

An Overview of Reviews of Personal Health Records (PHRs) and Portals:
Barriers, Enablers and Benefits.

by

Steve Denman

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ABSTRACT

Background: Personal Health Records (PHRs) and Patient Portals (Portals) are said to be facilitators of a new paradigm emerging in the delivery of healthcare where the patients are empowered to take an active role in their health by setting goals and making decisions from gaining a greater understanding of one's conditions and treatment options. These systems have the potential to increase patient engagement, improve communication between patient and the healthcare system, and enable the healthcare system to move towards a more personalized medical model. Despite the promises of these systems, recent studies have identified barriers to use from both patients and providers, and limited conclusive benefits.

Objective: To explore previous research that have examined the use of PHRs and Portals in order to identify any barriers, enablers and benefits of use.

Method: An overview of reviews was conducted to present the barriers, enablers and benefits of PHR and Portal use as identified in systematic reviews over the past 10 years. Eleven systematic reviews were evaluated and selected for the overview. An adapted Clinical Adoption Framework was used to capture the findings of the reviews and to show how they interlinked and influenced each other.

Conclusion: Several barriers to use were identified, namely, the socio-economic background of users, the patient's and provider's beliefs of the system, and the usability and usefulness of the systems. An enabler of use included encouragement from social supports and providers to use these systems. The use of PHRs and Portals do appear to produce some benefits, such as improved communication. However, the ability of these systems to empower patients leading to positive health outcomes remains to be confirmed with inconclusive results being reported for improvements in self-care and/or management or participation in care, and inconclusive results for improvements in disease/health outcomes.

Recommendations for future research and implementation of PHRs and Portals include improving access and use for those who are less empowered, developing systems to meet the needs of patient and providers, and ensuring users are encouraged and supported to use these systems once implemented.

1.0 INTRODUCTION

A new paradigm is said to be emerging in the delivery of healthcare where instead of a physician being the focal point of control and decision making, this power is moving unto patients (Schneider et al., 2016; Wasson et al., 2012 in Thompson et al., 2016). Patient empowerment is where a patient takes an active role in their healthcare by setting own health goals and making decisions from gaining an understanding of their condition and the possible treatment options. By patients taking an active role, it is hoped that patients work together with physicians in shared decision making and initiate changes in behaviour that help to better manage a condition, potentially leading to positive health outcomes. This shift in care revolves around providing patients access to their medical information and tools to help manage their care. Health Information Technology (IT) has been developed to facilitate this new paradigm in the form of Personal Health Records and Patient Portals which, when used, are said to have the potential to increase patient engagement, improve communication between patients and the healthcare system, and enable the healthcare system to move towards a more personalized medical model (Cimino et al., 2002; Nobin et al., 2013; Nobin et al., 2012; Price et al., 2015; Donje et al., 2014; Archer et al., 2011).

A Personal Health Record (PHR) is a complete or partial health record, which is owned by the person rather than a health care provider, and as it is owned by the patient or user, the user can manage, control, or share information as preferred (Canada Health Infoway 2016; Archer et al., 2011). The PHR can hold relevant electronic health information or data about that person over their lifetime, drawing data from multiple sources (Canada Health Infoway, 2016; Archer et al., 2011). PHRs can be standalone or tethered to other information systems such as an Electronic Health Record (EHR) (Price et al., 2015). Through PHRs, users can review medical data from providers such as consults and lab results, access health information which can help to educate patients on their conditions, record and track conditions overtime, receive decision support and communicate with care teams and support groups (Price et al., 2015).

Patient Portals provide similar functionality as a tethered PHR such as direct access to a patient's Electronic Health Record and functions or tools to communicate with care teams and to manage conditions, however the portals are owned by the care provider, not the patient (Amante et al., 2014; Ammenwerth et al., 2012; Goldzweig et al., 2013; Kruse et al., 2015a). The advantage of tethered PHRs or Portals are that they are updated automatically, whereas standalone systems rely on the patient to enter data (Kruse et al., 2015). The introduction of these systems aide to bridge episodic care and allows the

access to services in-between clinical visits (Amante et al., 2014).

The potential benefit of allowing patients access to their medical records facilitated by these systems has led to Canada Health Infoway to invest in the development of patient portals and e-viewer services across Canada (Canada Health Infoway, 2016a) and so there is the likelihood of patients having increased access to their information. The increasing investments being made in these systems stress the importance of analyzing existing literature on enrollment, utilization and benefits (Goal et al., 2011 in Amante et al., 2014). Despite the promises of these systems, recent studies have identified barriers to use from both patients and providers, and limited conclusive benefits of use (Thompson et al., 2016; Amante et al., 2014; Price et al., 2015; Bush et al., 2015; Mold et al., 2015).

2.0 RATIONALE FOR THE OVERVIEW

It is argued that in order to fully comprehend the differences in the use of health IT; potential barriers to adoption and utilization must be considered from several perspectives (Gibbons, 2011). These perspectives include the provider and healthcare system perspective, the perspective of patients, families, and caregivers, and the impact of the system, and the environment perspective in which the system is to be deployed (Gibbons, 2011). Issues or barriers arising in any of these different areas or domains could directly impact the use and outcomes associated with a system (Gibbons, 2011).

Consequently, in order to fully comprehend potential barriers to adoption and utilization of PHRs and Portals and to explore the outcomes of use, an overview would need to capture factors impacting use which are associated with patients, caregivers, providers, the healthcare system, the system itself and the environment in which the system is being deployed. Combining these factors and how they interlink may shed light into the reasons as to why use is low and why there are currently inconclusive benefits from use.

3.0 OBJECTIVE

To support the rationale, the objective of this overview was to explore previous research that had examined the use of PHRs and Portals in order to identify any barriers, enablers and benefits of use. Themes were then drawn from the findings to show how the different factors can interlink and influence the use and outcomes of PHRs and Portals. Recommendations for future implementation of PHRs and Portals were

then formed that may improve and/or increase use and potentially any benefits from use.

4.0 METHODOLOGY

4.1 METHOD

Systematic reviews of individual studies have been identified as a useful method for appraising, summarizing and bringing together existing studies into one place, as such there has been an increase in the volume of systematic reviews (Smith et al., 2011). Multiple systematic reviews on a topic may provide challenges for decision makers when trying to interpret, extract and apply any findings to practice (Smith et al., 2011). To assist decision makers, a research method called an Overview of Reviews has been developed, which allows for the findings of individual systematic reviews to be compared and contrasted in a single place (Smith et al., 2011; The Cochrane Collaboration, 2011).

