

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 395 items; screening identified 34 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 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.

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11 **Abstract**

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40 implementation of PHR initiatives can make allowance for patient level barriers to PHR adoption
41 and use, with appropriate actions to mitigate the effect of those barriers for more disadvantaged
42 patients.

43 **Introduction**

44 There is an increasing focus on personal electronic health records (PHRs) as a part of the
45 implementation of ehealth services to support improvements in healthcare. PHRs have been
46 defined as "...a private, secure application through which an individual may access, manage, and
47 share his or her health information. The PHR can include information that is entered by the
48 consumer and/or data from other sources such as pharmacies, labs, and health care providers."

49 (Jones et al., 2010, p. 334) Most publications about personal health record systems now focus on
50 electronic versions which provide online access for patients, which may be through provider
51 portals. PHRs offer a number of benefits including better access to data and information,
52 improved communication between patients and providers, the empowerment of patients, and
53 opportunities for health self-management (Tang & Lansky, 2005; Pagliari, Detmer & Singleton,
54 2007).

55 These benefits are certainly worthwhile, particularly for disadvantaged patients, who face
56 challenges in receiving safe effective healthcare (Adler & Newman, 2002), and who are likely to
57 have worse health outcomes than more privileged patients (Olshansky et al., 2012). However, the
58 benefits which result from the use of a PHR cannot be guaranteed. The use of specialised medical
59 language within a PHR can marginalise non-specialist users (Showell, Cummings & Turner,
60 2010), and in Australia, patients have largely been left out of discussions about policies affecting
61 national PHR developments (Showell, 2011).

62 Information about demonstrated benefits to patients is limited Most of the evidence of benefit
63 applies to technically competent patients (Green et al., 2008; Ralston et al., 2009), with few
64 details about how beneficial outcomes can be provided for other types of patients and patient
65 groups. Concerns have been expressed previously about a risk that the development of PHRs may
66 be skewed in favour of users with good levels of text, technical and health literacy; as a result
67 PHRs may be less suitable for users who are at a socioeconomic disadvantage (Showell & Turner,
68 2013a,b). Low levels of text, technical and health literacy can act as barriers to the effective use
69 of technology (Wilson, Wallin & Reiser, 2003), including personal health records (Angaran,
70 2011; Newman, Biedrzycki & Baum, 2012), and a number of other barriers have been identified
71 (Sarkar et al., 2011).

72 Objectives

73 The concerns outlined above suggest that there are significant barriers to the adoption and
74 continued use of PHRs by patients, particularly for those among disadvantaged and under-served
75 populations. These barriers may relate specifically to the use of PHRs, or may entail more general
76 problems with access to or the use of technology.

77 The broad intention of this literature review is to bring to the attention of informatics practitioners
78 the range of issues and associated barriers which might prevent an equitable approach to PHR
79 implementation.

80 The review is designed to address three specific questions:

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

84 The review seeks information about those barriers, and the nature of the available evidence, as a
85 way to establish, maintain and enhance equity in the development and implementation of PHRs.
86 The intention is to provide an inclusive presentation of all identified barriers, and maintain the
87 broadest possible scope.

88 **Methods**

89 **Eligibility criteria**

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

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

100 The types of publication which were sought included:

- 101 • Comparative trials involving multiple participating sites;
- 102 • Evaluations which involved the collection of data from patients about PHR barriers (using
103 focus groups, interviews, surveys or questionnaires);
- 104 • Observational studies; and
- 105 • Details of the attitudes and opinions of patients about possible future PHR use.

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

109 A conventional systematic review seeks to provide some degree of quantitative rigour within the
110 findings. However, this structured review has applied a more inclusive, wide-ranging approach to
111 the identification of barriers. Although raw counts of identified barriers are included in the text,
112 there has been no attempt (or intention) to provide an overall qualitative assessment of barriers,
113 or to evaluate their likely impact in particular settings.

114 **Study selection and data extraction**

115 The review process followed published guidelines on Preferred Reporting Items for Systematic
116 Reviews and Meta-Analyses (PRISMA) (Liberati et al., 2009). Full literature searches were
117 conducted in PubMed, Embase, CINAHL and ProQuest databases between January and April
118 2014, with additional searches conducted in May 2014. Details were retrieved for all publications
119 in English from January 2004 to the date of the search.

