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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 underserved 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.

1 Barriers to meaningful use of personal 2 health records by patients: A structured 3 review

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6 ABSTRACT

7 **introduction:** An increasing focus on personal electronic health records (PHRs) offers healthcare
8 benefits for patients, particularly those in undeserved and marginalised populations, who are at risk
9 of receiving less effective healthcare, and may have worse health outcomes. However, PHRs are
10 likely to favour text, technical and health literate users, and be less suitable for disadvantaged patients.
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24 continued use, and the impact of particular barriers may vary at different phases of PHR adoption. The
25 complex interrelationships which exist between many of the barriers is suggested in some publications,
26 and emerges more clearly from this review. Many PHR barriers appear to be related to low socioeconomic
27 status. A better understanding is needed of how the effect of barriers is manifested, how that that effect
28 can be countered, and how planning and implementation of PHR initiatives can make allowance for
29 patient level barriers to PHR adoption and use, with appropriate actions to mitigate the effect of those
30 barriers for more disadvantaged patients.

31 Keywords: eHealth, Personal health records, Barriers; Bias; Systematic review

32 INTRODUCTION

33 There is an increasing focus on personal electronic health records (PHRs) as a part of the implementation
34 of ehealth services to support improvements in healthcare. PHRs have been defined as "...a private, secure
35 application through which an individual may access, manage, and share his or her health information.
36 The PHR can include information that is entered by the consumer and/or data from other sources such
37 as pharmacies, labs, and health care providers." (Jones et al., 2010) Most publications about personal
38 health record systems now focus on electronic versions providing online access for patients, which may be
39 through provider portals. PHRs offer a number of benefits including better access to data and information,
40 improved communication between patients and providers, the empowerment of patients, and opportunities
41 for health self-management (Tang and Lansky, 2005; Pagliari et al., 2007).

42 These benefits are certainly worthwhile, particularly for disadvantaged patients, who face challenges
43 in receiving safe effective healthcare (Adler and Newman, 2002), and are likely to have worse health
44 outcomes than more privileged patients (Olshansky et al., 2012). However, the benefits which result
45 from the use of a PHR cannot be guaranteed. The use of specialised medical language within a PHR can
46 marginalise non-specialist users (Showell et al., 2010), and in Australia, patients have largely been left

47 out of discussions about policies affecting national PHR developments (Showell, 2011).

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

57 1 OBJECTIVES

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

- 63 • What patient level barriers to the adoption and continued use of PHRs have been identified?
- 64 • What is the nature of the evidence for each of those barriers?
- 65 • At what stage of PHR adoption and use are those barriers most likely to apply?

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

68 2 METHODS

69 2.1 Eligibility criteria

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

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

79 The types of publication which were retrieved included:

- 80 • Comparative trials involving multiple participating sites;
- 81 • Evaluations which involved the collection of data from patients about PHR barriers (using focus
82 groups, interviews, surveys or questionnaires);
- 83 • Observational studies;
- 84 • Details of the attitudes and opinions of patients about possible future PHR use;
- 85 • Observations from health professionals about patient use of PHRs; and
- 86 • Literature reviews about barriers to PHR use.

87 2.2 Study selection and data extraction

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

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

97 All publications were initially screened to remove items which were considered to be out of scope,
98 for example where the reference to PHRs was incidental. (Bonacina and Pinciroli, 2010; Abimbola et al.,
99 2012) where the barriers identified were exclusively those affecting healthcare providers and organisations
100 (Hart, 2009; Gaskin et al., 2011), or where the focus was on PHR infrastructure issues (Hammond, 2005;
101 Tejero and de la Torre, 2012). The screening process also removed items which made only incidental
102 mention of PHRs (Stead et al., 2005) or barriers (Burke et al., 2010). Publications were included if they
103 provided specific evidence about barriers which might influence the intended or actual adoption of PHRs
104 by patients or their continued use. Literature reviews were removed if they included only publications
105 which had already been retrieved for this review and added no helpful additional commentary.