For the purpose of providing a single source for decision makers concerning PHR and Portal adoption, this study undertook an overview of reviews to appraise, compare and summarize the existing literature of review studies over the past 10 years that have examined the use and outcomes of PHRs and Portals (Smith et al., 2011). The method on how to conduct an overview of reviews was borrowed from the Cochrane Handbook of reviews which provides a step by step guide on the overview process (The Cochrane Collaboration, 2011). For the structure and reporting of the findings, this overview followed the check-list of the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) statement including the four-phase flow diagram with an additional phase for a quality assessment of each review (Moher et al., 2009).

4.2 THE INTERVENTION

For the purpose of this overview a Personal Health Record (PHR) is defined as a complete or partial health record, which is owned by the patient but is tethered to their medical record so to allow access to medical data from providers, access to health information which can help to educate them on their conditions and contain tools that allow them to record and track conditions overtime, receive decision support and communicate with care teams and support groups (Price et al., 2015; Bush et al., 2015; Amante et al., 2014).

A Patient Portal is defined as a system that is owned by the care provider and that allows direct access to a patient's medical Record as well as functions or tools to communicate with care teams and to manage

conditions (Amante et al., 2014; Ammenwerth et al., 2012; Goldzweig et al., 2013; Kruse et al., 2015a).

4.3 THE SEARCH STRATEGY

The search strategy for an overview of reviews is said to be a similar process to when conducting a review of individual studies (Smith et al., 2011) and similarly for this overview, the process involved assessing the retrieved abstracts for relevance, obtaining full text of chosen reviews for further review of eligibility, performing an appraisal of methodological quality before finally identifying reviews for the analysis. Figure 1 shows the flow diagram of the literature selection process (Smith et al., 2011; Moher et al., 2009).

For identifying review studies, a search string used by the McMaster Hedges Project to identify reviews was applied along with MeSH 2017 terms to query the MEDLINE database for reviews on PHRs and Portals conducted between 2006-2016 with restrictions to articles that have an abstract, are written in English and are freely accessible (Black et al., 2011; ULM, 2017). Applying the search string by McMaster Hedges Project along with MeSH terms aided in standardizing and increasing the quality of the search strategy (Table 1).

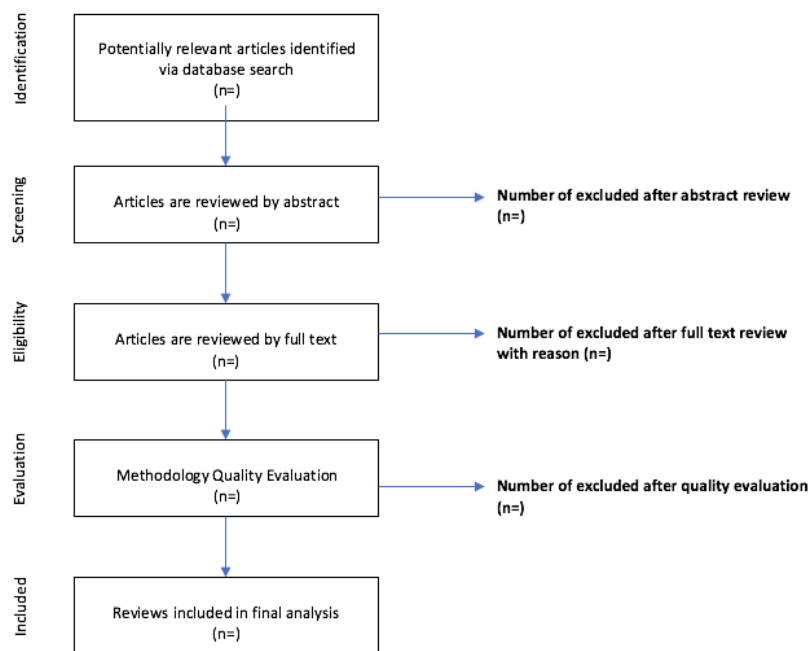


Figure 1: Flow Diagram for Literature Search

Table 1: Search Strategy

| | |
|-----------------------|--|
| MeSH Term(s) | Health record, personal <i>Longitudinal patient-maintained records of individual health history and tools that allow individual control of access.</i> |
| Keywords | PHR, Patient Portal |
| Search String | ((systematic review [ti] OR meta-analysis [pt] OR meta-analysis [ti] OR systematic literature review [ti] OR this systematic review [tw] OR pooling project [tw] OR (systematic review [tiab] AND review [pt]) OR meta synthesis [ti] OR meta-analy*[ti] OR integrative review [tw] OR integrative research review [tw] OR rapid review [tw] OR umbrella review [tw] OR consensus development conference [pt] OR practice guideline [pt] OR drug class reviews [ti] OR cochrane database syst rev [ta] OR acp journal club [ta] OR health technol assess [ta] OR evid rep technol assess summ [ta] OR jbi database system rev implement rep [ta]) OR (clinical guideline [tw] AND management [tw]) OR ((evidence based[ti] OR evidence-based medicine [mh] OR best practice* [ti] OR evidence synthesis [tiab]) AND (review [pt] OR diseases category[mh] OR behavior and behavior mechanisms [mh] OR therapeutics [mh] OR evaluation studies[pt] OR validation studies[pt] OR guideline [pt] OR pmcbook)) OR ((systematic [tw] OR systematically [tw] OR critical [tiab] OR (study selection [tw]) OR (predetermined [tw] OR inclusion [tw] AND criteri* [tw]) OR exclusion criteri* [tw] OR main outcome measures [tw] OR standard of care [tw] OR standards of care [tw]) AND (survey [tiab] OR surveys [tiab] OR overview* [tw] OR review [tiab] OR reviews [tiab] OR search* [tw] OR handsearch [tw] OR analysis [ti] OR critique [tiab] OR appraisal [tw] OR (reduction [tw]AND (risk [mh] OR risk [tw]) AND (death OR recurrence))) AND (literature [tiab] OR articles [tiab] OR publications [tiab] OR publication [tiab] OR bibliography [tiab] OR bibliographies [tiab] OR published [tiab] OR pooled data [tw] OR unpublished [tw] OR citation [tw] OR citations [tw] OR database [tiab] OR internet [tiab] OR textbooks [tiab] OR references [tw] OR scales [tw] OR papers [tw] OR datasets [tw] OR trials [tiab] OR meta-analy* [tw] OR (clinical [tiab] AND studies [tiab]) OR treatment outcome [mh] OR treatment outcome [tw] OR pmcbook)) NOT (letter [pt] OR newspaper article [pt]))) AND ("Health Records, Personal"[Mesh] OR PHR[tiab] OR "patient portal"[tiab]) |
| Database | MEDLINE (PubMed) |
| Restriction(s) | 2006-2016 Abstract available English |

4.4 INCLUSION/EXCLUSION CRITERIA

Under the selection criteria in the method by Cochrane, it is stated that an inclusion and exclusion criteria should be provided (The Cochrane Collaboration, 2011). During the screening of titles and abstracts, articles were assessed for their relevance and excluded if they were identified as either being off topic (did not focus on the use of PHRs or Portals), if they were not a systematic review or if they focused on a paper-based record. The remaining articles underwent a full text review to assess eligibility and again were excluded if they were identified as either being off topic (did not focus on the use of PHRs or Portals), if they were not a systematic review, if they focused on a paper-based record and also if they were identified as a duplicate study or if the full text was not freely accessible. The articles excluded from the overview are available in Appendices 2 and 3, each with an assigned reason for exclusion. Apart from excluding articles that were not identified as systematic reviews, no restrictions were used to exclude articles based-on methodology used, such as qualitative, quantitative or mixed methods.

