roblin et al., 2009; Nijland et al., 2011; Hilton et al., 2012; Butler et al., 2013; Luque et al., 2013). Early adopters of a PHR were significantly more likely to self-report being ‘comfortable’ or ‘very comfortable’ with Internet use (Butler et al., 2013) while those with rudimentary computer skills showed little improvement in PHR use over time (Hilton et al., 2012).
3.10 Health related

3.10.1 Health, Chronic disease

Data from ten studies and one literature review identified a complex relationship between health and both Internet use and PHR adoption and use. Those whose self-reported health status was excellent or very good were more likely to be internet users (Kruse et al., 2012), while patients with poorer health overall were less likely to adopt a PHR (Emani et al., 2012). However, those with multiple comorbidities were identified as being more likely to adopt a PHR (Roblin et al., 2009) or expressed willingness to choose a healthcare provider based on the provider’s use of information from their PHR (Logue and Effken, 2012).

3.10.2 Disability

Disability can create practical barriers to the use of information technology, including PHRs (Angaran, 2011). Two publications identified disability as a generic barrier to PHR use; physical impairment was identified in two studies and one literature review; cognitive impairment in five studies and one literature review; and visual impairment in three studies. Physical, visual and cognitive impairment have all been identified as barriers to successful use of a PHR (Lober et al., 2006; Kim et al., 2009), although design adaptations may help to reduce the severity of those barriers (Atreja et al., 2005).

3.11 PHR factors

3.11.1 Usability

Three studies and one literature review identified usability as a barrier to successful adoption and use of a PHR by patients. One study which looked for specific barriers affecting patients with multiple sclerosis (Atreja et al., 2005) found that issues such as a cluttered display, small font size, and poor contrast created barriers while another (Fuji et al., 2014) reported patient difficulties with navigation between pages and repeated clicking during data entry.

3.11.2 Cost

Three studies and one literature review identified costs to users as a barrier for PHRs, with patients reporting that they could not afford the cost of a computer and a broadband Internet connection (Kruse et al., 2012; Luque et al., 2013).

3.11.3 Lack of information

Three studies identified that a lack of information about the availability of a particular PHR (Mishuris et al., 2014), or accessibility of information about options within a PHR (Atreja et al., 2005) could interfere with use.

3.12 Attitudinal factors

3.12.1 Discomfort with computer use

Five studies and two literature reviews identified some form of discomfort with the use of a computer as a barrier to the adoption and use of a PHR (Kruse et al., 2012). This barrier was also described as a lack of confidence and fear of failure (McInnes et al., 2013), and as ‘computer anxiety’ (Lober et al., 2006; Kim et al., 2009).

3.12.2 Privacy and confidentiality concerns

Patient concerns about privacy or confidentiality of personal health information stored in a PHR were reported in seven studies (Anderson, 2004; McCleary-Jones et al., 2013). In some cases these concerns were specifically related to the need to access a PHR from a public or shared computer (Luque et al., 2013; Mishuris et al., 2014).

3.12.3 Lack of motivation

Three studies and one literature review provided evidence that a lack of motivation could be a barrier to the use of a PHR. Potential users did not see the PHR as providing added value (Fuji et al., 2014; Mishuris et al., 2014) or thought that using a PHR would take up too much time (Nijland et al., 2011; Fuji et al., 2014).

4 SECONDARY OUTCOME: SELECTION BIAS

Eleven of the publications which identified PHR barriers may have inadvertently introduced a bias by using a data collection methodology which could exclude participants who were less affluent, less capable,
or marginalised. Those methodological choices fell into four broad categories, with one publication (McCleary-Jones et al., 2013) including more than one type of bias:

4.1 A focus on those already using technology
In five publications participation was restricted to subjects who already had experience using a web browser (Lin et al., 2005; Nijland et al., 2011), had an existing portal account (Byczkowski et al., 2011), who had received training in the use of a PHR (Fuji et al., 2014), or who were required to complete web based surveys during the study (Hilton et al., 2012). These studies did not report barriers related to Capability factors, or to disability.

4.2 Exclusion of participants with serious illness or infirmity
In two publications subjects were excluded if they were prevented from participating in an interview as a result of a serious comorbidity (Atreja et al., 2005) or if obvious cognitive deficits were observed (McCleary-Jones et al., 2013). These studies did not report any barriers associated with Individual or Demographic factors, and only health literacy was identified as a Capability factor.