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

116 2.2.1 Implementation phase

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

122 2.2.2 Investigation type

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

127 2.2.3 Barriers

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

133 3 RESULTS

134 3.1 Summary

135 Searches in PubMed, Embase, CINAHL and ProQuest retrieved a total of 439 publications. Another 36
136 items were identified from citation tracking and other sources, giving a total of 475 publications. After
137 removing 81 duplicates, 395 publications remained for initial screening. This resulted in the exclusion
138 of 256 records, leaving 138 full text articles to be evaluated for eligibility. This evaluation removed 98

139 articles which provided no direct evidence about PHR barriers or did not address patient barriers to PHR
 140 adoption and use, and literature reviews whose content duplicate other retrieved publications. This left 40
 141 articles for the synthesis of evidence. This process is outlined in Figure 1 below:

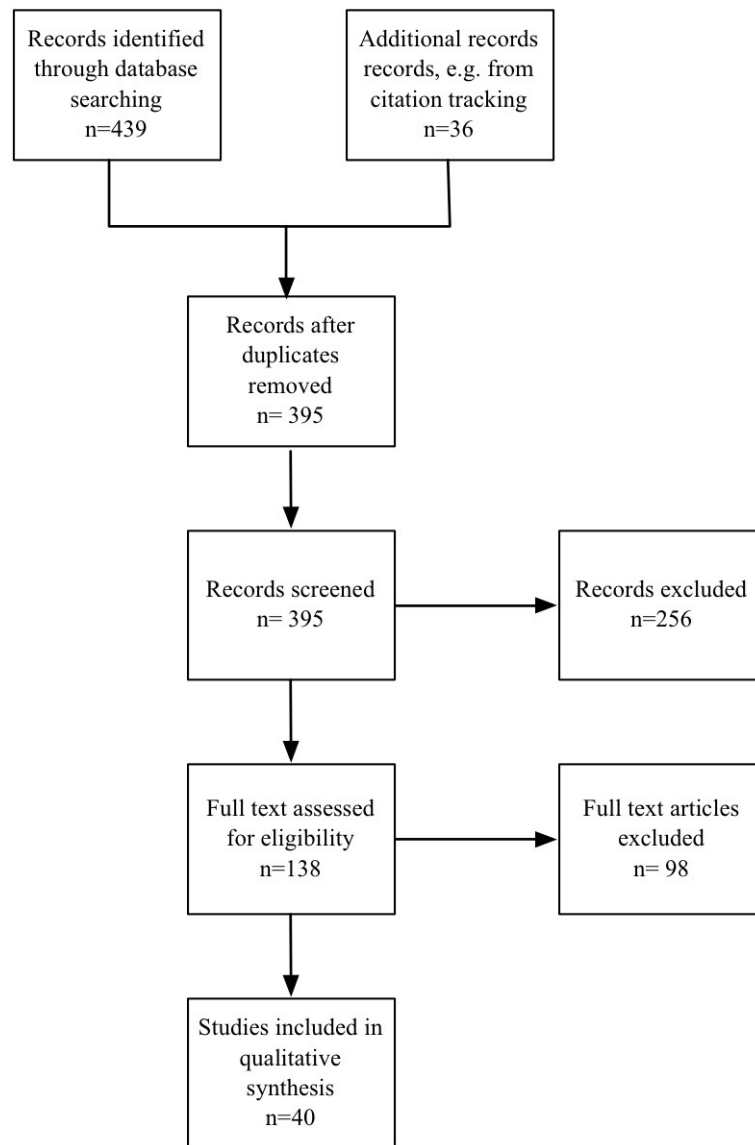


Figure 1. PRISMA flowchart.

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

145 3.2 Key features of selected studies

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

Table 1. Summary of included publications.