For the purpose of this overview, a systematic review is defined as a review that attempts to collate all empirical evidence that fits pre-specified eligibility criteria in order to answer a specific research question (The Cochrane Collaboration, 2011). Systematic reviews are said to include 1) a clearly stated set of

objectives with pre-defined eligibility criteria for studies, 2) an explicit, reproducible methodology, 3) a systematic search that attempts to identify all studies that would meet the eligibility criteria, 4) an assessment of the validity of the findings of the included studies, and 5) a systematic presentation, and synthesis, of the characteristics and findings of the included studies (The Cochrane Collaboration, 2011). There are said to be three types of systematic reviews: meta-analyses, qualitative systematic reviews, and realist reviews (Pare et al., 2015).

4.5 ASSESSMENT OF METHODOLOGICAL QUALITY OF INCLUDED REVIEWS

Once the systematic reviews were identified for inclusion, each systematic review was appraised for its methodology. An evaluation of the methodological quality of the reviews included in this overview is vital in order to assess the validity of findings and avoid the presentation of inaccurate or misleading data which may be then used by decision makers (Shea et al., 2007; Faggion, 2015). The AMSTAR Tool has been frequently used for the purpose of assessing systematic reviews to see if they meet the minimum requirement based on quality and it has been suggested that this tool can also be applied in the assessment of review studies in an overview of reviews (Smith et al., 2011; Shea et al., 2007; Faggion, 2015). Although frequently used, it is recognized that the tool has some limitations, including the opinion that the tool assesses the quality of reporting of a systematic review more than its methodological quality, that it does not assess the quality of the primary studies and that the interpretation of the checklist can also be challenging to the user (Faggion, 2015; AHRQ, 2014).

Another identified flaw is that the tool generates a qualitative evaluation, and does not quantify the systematic review quality (Kung et al., 2010). Although the AMSTAR tool was not intended to provide quantitative scores, researchers have adapted and revised the tool to include scoring by imbedding criteria within the 11 domains of the original AMSTAR that produces scores based on the satisfactory vs. unsatisfactory meeting of each criterion (Kung et al., 2010). The revised tool, R-AMSTAR (Appendix 11.) underwent a number of pilot studies which lead to refinements of the criteria within each of the 11 domains. The R-AMSTAR tool is said to detract nothing from its original version in forms of content and construct validity, which despite limitations as a tool, it is said to have good face and content validity for measuring the methodological quality of systematic reviews (Shea et al., 2007; Kung et al., 2010). The revised tool is not without limitations also, as it is suggested that the tool poses challenges for the user when assigning adequate weighting of items according to their importance of inclusion. It is suggested that the need for the tool to contain a quantifiable measure remains open for discussion. For the purpose

of this overview, however and to allow for quantitative comparison of systematic reviews based on their methodology quality, the revised R-AMSTAR tool by Kung et al. (2010) was used to assess the quality of the included reviews. The results of the evaluation of each review were captured in 2 tables which have been adapted from the paper by Kung et al. (2010) who present the revised tool.

An example for the first table is available as Table 2, which captures the scores for each of the reviews based on the R-AMSTAR rating. For each domain, score ranges between 1 and 4 (maximum), and the total score has a range of 11 (no criteria met) to 44 (all criteria met). Reviews with lower scores would indicate concern around the confidence in the findings of the study.

Table 2: R-AMSTAR Scores

| Study | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | Total |
|-------|---|---|---|---|---|---|---|---|---|----|----|-------|
| 1 | | | | | | | | | | | | |
| 2 | | | | | | | | | | | | |
| 3 | | | | | | | | | | | | |

The example in Table 3 shows the comparison of scores across the literature and each review has a A-D grading based on their percentile of the aggregate scores. The grading and scoring of the reviews is applicable when excluding reviews for analysis due to concerns around quality. An example of a cut off criteria is provided in the paper by Kung et al. (2010), which suggests excluding studies which score 22 points or less as a total of 22 indicates that on average only two criteria for each of the domains tested were satisfied. For the purpose of this overview and to ensure lesser quality reviews are excluded from the findings and subsequent analysis, all reviews that scored 22 or less were excluded.

Table 3: Comparison of Studies by R-AMSTAR Scores

| Study | Total | Rank |
|-------|-------|------|
| 1 | | |
| 2 | | |
| 3 | | |

4.6 DATA COLLECTION AND ANALYSIS

Once appraised, the reviews first underwent data extraction where the findings of the reviews were extrapolated into two tables: Characteristics of Included Reviews and a Summary of Findings (Smith et al., 2011; The Cochrane Collaboration, 2011). The Characteristics of Included Reviews includes details of the scope of each review, sources of evidence and the assessment of quality (Table 4).

Table 4: Characteristics of Included Reviews

| Author/Year | Aim/Objective | Time Period & No. of Studies Included | No. of Participants | Population | Origin of Primary Studies/Language | R-AMSTAR Grade | Conclusions |
|-------------|---------------|---------------------------------------|---------------------|------------|------------------------------------|----------------|-------------|
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |

Following the methodology in the Cochrane Handbook for conducting an overview of reviews, the purpose of this overview was to summarize evidence from the included systematic reviews of the effects of the interventions, in this case PHRs and Portals, and to rely on the analyses reported in the included reviews (The Cochrane Collaboration, 2011). The Summary of Findings table (Table 5) provides a comparison of the findings in each systematic review and captures the reported barriers, enablers and outcomes of PHR and Portal use. Where possible, a summary of the findings from the primary studies were pulled from the either an included summary of findings table or extrapolated from the text instead of pulling data from each primary study.

Table 5: Summary of Findings

| Author(s)/Year | Barriers/Enables/Outcomes | Description | A-CAF Coding |
|----------------|---------------------------|-------------|--------------|
| | | | |
| | | | |
| | | | |

In addition to providing a summary of review results; Cochrane states that additional analyses may be undertaken for comparisons across reviews (The Cochrane Collaboration, 2011). For this purpose, the results were analyzed for themes using a form content analysis where the identified barriers, enablers and outcomes of use from Summary of Findings table were coded to the factors of an adapted version of the Clinical Adoption Framework (Pare et al., 2015; Hsieh and Shannon, 2005; Archer et al., 2011).