4.3 Excluding participants on the basis of language and literacy
Selection of participants for four studies (Logue and Effken, 2012; Kruse et al., 2012; Patel et al., 2012; McCleary-Jones et al., 2013) required them to be able to speak, read or write English. These studies identified a wide range of barriers in all categories (11 in all).

4.4 Selection of subjects from within a population less likely to be disadvantaged
In these three publications data collection was restricted to participants with a landline telephone (Anderson, 2004), to university undergraduates in schools of business and information systems (Whetstone and Goldsmith, 2009), or to members of a community less likely to be disadvantaged (McCleary-Jones et al., 2013). Health literacy and privacy concerns were the only barriers to PHR adoption and use identified in these studies.

Identification of these potential sources of bias is not intended as a criticism of the studies, or of the authors. However, bias within a methodology may mean that any evaluation of barriers within publications (such as that provided by this review) is likely to underestimate the prevalence and significance of barriers, particularly if those barriers are related to exclusion criteria used in the selection of participants.

5 DISCUSSION
5.1 Barriers
This literature review has identified evidence for 21 barriers, categorised as Individual, Demographic, Capability, Health related, PHR related and Attitudinal factors, which could interfere with or prevent a patient’s adoption or continued use of a personal health record. The evidence is consistent, with 12 of the barriers being identified in six or more publications. However, the frequency with which a particular barrier is identified provides little indication of that barrier’s significance. The low incidence (four publications or fewer) of reports identifying text literacy, numeracy, generalised disability, and physical and visual impairment as barriers is more likely to result from inadvertent bias, or the relative ‘invisibility’ of disadvantaged participants, rather than from the insignificance of these barriers.

The complex interrelationship which exists between many of the barriers is suggested in some publications, and emerges more clearly from this review. Socioeconomic status and educational attainment are closely related, and associated with text, technical and health literacy, and with numeracy; Internet and computer access, computer skills and discomfort with the use of a computer are closely intertwined; and lastly PHR usability is likely to have a greater impact on users with lower capabilities, and PHR costs will be more challenging for poorer patients. Furthermore, socioeconomic disadvantage is likely to be statistically more prevalent among older citizens, and within non-Caucasian communities. The review identified predominantly US data, and identifies specific issues for elderly, African American, and Latino communities.

5.1.1 Barriers by type of investigation
The evidence about barriers to PHR adoption and use varies with the types of investigation (coded in Table 2 as A, B, C and D). Firstly, data collected from patients themselves provides direct evidence about
actual barriers which they face in adopting and continuing to use a PHR, although there may be a tendency for self-reports to underestimate the importance of barriers such as socioeconomic status, text literacy, health literacy and numeracy, which can carry a social stigma.

Secondly, observational studies using PHR usage logs and health administrative data for PHR users and non-users can provide evidence about barriers, but only from the data items which are included in those records. In many cases socioeconomic status, text and health literacy or computer and Internet use are not recorded, although an area measure of socioeconomic status could be imputed from the patient’s home address. Next, attitudes and opinions of patients about PHR benefits and barriers, and usage intention can be informative, although there may be a gap between stated intention and future actions. Observations by health professionals about barriers to patient use of PHRs may also be instructive, although these could be based on assumptions rather than an objective assessment.

Lastly, literature reviews provide a summation and interpretation of publications about PHRs, including barriers which might interfere with adoption; the reference sources included in these reviews are likely to fall within one of the categories described above. The evidence provided by the review is shaped by the evidence being reviewed, with some moderation as a result of the authors’ analysis and expertise.

5.1.2 Barriers by phase of implementation
Evidence about PHR barriers also varies by the phase of implementation being investigated (coded in Table 2 as 1.1-1.3, 2, 3, 4, and 5). In Phases 1 and 2 (pre-adoption and initial registration) evidence about barriers is most likely to be about usage intention. Evidence suggests a gap between usage intention and actual PHR use. Disadvantaged and low capability users may see use of a PHR as beneficial, but may overestimate their own capabilities, and underestimate the challenges involved in using a PHR; individuals may lack full awareness of the extent of their limitations, or see those limitations as a making PHR use more difficult.

In Phase 3 (early use) enthusiasm about first use may revert to a lack of interest once the reality of PHR use becomes apparent; evidence about barriers from evaluations of registration and first use are likely to provide an indication of those barriers which might interfere with the decision to use a PHR.