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

125 All publications were initially screened to remove items which were considered to be out of
126 scope, for example where the reference to PHRs was incidental (Bonacina & Pinciroli, 2010;
127 Abimbola et al., 2012), where the barriers identified were exclusively those affecting healthcare
128 providers and organisations (Hart, 2009; Gaskin et al., 2011), or where the focus was on PHR
129 infrastructure issues (Hammond, 2005; Tejero & de la Torre, 2012). The screening process also
130 removed items which made only incidental mention of PHRs (Stead, Kelly & Kolodner, 2005) or
131 barriers (Burke et al., 2010). Publications were included if they provided specific evidence about
132 barriers which might influence the intended or actual adoption of PHRs by patients, or their
133 continued use of a PHR.

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

145 **Implementation phase**

146 For each publication, the authors' description of the phase of PHR implementation under
147 investigation was reviewed, and thematic coding used to establish a schema describing each
148 phase of implementation. This schema was then used to categorise all publications. The majority
149 were focused on a single phase of implementation, with three (Atreja et al., 2005; Cho et al.,
150 2010; Luque et al., 2013) addressing two phases.

151 **Investigation type**

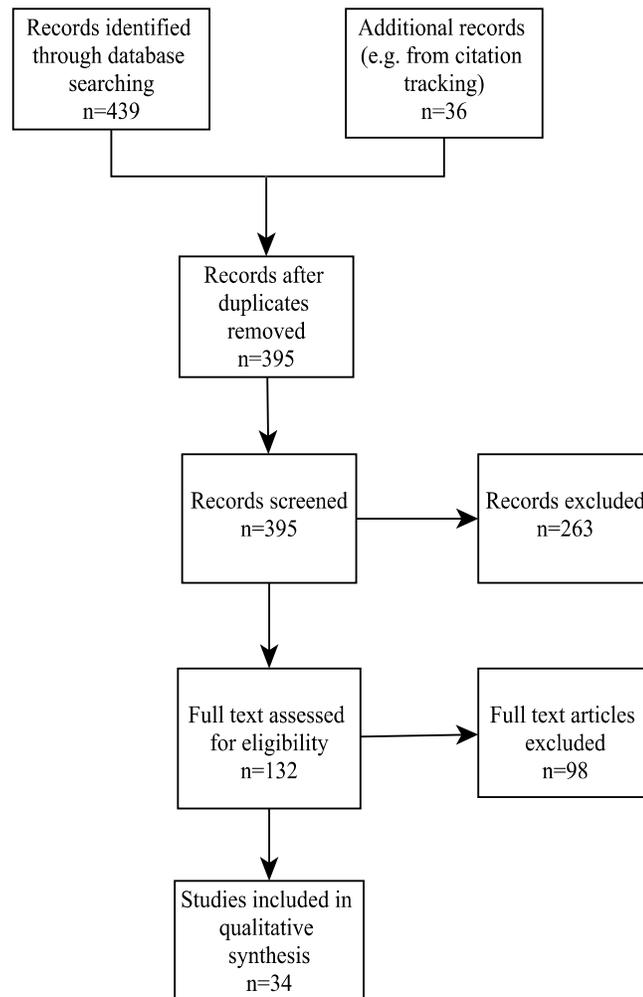
152 For each publication, descriptions of the type of study were reviewed, and used to develop a
153 categorisation by type of investigation. Publications were assigned to a category of investigation
154 type, with the majority of publications using a single type of investigation, and two (Nijland et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

156 **Barriers**

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

162 **Results**163 **Summary**

164 Searches in PubMed, Embase, CINAHL and ProQuest retrieved a total of 439 publications.
165 Another 36 items were identified from citation tracking and other sources, giving a total of 475
166 publications. After removing 80 duplicates, 395 publications remained for initial screening. This
167 resulted in the exclusion of 263 records, leaving 132 full text articles to be evaluated for
168 eligibility. This evaluation removed 98 articles which provided no direct evidence about PHR
169 barriers or did not address patient barriers to PHR adoption and use, and literature reviews. This
170 left 34 articles for the synthesis of evidence. This process is outlined in Figure 1 below:



171

Figure 1: PRISMA flowchart

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

175 Key features of selected studies

176 Publications were categorised according to investigation type (data from users and non-users;
177 observational studies; patient attitudes and opinions; or mixed). The four tables which follow are
178 grouped by investigation type, and provide details of the included publications, including method,
179 size of target population and number of participants.

180 Table 1 summarises 20 studies involving the collection of data about barriers about from PHR
181 users, or participants who did not initiate or continue PHR use (using focus groups, interviews,
182 surveys or questionnaires). One study in this category used semi structured interviews with health
183 professionals about the characteristics of patients likely to use a PHR, as well as patient
184 questionnaires. Barriers which were identified by both patients and clinic staff were included in
185 the overall summation of barriers.