First author(yr)	Investigation type	Population	Participants
A: Collection of data from PHR users, or non-participants			
Continued on next page			

Table 1 – continued from previous page

First author(yr)	Investigation type	Population	Participants
Anderson (2004)	Telephone interview survey	3,000	186
Atreja (2005)	Focus groups/interviews with clinic staff; observation	-	15
Cho (2010)	Postal survey questionnaire	-	201
Chrischilles (2014)	Mixed methods: UCD with evaluation; questionnaire	15,000	1,075
Crabb (2011)	Interview survey	75	50
Emani (2012)	Postal survey questionnaire	1,500	760
Fuji (2014)	Interviews with trained users	59	23
Goel/Cooper (2011)	Telephone interviews with non adopters		159
Greenhalgh (2008)	Mixed methods: Interviews/focus groups		103/67
Hall (2014)	Trial of result communication via PHR	66	49
Hilton (2012)	Online survey (within supported PHR use	2,871	338
Kim (2009)	Mixed methods: Paper questionnaire, analysis of user logs	330	70
Kruse (2012)	Interviews about Internet use	713	638
Lober (2006)	Analysis of data about PHR use	170	41
McCleary-Jones (2013)	Interviews	350	88
Mishuris (2014)	Semistructured interviews with patients		3
Roblin (2009)	Paper survey with online option (non-adopters)	5,309	1,777
Taha (2013)	Lab usability test of a simulated PHR		107
Weitzman (2009)	Focus groups, usability testing, email		302
B: Observational studies			
Byczkowski (2011)	Retrospective observational study	1,900	498
Goel/Hasnain(2011)	Retrospective data analysis with adopters	7,088	4,891
Nielsen (2012)	Retrospective chart review	240	154
Sarkar (2010)	Telephone, web and written survey	14,102	5,671
Sarkar (2011)	Telephone, web and written survey	141,02	5,671
Yamin (2011)	Data analysis comparing adopters and non-adopters	75,056	32,274
C: Patient attitudes and opinions			
Logue (2012)	Survey questionnaire)		38
Luque (2013)	Mixed methods: Written questionnaire/Focus group	120/8	90/
Noblin (2012)	Paper survey on health literacy and PHR usage intention		562
Patel (2011)	Telephone survey		200
Patel (2012)	Paper survey of support for HIE and PHR		117
Zarcadoolas (2013)	Focus groups		28
Multiple types			
Continued on next page			

Table 1 – continued from previous page

First author(yr)	Investigation type	Population	Participants
Butler (2013)	Mixed methods: Semistructured interviews with staff/Telephone interviews with patients (A, D)	9/404	/39
Gordon (2012)	Mixed methods: Surveys, database analysis, usage logs (A, C)	8,249	509
Nijland (2011)	Mixed methods: Survey; interviews; log files; usability assessment (A, B)	350	50
Literature reviews			
Archer (2011)			
Goldzweig (2012)			
Jimison (2008)			
McInnes (2013)			
Or (2009)			
Urowitz (2012)			

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

153 3.3 Implementation phase

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

- 156 1. Readiness to use a PHR, including evaluations of Internet use:
 - 157 1.1 – Patient use of technology, including the Internet;
 - 158 1.2 – PHR usage intentions; or
 - 159 1.3 – Design of PHRs, with User Centred Design (UCD), or usability studies.
- 160 2. Initial registration for an account within a PHR system;
- 161 3. Initial use of a PHR; publications which studied any use of a PHR at an unspecified time after
 162 registration were included in this category;
- 163 4. Continued use of a PHR, including long term use; or
- 164 5. PHR benefits affecting the patient's health and wellbeing.