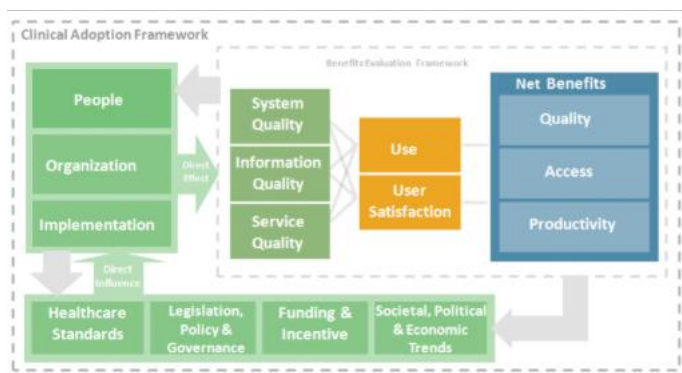


Figure 2: Clinical Adoption Framework (eHealth Observatory, 2017)

The Clinical Adoption Framework (CAF) (Figure 2), developed by eHealth Observatory (eHealth Observatory, 2017), was derived from DeLone and McLean and their Information Systems Success Model and extends the Benefits Evaluation Framework to create a multi-level view of adoption of health information systems and the different factors that interplay and impact adoption (eHealth Observatory, 2017; DeLone and McLean, 2003).

The CAF consists of 3 core dimensions of the Benefits Evaluation Framework, developed by Canada Health Infoway in partnership with the eHealth Observatory, that focus on the micro level of adoption, these are: health information quality, use and net benefits. The quality dimension examines the functionality of the system including the 3 dimensions from the DeLone and Mclean IS Success Model: System Quality, Information Quality and Service Quality (DeLone and McLean, 2003). The user dimension examines system usage and user satisfaction, including impressions of usefulness, ease of use and competency (Lau et al., 2011). The Information Quality, System Quality, and Service Quality interconnect and impact or influence the latter 3, as they will affect the use of or intention to use the system, user satisfaction associated with using the system and any net benefits (either positive or negative) achieved from using the system (Abu-Khadra and Ziadat, 2012).

The net benefits achieved could be in the terms of care quality (patient safety, appropriateness/effectiveness and health outcomes), patient access (provider/patient participation and availability/access to services), and provider productivity (care coordination, efficiency and net cost) (eHealth Observatory, 2017; Lau et al., 2011). By extending the Benefits Evaluation Framework to include the additional levels allows the capture of contextual factors such as organizational, political and socio-economic and how these factors interplay and impact adoption. The meso level (people, organization and implementation) is said to have a direct effect on the micro level and the adoption of health information systems by clinicians. The meso level is then affected by changes in the macro level (health care standards, legislation, policy and governance, funding & incentives, and societal, political and economic trends). The interplay of dimensions as noted in DeLone and Mclean's model: Quality, Use and Net Benefits can be expected to magnify when there is correlation or alignment between the dimensions of the meso level and that higher adoption is likely if the organization's efforts are aligned with the micro dimensions (eHealth Observatory, 2017).

An example of an outcome would be where a PHR that has a high system, information and service quality

is associated with more use and greater user satisfaction, which then potentially leads to a positive result or net benefit with the knowledge of success being fed back into the environment level and informing opinion and knowledge of PHR use. Whereas, a PHR with a negative net benefit could be as a result of a poor-quality system with greater dissatisfaction and less use and in turn, negatively affect the opinion of PHRs (Lau et al., 2011).

The purpose of an adapted version of the CAF (Figure 3) is to encompass factors that are specific to PHR and portal adoption and show how these factors can influence each other. According to Emani et al. (2012), there has been little work undertaken that has applied a theoretical framework to the study of patient adoption and use of PHRs. The Summary of Findings table initially categorized each finding as a general overarching factor under the adapted version of the CAF, these were; Environment, People, Organization, Technology, Use/User Satisfaction or Outcomes. The factors are based on the original factors of the CAF in the Micro, Meso and Macro levels and from additional codes generated from the findings of the systematic reviews in this Overview.

The findings from this Overview were then extracted into a further table called Synthesis of Results (Table 6) and grouped into categories under each overarching factor (Environment, People, Organisation, Technology, Use/User Satisfaction and Outcomes) to include additional specific factors that impact the use and outcome of PHRs and Portals.

Table 6: Synthesis of Results

| | |
|-------------------------------------|------------------|
| <u>Environment</u> | |
| Factor | Reference |
| <i>Example of factor</i> | |
| <u>People</u> | |
| Factor | Reference |
| <i>Example of factor</i> | |
| <u>Organisation</u> | |
| Factor | Reference |
| <i>Example of factor</i> | |
| <u>Technology</u> | |
| Factor | Reference |
| <i>Example of factor</i> | |
| <u>Use/User Satisfaction</u> | |
| Factor | Reference |
| <i>Example of factor</i> | |
| <u>Outcomes</u> | |
| Factor | Reference |
| <i>Example of factor</i> | |

The specific factors under Environment were: 1) Societal/Family Beliefs, Preferences and Trends, 2) Policies, Standards and Governance and 3) Funding and Incentives. Under People the factors were 1) Health/Computer Literacy, 2) Demographic/Health, 3) Beliefs, preferences and behaviour, and 4) Awareness and Access. Under Organization the factors were 1) Provider Demographics and Location, 2) Provider's Beliefs and Preferences, 3) Implementation, 4) Service Quality, 5) Provider Skills and Computer Literacy, and 6) Provider Awareness and Access. Under Technology the factors included 1) System Quality, 2) Information Quality, 3) Fit to Patient/Caregiver and 4) Fit to Workflow. Outcomes captured the specific factors of 1) Quality, 2) Knowledge, 3) Productivity, 4) Behaviour and 5) Access. The Synthesis of Results table also provides examples of each of the factors as derived from the findings of the systematic reviews.