186 *Table 1: Studies collecting data from PHR users or non-participants*

Author(s), year	Investigation type	Population	Participants
(Anderson, 2004)	Telephone interview survey	3,000	186
(Atreja et al., 2005)	Focus groups/interviews with clinic staff; observation	-	15
(Butler et al., 2013)	Telephone interviews with patients	404	39
(Cho et al., 2010)	Postal survey questionnaire	-	201
(Chrischilles et al., 2014)	Mixed methods: user-centred design with evaluation; questionnaire	15,000	1,075
(Crabb, Rafie & Weingardt, 2011)	Interview survey	75	50
(Emani et al., 2012)	Postal survey questionnaire	1,500	760
(Fuji, Abbott & Galt, 2014)	Interviews with trained users	59	23
(Goel et al., 2011a)	Telephone interviews with non adopters	-	159
(Greenhalgh et al., 2008)	Mixed methods: Interviews/focus groups	-	103/67
(Hall et al., 2014)	Trial of result communication via PHR	66	49
(Hilton et al., 2012)	Online survey (within supported PHR use)	2,871	338
(Kim et al., 2009)	Mixed methods: Paper questionnaire, analysis of user logs	330	70
(Kruse et al., 2012)	Interviews about internet use	713	638
(Lober et al., 2006)	Analysis of data about PHR use	170	41
(McCleary-Jones et al., 2013)	Interviews	350	88
(Mishuris et al., 2014)	Semistructured interviews with patients	-	3
(Roblin et al., 2009)	Paper survey with online option (non- adopters)	5,309	1,777
(Taha et al., 2013)	Lab usability test of a simulated PHR	-	107
(Weitzman, Kaci & Mandl, 2009)	Focus groups, usability testing, email	-	302

187 Table 2 outlines six observational studies which provide a qualitative or quantitative evaluation of
 188 demographic data and records of users and non-users, as well as patterns of activity for PHR
 189 users.

190

Table 2: Observational studies

First author (yr)	Investigation type	Population	Participants
(Byczkowski, Munafo & Britto, 2011)	Retrospective observational study	1,900	498
(Goel et al., 2011b)	Retrospective data analysis with adopters	7,088	4,891
(Nielsen, Halamka & Kinkel, 2012)	Retrospective chart review	240	154
(Sarkar et al., 2010)	Telephone, web and written survey	14,102	5,671
(Sarkar et al., 2011)	Telephone, web and written survey	141,02	5,671
(Yamin et al., 2011)	Data analysis comparing adopters and non-adopters	75,056	32,274

191 The six studies in the third category, which collected details of the attitudes and opinions of
 192 patients about barriers to possible future PHR use, and the demographic characteristics of those
 193 with particular usage intentions, are provided in Table 3

194

Table 3: Patient attitudes and opinions

First author (yr)	Investigation type	Population	Participants
(Logue & Effken, 2012)	Survey questionnaire	-	38
(Luque et al., 2013)	Written questionnaire/Focus group	120/8	90/ -
(Noblin, Wan & Fottler, 2012)	Paper survey on health literacy and PHR usage intention	-	562
(Patel et al., 2011)	Telephone survey	-	200
(Patel et al., 2012)	Paper survey of support for Health Information Exchange and PHR	-	117
(Zarcadoolas et al., 2013)	Focus groups	-	28

195 Table 4 outline two studies using more than one of the previous categories of investigation

196

Table 4: 'Mixed methods' using multiple study types

First author (yr)	Investigation type	Population	Participants
(Gordon et al., 2012)	Mixed methods: Surveys, database analysis, usage logs	8,249	509
(Nijland et al., 2011)	Mixed methods: Survey; interviews; log files; usability assessment	350	50

197 The publications retrieved for this review displayed a distinct geographic bias, with 32 out of a
 198 total of 34 studies reporting on PHR implementations in the USA (with one each from the United
 199 Kingdom and the Netherlands). Three particular PHR systems – MyHealthVet, kp.org and

200 MyChart – accounted for nine of the publications (with three each). Data about a possible bias in
201 the selection of participants was retrieved during the data extraction, and evaluated as a
202 secondary outcome.

203 **Implementation phase**

204 For the purposes of categorising publications, the following schema was developed in order to
205 identify which phase of PHR readiness, adoption and use was being studied in each investigation.

206 1. Readiness to use a PHR, including evaluations of internet use:

207 1.1 – Patient use of technology, including the internet;

208 1.2 – PHR usage intentions;

209 1.3 – Design of PHRs with User Centred Design (UCD), or usability studies.