165 3.4 Investigation type

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

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

175 3.5 Barriers

176 Each of the included publications provided statements about barriers to patient adoption and continued
 177 use of a PHR. This evidence was either: described by potential users in advance or anticipation of PHR
 178 use; reported by potential users as a reason for not commencing use of a PHR, or not continuing that use;
 179 inferred from demographic differences between users and non-users; or identified in a literature review.
 180 Thematic analysis was used to identify barriers and categorise barrier types. This process involved a
 181 degree of simplification for some of the barrier concepts described in publications. For example, while
 182 'Age' could be applied as a straightforward description for a barrier, the term 'Health literacy' was

183 applied to a number of terms, including “Patient comprehension of medical terminology and health-
 184 related information...”,(Urowitz et al., 2012) and ‘Lack of motivation’ was assigned to descriptions such
 185 as “Participants did not perceive the PHR as having added value for managing their existing self-care
 186 behaviors...”(Fuji et al., 2014)

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

198 3.6 Primary outcome: PHR barriers

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

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

	Implementation phase							Investigation type				Literature review	Number of occurrences	
	1.1	1.2	1.3	2	3	4	5	A	B	C	D			
Individual factors														
Age	4	4		1	4	3		8	3	2	1	2	16	
Sex		3	2	1					3	1			6	
Race/ethnicity ^a				2	3	4		5	4			2	11	
Demographic factors														
Income, socioeco- nomic status ^a	4	3			2	2		3	3	2		2	11	
Education	4	2		1	1	1		4	1	1		3	10	
Internet and com- puter access	3	3		3	2	2		8	1	2	1	4	15	
Capability factors														
Text literacy ^a			1			1		1		1		2	4	
Numeracy ^a					1			1				1	2	
Health literacy ^a	2	2				2	1	4	1	1		3	10	
Technical literacy, skills ^a	4	4	2		2	5		10	1	4	1	5	19	
Health related factors														
Health, chronic disease disability (gen- eral) Physical disabil- ity	1	2		1	2	4		6	2	2	1			
Continued on next page														

Table 2 – continued from previous page

	Implementation phase							Investigation type				Literature review	Number of occurrences
	1.1	1.2	1.3	2	3	4	5	A	B	C	D		
Cognitive disability													
Visual disability													
PHR factors													
Usability													
Cost													
Lack of information													
Attitudinal factors													
Discomfort with computer use													
Privacy concerns													
Lack of motivation													

207 ^a Barrier associated with socioeconomic disadvantage

208 **Key: Implementation phase**

209 1.1 PHR readiness - use of technology

210 1.2 PHR readiness - usage intentions.

211 1.3 PHR readiness - participation in design of PHRs,

212 2 Initial registration

213 3 Initial use

214 4 Continued use

215 5 PHR benefits

216 **Key: Investigation type:**

217 A Collection of data from PHR users, or non-participants

218 B An observational study using demographic data and records of users and non-users;

219 C Attitudes and opinions of patients about barriers

220 D Observations by health professionals.

221

222 **3.7 Individual characteristics**

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

224 **3.7.1 Age**

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

237 **3.7.2 Sex**

238 The sex of participants was noted as a barrier in statistical analyses, but the effect was generally modest,
 239 and inconsistent between publications. Studies found that found that men were more likely to find
 240 computer use enjoyable and be confident about using the Internet and online PHR (Logue and Effken,

241 2012), more likely to go online (Cho et al., 2010), and more likely to be higher users of PHRs, and more
242 engaged (Chrischilles et al., 2014). However, one study found that women were 15% more likely to adopt
243 a PHR (OR 1.15, CI 1.08-1.21) (Yamin et al., 2011).

244 **3.7.3 Race and ethnicity**

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

250 **3.8 Demographic factors**

251 **3.8.1 Income, socioeconomic status**

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

256 **3.8.2 Level of education**

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

261 **3.8.3 Internet and computer access**

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

265 **3.9 Capabilities**

266 **3.9.1 Text literacy/functional literacy**

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

271 **3.9.2 Numeracy**

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

276 **3.9.3 Health literacy**

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

282 **3.9.4 Technical literacy and skills**

283 A lack of technical literacy and computer or Internet skills were the most frequently identified barrier,
284 with 19 publications identifying this as a barrier to either technology use (Olshansky et al., 2012) or the
285 use of a PHR (Lober et al., 2006; Roblin et al., 2009; Nijland et al., 2011; Hilton et al., 2012; Butler et al.,
286 2013; Luque et al., 2013). Early adopters of a PHR were significantly more likely to self-report being
287 'comfortable' or 'very comfortable' with Internet use (Butler et al., 2013) while those with rudimentary
288 computer skills showed little improvement in PHR use over time (Hilton et al., 2012).