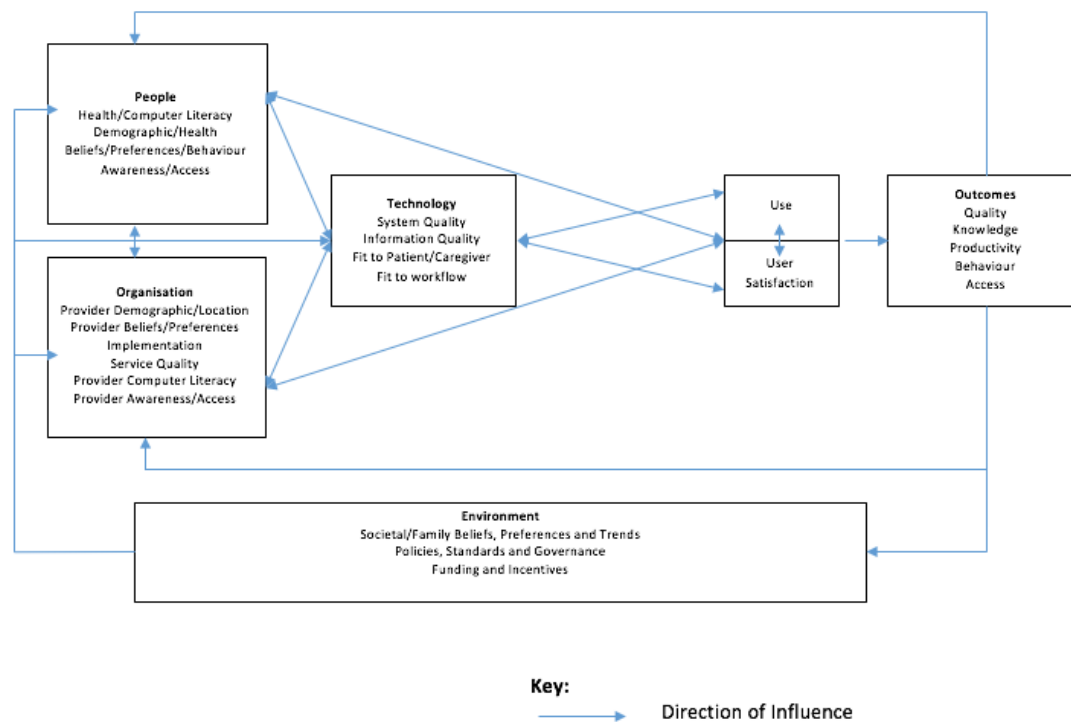


Figure 3: Adapted Clinical Adoption Framework

The micro level of the adapted CAF still focusses on the health information quality, use and net benefits. Technology is used at the umbrella term for system quality factors in the micro level. The meso level including people factors and organization factors (including implementation) is said to have a direct effect on the micro level and the adoption of the system. Then as per the original CAF, the meso level is then affected by changes in the macro level, Environmental factors, in terms of standards, legislation, policy and governance, funding & incentives, and societal beliefs, preference and trends. As with the original

CAF, the adapted CAF aims to illustrate how these different factors impact or influence each other at different levels. Significant themes identified in the findings are provided in the Results and Discussion chapters including an analysis on how these factors interlink and influence each other.

After the synthesis, an additional analysis was performed to explore the extent of overlap of primary studies within the included reviews to see if the findings of individual studies have been reported more than once. The purpose of the analysis was to highlight any duplication of primary studies and how their inclusion may have had an effect on the findings and caused a distortion in the data (Smith et al., 2011).

In summary, there were 7 outputs from this overview: 1) Details of search process (the inclusion/exclusion of reviews), 2) R-AMSTAR scores table, 3) Comparison of R-AMSTAR scores table, 4) Characteristics of Included Reviews table, 5) Summary of Findings table, 6) Synthesis of Results table and 7) an Adapted Clinical Adoption Framework that captures factors that impact the level of PHR and portal adoption over the past 10 years.

The extraction of data and analysis was conducted by the author in consultation with a Research Supervisor.

4.7 ETHICAL APPROVAL

Permission and approval for this overview of reviews was sought from the University of Victoria's Research Ethics Board. Documentation of approval is provided in Appendix 12.

5.0 RESULTS

5.1 STUDY SELECTION

The initial search of the Medline database using the MeSH terms, Keywords, Search String and Restrictions listed in Table 1 returned 410 citations. Screening of titles and abstracts left 18 citations which were then subjected to full text review. Articles were included for further review if they 1) focused on the use of an electronic PHR/Portal, 2) were in English, 3) had an abstract available, and 4) were published between Jan 2006 - Dec 2016. Articles were excluded if 1) they were off topic or were not relevant to study, 2) they focused on a paper based record, and 3) were not identified as a systematic review. A further 7 articles

were removed after full text review (either off topic or a duplicate) leaving 11 articles to be included for analysis (Figure 4).

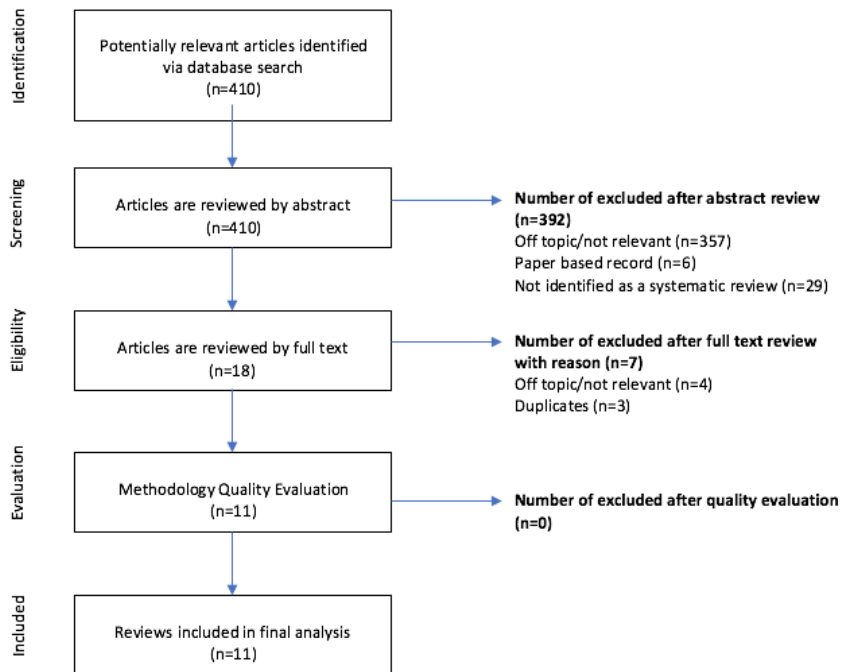


Figure 4: Literature Search Flow Diagram

5.2 STUDY CHARACTERISTICS

Of the 11 reviews included, 2 were from 2016 (Thompson et al., 2016; Otte-Trojel et al., 2016), 5 from 2015 (Mold et al., 2015; Kruse et al., 2015; Kruse et al., 2015a; Bush et al., 2015; Price et al., 2015), 2 from 2014 (Giardina et al., 2014; Amante et al., 2014), 1 from 2013 (Goldzweig et al., 2013) and 1 from 2012 (Ammenwerth et al., 2012). Patient portals were a focus of 7 of the included reviews (Amante et al., 2015; Ammenwerth et al., 2012; Bush et al., 2015; Goldzweig et al., 2013; Kruse et al., 2015; Kruse et al., 2015a; Otte-Trojel et al., 2016), 2 focused on PHRs (Price et al., 2015; Thompson et al., 2016) and 2 focused on patient accessible records in general (not stipulating type of system) (Giardina et al., 2014; Mold et al., 2015). The perspectives of patients and providers were captured in 3 reviews (Thompson et al., 2016; Mold et al., 2015; Kruse et al., 2015) and 2 of the reviews also focused on the perspectives of caregivers and the use of a PHR or Portal (Thompson et al., 2016; Mold et al., 2015). A further study also captured the perspectives of pediatric patients and their parents/caregivers (Bush et al., 2015). Six of the studies focused solely on the perspectives of patients (Kruse et al., 2015a; Price et al., 2015; Giardina et al., 2014; Amante et al., 2014; Goldzweig et al., 2013; Ammenwerth et al., 2013) and 4 specifically focused on