210 2. Initial registration for an account within a PHR system;

211 3. Initial use of a PHR; publications which studied any use of a PHR at an unspecified time
212 after registration were included in this category;

213 4. Continued use of a PHR, including long term use;

214 5. PHR benefits affecting the patient’s health and wellbeing.

215 **Barriers**

216 Each of the included publications provided statements about barriers to patient adoption and
217 continued use of a PHR. This evidence was either: described by users in advance or anticipation
218 of PHR use; reported by potential users as a reason for not commencing use of a PHR, or not
219 continuing that use; or inferred from demographic differences between users and non-users.
220 Thematic analysis was used to identify barriers and to categorise barrier types. This process
221 involved a degree of simplification for some of the barriers described in publications.

222 Some concepts related to PHR barriers were unambiguous, and required little or no
223 simplification. A reference to ‘Age’, for example, was taken as a straightforward description of a
224 barrier, with no further interpretation required. However, some more diffuse concepts required a
225 degree of interpretation. For example, “...problems due to reading, understanding and filling out
226 forms, not due to poor vision” (Sarkar et al., 2010, p. e4) was recorded as a barrier resulting from
227 poor health literacy, while an observation that “[p]articipants did not perceive the PHR as having
228 added value for managing their existing self-care behaviors...” (Fuji, Abbott & Galt, 2014) was
229 interpreted as a barrier related to ‘Lack of Motivation’. The analysis identified 21 distinct barriers,
230 which are listed by barrier category in Tables 5 - 10.

231 **Primary outcome: PHR barriers**

232 Each of the following sections summarises a barrier category, and provides a table which
233 summarises the barriers which were identified in each investigation type, and in each phase of
234 PHR implementation. Most barriers were identified in most phases of PHR implementation, and
235 in most types of study. Barriers which are likely to be associated with socioeconomic
236 disadvantage are flagged. It should be noted that failure to identify a barrier within a particular
237 publication does not provide evidence that the barrier was absent in the population studied,

238 merely that it was not identified. It should also be noted that some of the publications report
239 multiple phases or investigation types.

240 In the sections which follow, each table identifies the number of times a particular barrier factor
241 was identified, by implementation phase and investigation type.

242 Individual characteristics

243 Barriers related to age, sex and race or ethnicity are innate characteristics of an individual user,
244 not amenable to change, and were categorised as Individual factors.

245 *Table 5: Barriers related to individual characteristics*

	Age	Sex	Race/Ethnicity ^a
Implementation phase			
1 PHR readiness			
1.1 Use of technology	1		
1.2 Usage intentions.	3	1	
1.3 Participation in design of PHRs,		2	
2 Initial registration	1	1	2
3 Initial use	3		2
4 Continued use	2		1
5 PHR benefits			
Investigation type:			
A Collection of data from PHR users, or non-participants	8		4
B An observational study using demographic data and records of users and non-users;	3	2	4
C Attitudes and opinions of patients about barriers	2	1	

246 ^a Barrier associated with socioeconomic disadvantage

247 Age

248 A total of 13 of the included studies identified patient age as a barrier which has an impact on the
249 adoption and continued use of PHRs. However, the effect was not clearly delineated. It is likely
250 that age has a variable impact on ability, usage intention and motivation to continue using a PHR
251 after enrolment. Internet use was more common for younger patients, with use declining with
252 increasing age (Kruse et al., 2012). PHR ‘innovators’ were younger than other other users and
253 ‘non-adopters’ (Emani et al., 2012), with older patient less likely to enrol for a PHR (Goel et al.,
254 2011b), although one study found that, once receiving a password, older patients were more
255 likely to log on to the system (Sarkar et al., 2011).

256 Sex

257 The sex of participants was noted as a barrier in statistical analyses, but the effect was generally
258 modest, and inconsistent between publications. Studies found that found that men were more

259 likely to find computer use enjoyable and be confident about using the internet and an online
260 PHR (Logue & Effken, 2012), more likely to go online (Cho et al., 2010), and more likely to be
261 higher users of PHRs, and more engaged (Chrischilles et al., 2014). However, one study (Yamin
262 et al., 2011) found that women were 15% more likely to adopt a PHR (OR 1.15, CI 1.08-1.21).

263 **Race and ethnicity**

264 Race and ethnicity were identified as a barrier in eight studies, all undertaken in the US. The
265 studies found that racial and ethnic background could either inhibit the adoption of a PHR (Kim
266 et al., 2009; Roblin et al., 2009; Goel et al., 2011b; Emani et al., 2012) or make its continued use
267 less likely (Yamin et al., 2011; Byczkowski, Munafò & Britto, 2011; Sarkar et al., 2011).
268 Publications did not always clarify the extent to which variations in PHR use were associated
269 with related barriers such as education, income and socioeconomic status, literacy or computer
270 and internet access.