Barriers identified in Phase 4 (continued use) provide insight into the constraints which are likely to interfere with long term use. Depending on the particular PHR, maintaining regular use could be difficult, although moderated by the skills and capabilities of the user. Continued interest in PHR use is likely to be influenced by a perception of healthcare need, and how that need is met by the PHR, relative to other care that they receive. Barriers may also be context-sensitive, and influenced by PHR usability and user capabilities. PHRs need to be suitable for all users; testing with volunteers with good text-, technical-, and health literacy may overestimate the suitability of the PHR for a broader population.

5.2 Bias
There are two potential sources of bias which could affect these results: bias within the studies which were evaluated, and bias resulting from the limitations of the methodology applied.

5.2.1 Within studies
A number of the studies included in the review chose participants in a way that might result in a lower proportion of disadvantaged and low-capability users, compared with the initial population, resulting in a possible under-reporting of PHR barriers, and indeed, some degree of bias may be unavoidable. Acquiring evidence about PHRs, including evidence about barriers, must rely on subjects who are able to participate: studies of PHR usage must rely on PHR users, participants must read a written questionnaire in order to respond, and it can be difficult to ethically engage research subjects with cognitive limitations. On the other hand, PHRs are intended for users who are unwell, not just healthy, educated, well-off patients. Note that one study (Zarcadoolas et al., 2013) (not included in the evaluation of bias) deliberately introduced an inverse bias by seeking out participants with a low socioeconomic status.

5.2.2 Limitations of the review
This review has inevitably produced a biased evaluation of PHR barriers. Selecting publications in English has given an Anglophone, US-centric account of PHR barriers, from a restricted range of study locations, with little information from other countries. There may also be a publication bias: many of the publications from the US are from large (and possibly well resourced) healthcare organisations and academic institutions able to provide early support for PHR users; results for PHR implementations in smaller, less well resourced settings might report barriers differently.
6 CONCLUSIONS

6.1 Principal findings

This review has found evidence of a range of barriers which interfere with the adoption and continued use of PHRs, with 155 instances of 21 distinct barriers identified across 40 publications. This evidence was found in all types of investigation, and in all phases of PHR adoption. Further research may find other as yet unidentified barriers, as well as variants of barriers identified in this review. A close relationship is evident between socioeconomic status and other barriers, with 12 of the 21 barriers being associated with socioeconomic disadvantage. This confirms that the use of a PHR is likely to be harder for disadvantaged patients; PHRs as they are currently implemented may not provide a universal solution for problems with healthcare delivery or communication.

This review has not attempted to provide a precise quantification of PHR barriers. This has been a conscious decision - the relative importance of a PHR barrier cannot easily be deduced from the number of times that it appears within the research literature. Rather, the results highlight a need during PHR design, and during PHR implementation, to make a careful assessment of the likelihood of each barrier being present within the population being considered as users.

Furthermore, it should be borne in mind that early reports of successful PHR uptake are likely to depend on record access by competent PHR 'early adopters', rather than by disadvantaged users. Despite the problem of a growing 'ehealth divide'[58] this criterion as currently defined provides little impetus for health professionals or hospitals to encourage PHR enrolments among disadvantaged patients.

6.2 Future research priorities

While this review has identified a broad range of PHR barriers, there was insufficient consistency across multiple studies to provide a comprehensive picture of the effect of barriers during PHR implementation and use. If those barriers affecting the population of potential users are to be addressed early in the process of design and implementation, there will need to be a more thorough identification and characterisation of both barriers and users. As Kushniruk and Turner have observed, "...consideration of who the user is and how the user is involved and their inputs mediated needs to be further articulated. To address these issues it is useful to try to be more precise about who the users are, when and where they are engaged, what expectations we have about our users and why." (Kushniruk and Turner, 2010) Developing a better understanding of the impact of barriers on PHR users will help to ensure that resources allocated to PHR systems are used most effectively. There is also a need for a better appreciation of how barriers interfere with PHR adoption and use, and how that effect can be countered. Simply being aware of the possibility that a particular barrier may inhibit PHR use for some patients may be enough to ensure that this barrier is taken into account during PHR design and implementation. However, the apparent bias evident in a number of the studies suggests that the existence and significance of barriers is not universally recognised, and that further research may be warranted in order to provide stronger evidence. Finally, the results of this literature review raise a number of interesting questions which may suggest possibilities for future research:

- What does a PHR designed specifically for ‘low functional literacy’ users look like?
- What assistive options within a PHR could help to reduce the negative impact of poor health literacy?
- How can attention to PHR design minimise the impact of cognitive limitations for older patients?

The response to these question may help to identify a path towards PHRs designed for specific groups of disadvantaged patients, or with an interface sufficiently simple, and adaptable to meet the needs of all users.

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