patients with a chronic disease (Amante, et al., 2014; Price et al., 2015; Kruse et al., 2015a; Kruse et al., 2015). One review took a general approach on portal development and did not specifically focus on one type of user (Otte-Trojel et al., 2016).

Two reviews focused on barriers either for patient, provider, or caregiver use (Thompson et al., 2016; Amante et al., 2014). Six reviews aimed to capture the impact, outcomes or benefits of a system (Mold et al., 2015; Kruse et al, 2015a; Giardina et al., 2014; Goldzweig et al., 2013; Ammenwerth et al, 2012; Price et al., 2015). Then Bush et al. (2015), focused on use and utilization and Kruse et al. (2015) focused on the perspectives of patient and providers have and where systems can be improved. The final paper by Otte-Trojel et al. (2016) focused on problems and solutions to portal development.

Of the 11 reviews, 2 focused only on primary studies from the U.S.A (Amante et al., 2014; Goldzweig et al., 2013), whereas the remaining 9 did not specify a restriction and so it is assumed that, without examining the origin of each individual study, their findings may include studies from different countries (Thompson et al., 2016; Otte-Trojel et al., 2016; Ammenwerth et al., 2012; Bush et al., 2015; Giardina et al., 2014; Kruse et al., 2015; Mold et al., 2015; Price et al., 2015; Kruse et al., 2015a). Although the majority of reviews did not specify a restriction for region, eight did specify that the included studies are to be written in English (Thompson et al., 2016; Otte-Trojel et al., 2016; Amante et al., 2014; Bush et al., 2015; Giardina et al., 2014; Goldzweig et al., 2013; Kruse et al., 2015; Price et al., 2015).

Further details of each review are provided in the Characteristics of Included Reviews table in the Appendix 7.

5.3 EVALUATION OF METHODOLOGY QUALITY

The quality of each of the 11 included reviews were assessed using the R-AMSTAR evaluation tool. The highest score was 38 out of 44 with the lowest score recorded at 23 out of 44. As no review scored less than the cut-off of 22 points or less, all 11 reviews were included for analysis. Although no article was excluded due to what would be considered low quality, of the 11 articles, 8 (Bush et al., 2015; Price et al., 2015; Goldzweig et al., 2013; Thompson et al., 2016; Kruse et al., 2015a; Amante et al., 2014; Otte-Trojel et al., 2016; Kruse et al., 2015) only scored a grade of C indicating that 73% of included studies had a comparably low score of quality which may indicate concern around the confidence in the findings of these reviews (Kang et al., 2010). The remaining reviews had a higher quality rating with 1 review scoring

a grade of B (Giardina et al., 2014) and 2 reviews scoring the highest grade of A (Ammenwerth et al.2012; Mold et al., 2015) (Table 7.) which indicates that compared to the other reviews, these 3 may warrant higher level of confidence in the findings. Further information on the quality of each review is available in Appendices 4 and 5, which shows how each review compared to the 11 criteria of the R-AMSTAR tool.

Table 7: R-AMSTAR Results

| Study | Total (44) | Percentile |
|---------------------------|------------|------------|
| Ammenwerth et al. (2012) | 38 | A |
| Mold et al. (2015) | 35 | A |
| Giardina et al. (2014) | 30 | B |
| Bush et al. (2015) | 29 | C |
| Price et al. (2015) | 29 | C |
| Goldzweig et al. (2013) | 29 | C |
| Thompson et al. (2016) | 28 | C |
| Kruse et al. (2015a) | 28 | C |
| Amante et al. (2014) | 26 | C |
| Otte-Trojel et al. (2016) | 24 | C |
| Kruse et al. (2015) | 23 | C |

5.4 RESULTS OF INDIVIDUAL STUDIES

The findings of each of the included systematic reviews are captured in the Summary of Findings table available in Appendix 8. The findings are separated into barriers, enablers and outcomes of use and each finding is coded to an overarching factor of the Adapted CAF. The findings included 113 factors that were barriers of use, 28 factors that enable use and 50 outcomes of use.

5.5 SYNTHESIS OF RESULTS

The Synthesis of Results table, in Appendix 9, shows how the findings under each of the overarching factors from the Summary of Findings table are collated together to form further specific factors that impact the use and outcomes. The main specific factors identified in the Synthesis of Results are provided below which are categorized under the overarching factors: Environment, People, Organization, Technology, Use/User Satisfaction and Outcomes.

Environmental Factors

One of the specific factors captured under Environmental Factors, was Societal/Family Beliefs, Preferences and Trends, which included the finding that the recommendation or support of family and friends were found to enable the use of systems by patients (Amante et al., 2014). The normal technology

practices of a healthcare organization or instructions and incentive to use were also found to impact or influence use by providers (Thompson et al., 2016).

People Factors

Under People Factors, specific factors included the Health Literacy and Computer Literacy, and the Demographic and Health background of the users, which were mentioned in several studies as factors that impacted the use of either a PHR or Portal. Six articles referred to health literacy being a factor and included the ability of a user to understand the medical terminology captured in the medical record (Otte-Trojel et al., 2016; Thompson et al., 2016; Bush et al., 2015; Kruse et al., 2015; Kruse et al., 2015a; Amante et al., 2014). With this, the level of educational attainment of the user also appeared to be a factor with users tending to have a higher level of education than non-users (Thompson et al., 2016; Bush et al., 2015; Kruse et al., 2015a; Goldzeig et al., 2013; Amante et al., 2014). The age, gender, ethnicity and financial background of a user also appeared to be a factor with users tending to be younger in age (Thompson et al., 2016; Otte-Trojel et al., 2016; Mold et al., 2015; Bush et al., 2015; Kruse et al., 2015a; Amante et al., 2014), of a non-minority group (Thompson et al., 2016; Otte-Trojel et al., 2016; Mold et al., 2015; Bush et al., 2015; Kruse et al., 2015a; Goldzeig et al., 2013; Amante et al., 2014), and have a greater source of income with users more likely to have private insurance (Thompson et al., 2016; Otte-Trojel et al., 2016; Mold et al., 2015; Bush et al., 2015; Amante et al., 2014). Although users may be in a higher socio-economic group, this advantage does not appear to relate to health background as users tended to a chronic disease and greater morbidity (Otte-Trojel et al., 2016; Mold et al., 2015; Goldzeig et al., 2013; Amante et al., 2014; Bush et al., 2015).