271 The predominant finding was that white patients were more likely to start and continue the use of
272 a PHR, although one study (Goel et al., 2011b) found that while African American and Hispanic
273 patients were less likely to start using a PHR, their use of the system was no different once they
274 were enrolled. Two studies (Sarkar et al., 2011; Goel et al., 2011b) found that adoption and use of
275 a PHR was similar in white and Asian patients, while two others (Yamin et al., 2011; Nielsen,
276 Halamka & Kinkel, 2012) found that use by Asian patients was less likely.

277 It should be noted that these specific findings in a US context may not be relevant in other
278 countries, or with more recent arrivals.

279 **Demographic factors**

280 Income, socioeconomic status, level of education and internet and computer access were
281 categorised as Demographic factors related to an individual's circumstances.

282

Table 6: Barriers related to demographic factors

	Income, socio-economic status ^a	Level of education ^a	Internet and computer access ^a
Implementation phase			
1 PHR readiness			
1.1 Use of technology	2	2	1
1.2 Usage intentions.	2	1	2
1.3 Participation in design of PHRs,			
2 Initial registration		1	3
3 Initial use	2	1	2
4 Continued use	2	1	2
5 PHR benefits			
Investigation type:			
A Collection of data from PHR users, or non-participants	3	4	5
B An observational study using demographic data and records of users and non-users;	3	1	1
C Attitudes and opinions of patients about barriers	2	1	2

283 ^a Barrier associated with socioeconomic disadvantage

284 **Income, socioeconomic status**

285 PHR barriers for those with lower income and lower socioeconomic status were identified in
 286 eight studies. PHR adoption was less likely in groups with lower socioeconomic status (Yamin et
 287 al., 2011) and those without private health insurance, (Byczkowski, Munafo & Britto, 2011)
 288 although for those who did adopt a PHR, level of income did not appear to affect the degree of
 289 use (Yamin et al., 2011).

290 **Level of education**

291 Level of education was identified as a barrier in six studies, associated with both computer and
 292 internet access and use (Kruse et al., 2012) and with the adoption and use of a PHR, (Roblin et
 293 al., 2009; Emani et al., 2012). The association between level of education and continued use of a
 294 PHR following enrolment appeared less pronounced (Sarkar et al., 2011).

295 **Internet and computer access**

296 Lack of internet and lack of computer access were identified as barriers in ten studies. Problems
 297 with access did not appear to have a marked effect on PHR usage intention, (Goel et al., 2011a)
 298 although they did affect actual use of a PHR (Lober et al., 2006; Nijland et al., 2011; Kruse et al.,
 299 2012; Luque et al., 2013).

300 Capabilities

301 Four barriers to PHR use were related to the skills and abilities of users and potential users.
 302 Functional or text literacy, numeracy, health literacy, and technical literacy and skills were
 303 assigned to the Capability factors category.

304 *Table 7: Barriers related to individuals' capabilities*

	Text literacy /functional literacy ^a	Numeracy ^a	Health literacy ^a	Technical literacy and skills ^a
Implementation phase				
1 PHR readiness				
1.1 Use of technology			1	1
1.2 Usage intentions.			2	3
1.3 Participation in design of PHRs,	1			2
2 Initial registration				
3 Initial use		1		2
4 Continued use	1		2	5
5 PHR benefits			1	
Investigation type:				
A Collection of data from PHR users, or non-participants	1	1	4	7
B An observational study using demographic data and records of users and non- users;			1	1
C Attitudes and opinions of patients about barriers	1		1	4

305 ^a Barrier associated with socioeconomic disadvantage

306 Text literacy/functional literacy

307 Only two studies specifically identified low levels of text literacy or functional literacy as a
 308 barrier to the use of a PHR, with functional literacy identified as a potential barrier by a focus
 309 group discussion (Gordon et al., 2012). This limited evidence was despite the obvious limitation
 310 that an inability to read would impose on a potential PHR user. The risk of introducing an
 311 unintended bias in a PHR evaluation by excluding subjects with poor literacy is considered in the
 312 Discussion section.

313 Numeracy

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

318 Health literacy

319 Low health literacy was identified as a barrier in six studies, and was noted as having an impact
 320 on both adoption (Sarkar et al., 2011; Noblin, Wan & Fottler, 2012) and continued use (Lober et
 321 al., 2006; Kim et al., 2009). Greenhalgh et al. (2010) found that many subjects who described
 322 their attitude to portal use as "... 'not bothered' or 'don't care'..." were also judged by the
 323 researchers to have low levels of health literacy.