289 **3.10 Health related**

290 **3.10.1 Health, Chronic disease**

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

297 **3.10.2 Disability**

298 Disability can create practical barriers to the use of information technology, including PHRs (Angaran,
299 2011). Two publications identified disability as a generic barrier to PHR use; physical impairment was
300 identified in two studies and one literature review; cognitive impairment in five studies and one literature
301 review; and visual impairment in three studies. Physical, visual and cognitive impairment have all been
302 identified as barriers to successful use of a PHR (Lober et al., 2006; Kim et al., 2009), although design
303 adaptations may help to reduce the severity of those barriers (Atreja et al., 2005).

304 **3.11 PHR factors**

305 **3.11.1 Usability**

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

311 **3.11.2 Cost**

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

315 **3.11.3 Lack of information**

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

319 **3.12 Attitudinal factors**

320 **3.12.1 Discomfort with computer use**

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

325 **3.12.2 Privacy and confidentiality concerns**

326 Patient concerns about privacy or confidentiality of personal health information stored in a PHR were
327 reported in seven studies (Anderson, 2004; McCleary-Jones et al., 2013). In some cases these concerns
328 were specifically related to the need to access a PHR from a public or shared computer (Luque et al.,
329 2013; Mishuris et al., 2014).

330 **3.12.3 Lack of motivation**

331 Three studies and one literature review provided evidence that a lack of motivation could be a barrier to
332 the use of a PHR. Potential users did not see the PHR as providing added value (Fuji et al., 2014; Mishuris
333 et al., 2014) or thought that using a PHR would take up too much time (Nijland et al., 2011; Fuji et al.,
334 2014).

335 **4 SECONDARY OUTCOME: SELECTION BIAS**

336 Eleven of the publications which identified PHR barriers may have inadvertently introduced a bias by
337 using a data collection methodology which could exclude participants who were less affluent, less capable,

338 or marginalised. Those methodological choices fell into four broad categories, with one publication
339 (McCleary-Jones et al., 2013) including more than one type of bias:

340 **4.1 A focus on those already using technology**

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

346 **4.2 Exclusion of participants with serious illness or infirmity**

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

351 **4.3 Excluding participants on the basis of language and literacy**

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

355 **4.4 Selection of subjects from within a population less likely to be disadvantaged**

356 In these three publications data collection was restricted to participants with a landline telephone (Ander-
357 son, 2004), to university undergraduates in schools of business and information systems (Whetstone and
358 Goldsmith, 2009), or to members of a community less likely to be disadvantaged (McCleary-Jones et al.,
359 2013). Health literacy and privacy concerns were the only barriers to PHR adoption and use identified in
360 these studies.

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

365 **5 DISCUSSION**

366 **5.1 Barriers**

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

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

384 **5.1.1 Barriers by type of investigation**

385 The evidence about barriers to PHR adoption and use varies with the types of investigation (coded in
386 Table 2 as A, B, C and D). Firstly, data collected from patients themselves provides direct evidence about

387 actual barriers which they face in adopting and continuing to use a PHR, although there may be a tendency
388 for self-reports to underestimate the importance of barriers such as socioeconomic status, text literacy,
389 health literacy and numeracy, which can carry a social stigma.

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

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

402 **5.1.2 Barriers by phase of implementation**

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

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

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

420 **5.2 Bias**

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

423 **5.2.1 Within studies**

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

433 **5.2.2 Limitations of the review**

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

440 6 CONCLUSIONS

441 6.1 Principal findings

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

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

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

459 6.2 Future research priorities

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

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

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

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