Another specific factor, Beliefs/Preferences/Behaviour, focused on the beliefs the user had around the value, use and usefulness of the system (including prior experience of using one) which either impacted the use or willingness to use a system as noted in 4 reviews (Thompson et al., 2016; Otte-Trojel et al., 2016; Goldzeig et al., 2013; Amante et al., 2014). This may be coupled with concerns around security, privacy and confidentiality when using the system which included concerns around sharing data and impact on the user's insurance coverage and the possibility of being subjected to discrimination (Thompson et al., 2016; Otte-Trojel et al., 2016; Bush et al., 2015; Amante et al., 2014).

The behaviour of a user including prior level of health service utilization, practice of a healthy lifestyle, and norms for technology use and communication also played factor in who used the system (Thompson

et al., 2016; Kruse et al., 2015a; Amante et al., 2014). Users may have a greater engagement in health services, are following a healthy lifestyle and have adopted technology into their everyday activities.

A user's awareness of a technology and the ability to access the technology was also identified as another specific factor under People. Four reviews noted access to either the internet, computer, and/or a smartphone impacted a users' ability to use a system (Thompson et al., 2016; Otte-Trojel et al., 2016; Kruse et al., 2015; Amante et al., 2014). Furthermore, being aware of the system and its functions also impacted how and if a system is used (Thompson et al., 2016; Otte-Trojel et al., 2016; Kruse et al., 2015a; Amante et al., 2014).

Organization Factors

The Provider's Beliefs/Preference were identified as a specific factor under Organization as the use of a PHR or Portal was also impacted by the perspectives of a provider with 3 reviews commenting on a providers' belief around the value and benefits of a system including the cost benefit and how this would impact the providers' use of the system (Thompson et al., 2016; Kruse et al., 2015; Otte-Trojel et al., 2016). The beliefs around value maybe coupled with a providers' concerns with the impact that the system will have on either workload and workflow as noted in 5 reviews (Thompson et al., 2016; Otte-Trojel et al., 2016; Mold et al., 2015; Kruse et al., 2015; Amante et al., 2014). Furthermore, providers' expressed concern if they would be reimbursed or reimbursed appropriately from using the system (Thompson et al., 2016; Otte-Trojel et al., 2016; Kruse et al., 2015; Amante et al., 2014). The beliefs and attitudes towards the system would appear to correspond with the level of provider encouragement, support or promotion given to their patients to use the system, which was also found as a factor impacting use in 3 reviews with provider promotion and encouragement being seen as an enabler of patient use (Thompson et al., 2016; Amante et al., 2014; Otte-Trojel et al., 2016). The level of support and encouragement of providers to patients was captured under the factor of Service Quality.

Technology Factors

Under Technology Factors, the specific factor System Quality captured the usability (Thompson et al., 2016; Bush et al., 2015; Amante et al., 2014; Kruse et al., 2015), availability of functions and features (Thompson et al., 2016; Bush et al., 2015; Amante et al., 2014), level of security (Thompson et al., 2016; Otte-Trojel et al., 2016; Kruse et al., 2015) and interoperability of the system which were all found to impact use (Price et al., 2015; Thompson et al., 2016; Otte-Trojel et al., 2016).

A further factor included Information Quality as it was found the content of the system may also impact its use and/or usefulness with complexity of data or terminology used (Thompson et al., 2016; Bush et al., 2015; Kruse et al., 2015) and or the integrity of the data in terms of accuracy and completeness within the system (Thompson et al., 2016; Otte-Trojel et al., 2016; Amante et al., 2014) being factors that impacted use.

The ability of the system to fit to Patient/Caregiver needs was also identified as a specific factor under technology as three reviews referred to the ability of the system to fit into a user's or patient's everyday routines and time constraints with concerns expressed by users with how long the system takes to use and not having enough time in a busy life schedule to use the system (Thompson et al., 2016; Bush et al., 2015; Amante et al., 2014).

Use/User Satisfaction

The above technology factors may be linked to the formation of beliefs of the patients and providers have around the system as a system that seen is as easy to use and useful would likely enable use. However, the findings concerning Usability/Usefulness were mixed (Kruse et al., 2015; Giardina et al., 2014). Furthermore, satisfaction with the system was more so connected with the response time from providers when using the system (Thompson et al., 2016; Amante et al., 2014).

Outcomes

Several studies identified outcomes of use and included exploring if concerns around use materialised. Under Outcomes included the specific factor Quality which focused on the improvements to disease/health outcomes from using the systems, which were said to be mixed with some reviews identifying improvements whereas others stated that there was no evidence to support this (Kruse et al., 2015; Kruse et al., 2015a; Giardina et al., 2014; Goldzweig et al., 2013). There were however improvements noted in a patient's satisfaction with care (Mold et al., 2015; Kruse et al., 2015; Kruse et al., 2015a; Price et al., 2015; Giardina et al., 2014) and the communication between patient and provider (Mold et al., 2015; Bush et al., 2015; Kruse et al., 2015; Kruse et al., 2015a; Price et al., 2015; Ammenwerth et al., 2012) which were also captured under Quality. There was further conflicting evidence if the systems saved patients time and decreased telephone calls and clinic visits (Mold et al., 2015; Giardina et al., 2014; Ammenwerth et al., 2012) which were examples under the specific factor, Productivity.

The specific factor, Behaviour, captured one of the most reported outcomes which was on the notion that the systems improved self-care and/or management and participation in care (adherence to medication) and relates to the idea that these systems empower patients to be active in their healthcare. Although there were findings that showed improved participate and management in care, these results were again inconclusive (Mold et al., 2015; Bush et al., 2015; Kruse et al., 2015; Kruse et al., 2015a; Price et al., 2015; Giardina et al., 2014; Ammenwerth et al., 2012). A final significant finding related to outcomes, under Behaviour, concerns a patient emotional response from using the systems and 3 reviews noted that a user's anxiety or distress either decreased and did not increase as a result of using the systems (Bush et al., 2015; Price et al., 2015; Giardina et al., 2014).

5.6 STUDY OVERLAP AND DUPLICATION OF FINDINGS

A list of all the included primary studies for the 11 systematic reviews is provided in Appendix 10 which also shows which primary studies are included in multiple reviews. Table 8 shows an overview of the overlap of primary studies included in the 11 systematic reviews, for example, the review by Thompson et al. (2016) included 8 primary studies that were also found in the review by Amante et al. (2014).