324 Technical literacy and skills

325 Lack of technical literacy and lack of computer or internet skills were the most frequently
 326 identified barrier, with 13 publications identifying this as a barrier to either technology use (Adler
 327 & Newman, 2002) or the use of a PHR. (Lober et al., 2006; Roblin et al., 2009; Nijland et al.,
 328 2011; Hilton et al., 2012; Butler et al., 2013; Luque et al., 2013). Early adopters of a PHR were
 329 significantly more likely to self-report being 'comfortable' or 'very comfortable' with internet use
 330 (Butler et al., 2013) while those with rudimentary computer skills showed little improvement in
 331 PHR use over time (Hilton et al., 2012).

332 Health related

333 Barriers resulting from the individual's health and wellbeing, including the presence of a chronic
 334 disease, disability generally, and specific physical, cognitive or visual limitations, were
 335 categorised as Health related.

336

Table 8: Health related barriers

	Health, Chronic disease ^a	Disability (General) ^a	Physical disability ^a	Cognitive disability ^a	Visual disability ^a
Implementation phase					
1 PHR readiness					
1.1 Use of technology	1				1
1.2 Usage intentions.	2		1	1	1
1.3 Participation in design of PHRs,			1	1	1
2 Initial registration	1				
3 Initial use	2	1		1	
4 Continued use	4		1	2	1
5 PHR benefits					
Investigation type:					
A Collection of data from PHR users, or non-participants	6		2	4	3
B An observational study using demographic data and records of users and non-users;	2	1			
C Attitudes and opinions of patients about barriers	2			1	

337 ^a Barrier associated with socioeconomic disadvantage

338 **Health, Chronic disease**

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

346 **Disability**

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

353 **PHR factors**

354 Barriers associated with the usability of a PHR, the costs associated with access, or lack of
 355 information about the PHR were categorised as PHR factors.

356 *Table 9: Barriers related to the PHR itself*

	Usability	Cost	Lack of information
Implementation phase			
1 PHR readiness			
1.1 Use of technology		1	
1.2 Usage intentions.	1		
1.3 Participation in design of PHRs,	1	1	
2 Initial registration			2
3 Initial use			
4 Continued use	1		
5 PHR benefits			
Investigation type:			
A Collection of data from PHR users, or non-participants	2	1	2
B An observational study using demographic data and records of users and non-users;			
C Attitudes and opinions of patients about barriers	1	1	

357 Usability

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

363 Cost

364 Two studies identified costs to users as a barrier for PHRs, with patients reporting that they could
 365 not afford the cost of a computer and a broadband internet connection (Kruse et al., 2012; Luque
 366 et al., 2013).

367 Lack of information

368 Two studies identified that a lack of information about the availability of a particular PHR
 369 (Mishuris et al., 2014), or accessibility of information about options within a PHR (Atreja et al.,
 370 2005) could interfere with use.

371 Attitudinal factors

372 The remaining barriers – discomfort with computer use, concerns about privacy security and
 373 confidentiality, and lack of motivation – were categorised as Attitudinal factors.

374 *Table 10: Barriers related to individuals' attitudes to PHRs*

	Discomfort with computer use	Privacy and confidentiality concerns	Lack of motivation
Implementation phase			
1 PHR readiness			
1.1 Use of technology	1	2	
1.2 Usage intentions.		2	1
1.3 Participation in design of PHRs,	2	2	
2 Initial registration		1	2
3 Initial use	1		
4 Continued use	2		1
5 PHR benefits			
Investigation type:			
A Collection of data from PHR users, or non-participants	4	3	2
B An observational study using demographic data and records of users and non-users;			1
C Attitudes and opinions of patients about barriers		4	1

375 **Discomfort with computer use**

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

379 **Privacy and confidentiality concerns**

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

384 **Lack of motivation**

385 Three studies provided evidence that a lack of motivation could be a barrier to the use of a PHR.
386 Potential users did not see the PHR as providing added value (Fuji, Abbott & Galt, 2014;
387 Mishuris et al., 2014) or thought that using a PHR would take up too much time (Nijland et al.,
388 2011; Fuji, Abbott & Galt, 2014).

389 **Secondary outcome: Selection bias**

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

394 **A focus on those already using technology**

395 In five publications participation was restricted to subjects who already had experience using a
396 web browser (Lin et al., 2005; Nijland et al., 2011), had an existing portal account (Byczkowski,
397 Munafo & Britto, 2011) who had received training in the use of a PHR (Fuji, Abbott & Galt,
398 2014), or who were required to complete web based surveys during the study (Hilton et al.,
399 2012). These studies did not report barriers related to Capability factors, or to disability.

400 **Exclusion of participants with serious illness or infirmity**

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

406 **Excluding participants on the basis of language and literacy**

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

410 **Selection of subjects from within a population less likely to be** 411 **disadvantaged**

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

417 Identification of these potential sources of bias is not intended as a criticism of the studies, or of
418 the authors. However, inadvertent bias within the methodologies of studies may mean that any
419 evaluation of barriers within publications (such as that provided by this review) is likely to
420 underestimate the prevalence and significance of barriers, particularly if those barriers are related
421 to exclusion criteria which have been applied in the selection of participants.

422 **Discussion**

423 **Barriers**

424 This literature review has identified evidence for 21 barriers, categorised as Individual,
425 Demographic, Capability, Health related, PHR related and Attitudinal factors, which could
426 interfere with or prevent a patient's adoption or continued use of a personal health record. The
427 evidence is consistent, with ten of the barriers being identified in six or more publications.
428 However, the frequency with which a particular barrier is identified provides little indication of
429 that barrier's overall significance, or of its importance in particular settings. The low incidence
430 (four publications or fewer) of reports identifying text literacy, numeracy, generalised disability,
431 or physical and visual impairment as barriers is more likely to result from the research
432 methodology and from the relative invisibility of disadvantaged participants, rather than from the
433 insignificance or absence of these barriers. The complex interrelationship which exists between
434 many of the barriers is suggested in some publications, and emerges more clearly from this
435 review. Socioeconomic status and educational attainment are closely related, and associated with
436 text, technical and health literacy, and with numeracy; internet and computer access, computer
437 skills and discomfort with the use of a computer are closely intertwined; and lastly PHR usability
438 is likely to have a greater impact on users with lower capabilities, and PHR costs will be more
439 challenging for poorer patients. Furthermore, socioeconomic disadvantage is likely to be
440 statistically more prevalent among older citizens, and within non-Caucasian communities. The
441 review identified predominantly US studies, which identify specific issues for elderly, African
442 American, and Latino communities.

443 **Barriers by type of investigation**

444 The evidence about barriers to PHR adoption and use varies with the types of investigation.
445 Firstly, data collected from patients themselves provides direct evidence about actual barriers
446 which they face in adopting and continuing to use a PHR, although there may be a tendency for
447 self-reports to underestimate the importance of barriers such as socioeconomic status, text
448 literacy, health literacy and numeracy, all of which can carry a social stigma. Secondly,
449 observational studies using PHR usage logs and health administrative data for PHR users and
450 non-users can provide evidence about barriers, but only from an analysis of the data items which
451 are included in those records. In many cases socioeconomic status, text and health literacy, or

452 computer and internet use are not recorded, although an area measure of socioeconomic status
453 can be imputed from the patient's home address. Finally, attitudes and opinions of patients about
454 PHR benefits and barriers, and usage intention can be instructive, although there may be a gap
455 between stated intention and future actions.

456 The 'Diffusion of Innovations' theory (Rogers, 1983) which is sometimes applied to the uptake of
457 systems such as a PHR embodies an assumption that all potential users will eventually begin
458 using a new system. The 'Technology Acceptance Model' (Davis, 1989) provides a more
459 pragmatic approach, and suggests that actual system use is driven by an individual's perception
460 about ease of use and usefulness, and by his or her attitudes and behavioural intentions to the
461 system. However, initial perceptions about usefulness and ease of use may not be matched by the
462 reality of the system itself, This perception-reality gap may be greater among potential users who
463 have little or no previous experience with such systems, and initial attempts to use a new system
464 may not translate into continued long-term use.

465 **Barriers by phase of implementation**

466 Evidence about PHR barriers also varies by the phase of implementation being investigated. In
467 Phases 1 and 2 (pre-adoption and initial registration) evidence about barriers is most likely to be
468 about usage intention. Evidence suggests a gap between usage intention and actual PHR use.
469 Disadvantaged and low capability users may see use of a PHR as beneficial, but may
470 overestimate their own capabilities, and underestimate the demands and challenges involved in
471 using a PHR. Individuals may lack full awareness of the extent of their limitations, or may not
472 see those limitations as making PHR use more difficult. In Phase 3 (early use) enthusiasm about
473 first use may revert to a lack of interest once the effort required to use a PHR becomes apparent;
474 evidence about barriers from evaluations of registration and first use are likely to provide an
475 indication of those barriers which might interfere with the decision to use a PHR, while barriers
476 identified in Phase 4 (continued use) provide insight into the constraints which are likely to
477 interfere with long term use. Depending on the particular PHR, maintaining regular use could be
478 difficult, although moderated by the skills and capabilities of the user. A continued interest by
479 patients in using a PHR is likely to be influenced by perceptions of healthcare needs, and how
480 those needs are met by a PHR, relative to other care that they receive. Barriers may also be
481 context-sensitive, and influenced by PHR usability and user capabilities. PHRs need to be
482 suitable for all users; testing with volunteers with good text-, technical-and health literacy may
483 overestimate the suitability of the PHR for a broader population.

484 **Bias**

485 A number of the included studies chose participants in a way that might result in a lower
486 proportion of disadvantaged and low-capability users, compared with the overall population,
487 resulting in a probable underestimate of PHR barriers. Some degree of bias may be unavoidable.
488 Acquiring evidence about PHRs, including evidence about barriers, must rely on subjects who are
489 able to participate: studies of PHR usage must rely on PHR users, participants must read a written
490 questionnaire in order to respond, and it can be difficult to ethically engage research subjects with
491 cognitive limitations. On the other hand, PHRs are intended for users who are unwell, not just
492 healthy, educated, well-off patients. One study (Zarcadoolas et al., 2013) (not included in the
493 evaluation of bias) deliberately introduced an inverse bias by seeking out participants with a low
494 socioeconomic status.

495 **Limitations**

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

502 **Conclusions**

503 **Principal findings**

504 This review has found evidence of a range of barriers which interfere with the adoption and
505 continued use of PHRs, with 111 instances of 21 distinct barriers identified across 34
506 publications. This evidence was found in all types of investigation, and in all phases of PHR
507 adoption. Further research may find other as yet unidentified barriers, as well as variants of
508 barriers identified in this review. A close relationship is evident between socioeconomic status
509 and PHR barriers, with 13 of the 21 barriers being associated with socioeconomic disadvantage.
510 This confirms that the use of a PHR is likely to be harder for disadvantaged patients; PHRs as
511 they are currently implemented may not provide a universal solution for problems with healthcare
512 delivery or communication. The relative importance of a PHR barrier cannot easily be deduced
513 from the number of times that it appears within the research literature. Rather, there is an
514 obligation during PHR design, and during PHR implementation, to make a careful assessment of
515 the likelihood of each barrier being present within the population being considered as users. In
516 the US, the Meaningful Use Stage 2 compliance criterion for 2017, which requires that 5% of
517 patients access their record (Centers for Medicare and Medicaid Services, 2017), is more likely to
518 measure record access by competent PHR ‘early adopters’ than by disadvantaged users. Despite
519 the problem of a growing ‘ehealth divide’ (Cummings, Chau & Turner, 2008) this criterion as
520 currently defined provides little impetus for health professionals or hospitals to encourage PHR
521 enrolments among disadvantaged patients.

522 **Future research priorities**

523 While this review has identified a broad range of PHR barriers, there was insufficient consistency
524 across multiple studies to provide a comprehensive picture of the effect of barriers during PHR
525 implementation and use. If those barriers affecting the population of potential users are to be
526 addressed early in the process of design and implementation, there is a need for better
527 identification and characterisation of both barriers and users. As Kushniruk and Turner have
528 observed, “...greater consideration of who the user is and how the user is involved and their
529 inputs mediated needs to be further articulated. To address these issues it is useful to try to be
530 more precise about who the users are, when and where they are engaged, what expectations we
531 have about our users and why.” (Kushniruk & Turner, 2011, p. 281). Developing a better
532 understanding of the impact of barriers on PHR users will help to ensure more effective use of the
533 resources allocated to PHR systems. There is also a need for a better appreciation of how barriers
534 can affect PHR adoption and use, and how that effect can be countered. Simply being aware of
535 the possibility that a particular barrier may inhibit PHR use for some patients should be enough to
536 ensure that this barrier is taken into account during PHR design and implementation. However,
537 the apparent bias evident in a number of the studies suggests that the existence and significance

538 of barriers is not universally recognised, and that further research may be warranted in order to
 539 provide stronger evidence. Finally, the results of this literature review raise a number of
 540 interesting questions which may suggest possibilities for future research:

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

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

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550 **Acknowledgments**

551 My thanks go to Associate Professor Paul Turner and Dr Liz Cummings from the University of
552 Tasmania, who provided unstinting encouragement, advice and support during the preparation of
553 this review.