Table 8: Overlap of Primary Studies

| | Amante et al. (2014) | Ammenwerth et al. (2012) | Bush et al. (2015) | Giardina et al. (2014) | Goldzweig et al. (2013) | Kruse et al. (2015) | Kruse et al. (2015a) | Mold et al. (2015) | Otte-Trojel et al. (2016) | Price et al. (2015) | Thompson et al. (2016) |
|---------------------------|----------------------|--------------------------|--------------------|------------------------|-------------------------|---------------------|----------------------|--------------------|---------------------------|---------------------|------------------------|
| Amante et al. (2014) | 0 | 0 | 0 | 1 | 8 | 4 | 3 | 0 | | 3 | 8 |
| Ammenwerth et al. (2012) | 0 | 0 | 4 | 5 | 0 | 0 | 1 | | | 1 | 1 |
| Bush et al. (2015) | 0 | 0 | 0 | 1 | 4 | 1 | 0 | | | 0 | 3 |
| Giardina et al. (2014) | 1 | 4 | 0 | 10 | 0 | 1 | 2 | | | 4 | 3 |
| Goldzweig et al. (2013) | 8 | 5 | 1 | 10 | 3 | 4 | 6 | | | 8 | 18 |
| Kruse et al. (2015) | 4 | 0 | 4 | 0 | 3 | 12 | 1 | | | 2 | 7 |
| Kruse et al. (2015a) | 3 | 0 | 1 | 1 | 4 | 12 | 2 | | | 2 | 5 |
| Mold et al. (2015) | 0 | 1 | 0 | 2 | 6 | 1 | 2 | | | 0 | 2 |
| Otte-Trojel et al. (2016) | | | | | | | | | | | |
| Price et al. (2015) | 3 | 1 | 0 | 4 | 8 | 2 | 2 | | | | 9 |
| Thompson et al. (2016) | 8 | 1 | 3 | 3 | 18 | 7 | 5 | 2 | | 9 | |

The 11 reviews consisted of 267 primary studies (excluding studies in the review by Otte-Trojel et al., 2016), with which 96 (36%) were duplicates. By excluding the duplicates, results in 171 individual primary studies that are captured in this overview. It is important to identify any overlap of primary studies within

the included reviews to see if the results of papers are duplicated and in turn effect the overall findings by distorting the data (Smith et al., 2011).

Individual reviews have identified overlap with previous papers such as Kruse et al. (2015a) which states that its aim was to update and build upon the review by Ammenwerth et al. (2012) and also assess the outcome of patient portal use and its effect on quality of care and medical outcomes. This included duplicating the systemic review by Ammenwerth et al. (2012) with material published from 2011-2014 but including a wider array of publications which are considered to have weaker research designs such as observational studies. The Kruse et al. (2015a) included 27 primary studies and did not include any of the studies from the Ammenwerth et al. (2012) review. As a result, both papers produced different findings, such as the Ammenwerth et al. (2012) reportedly did not identify any improvements in health outcomes, whereas the review by Kruse et al. (2015a) identified several clinical and administrative improvements. Another review by Kruse et al. (2015) was the only review to include systematic reviews from this overview; Ammenwerth et al. (2012) and Goldzweig et al. (2013), which may mean the finding of those two reviews are duplicated in this review thus causing an over representation of the findings.

By comparing the synthesis of results with data on the overlap of findings may provide some indication of some results having an overrepresentation and thus distorting the findings of the overview. One of the outcomes of use included improvements in patient's satisfaction with care which was noted in 5 reviews: Mold et al. (2015), Kruse et al. (2015), Kruse et al. (2015a), Price et al. (2015) and Giardina et al. (2014). From looking at the Summary of Overlap table and exploring one review, such as Mold et al. (2015), it can be noted that this review has 1 paper that overlaps with Kruse et al (2015), 2 papers that overlap with Kruse et al. (2015a) and 2 papers that overlap with Giardina et al. (2014). It is possible that the reviews are referring to the same study that identified that patient satisfaction with care improved from using the system, but instead of this result being captured once, it is captured multiple times thus inflating the result. However, without looking at the findings of each individual primary study it will likely not be possible to identifying specifically which finding has been reported more than once, and this example of overrepresentation or distortion of data for patient satisfaction is theoretical. Only by removing the duplicates and then performing a reanalysis of the data would allow for a truer representation of the findings. Without this re-analysis, the findings of this review should be interpreted with some caution as it is possible that of some results have inflated power than others.

6.0 DISCUSSION

This discussion will present the key findings (Table 9) of the overview and how these findings are applied to the Adapted Clinical Adoption Framework. Included in this discussion are recommendations derived from the findings which may aid in increasing or improving the use and outcomes of use of PHRs and Portals.

Table 9: Key Barriers, Enablers and Benefits.

| | |
|---------------|---|
| Key Barriers: | <ul style="list-style-type: none"> • User's Socio-economic background (level of education, IT literacy, health literacy, employment, and income as well as their age, gender and ethnicity). • User's beliefs of the system. • Usability and usefulness of the systems. |
| Key Enablers: | <ul style="list-style-type: none"> • Influence or recommendations of family and friends for patients • Influence or recommendations of healthcare organizations for providers • Level of provider encouragement, promotion, engagement or support to use system provided to patients |
| Key Benefits | <ul style="list-style-type: none"> • Improved communication between the patient and provider. • Improved patients' satisfaction with care. |

6.1 KEY FINDINGS

The key message from this overview is that despite the promises of PHRs and Portals to foster patient engagement and empower them to be active participants in their care, this overview revealed inconclusive findings in this area. Some reviews identified improved decision making (Mold et al., 2015) and improved understanding of conditions (Bush et al., 2015; Giardina et al., 2014), but when it came to a change in behaviour such as improved self-care and/or management or participation in care, these results were mixed (Mold et al., 2015; Bush et al., 2015; Kruse et al., 2015; Kruse et al., 2015a; Price et al., 2015; Giardina et al., 2014; Ammenwerth et al., 2012). As a change in behaviour is inconclusive, it may be considered unsurprising that improvements on disease/health outcomes from use were also inconclusive (Kruse et al., 2015; Kruse et al., 2015a; Giardina et al., 2014; Goldzweig et al., 2013).

6.2 KEY BENEFITS

The use of PHRs and Portals do however appear to produce some positive outcomes with one of the key benefits of use found in this overview being that the use of the systems improved communication between the patient and provider (Mold et al., 2015; Bush et al., 2015; Kruse et al., 2015; Kruse et al., 2015a; Price et al., 2015; Ammenwerth et al., 2012). This outcome was recorded in more than half of the reviews. Another frequently reported benefit from use also identified in terms of quality was that use improved a patient's satisfaction with care.

6.3 KEY BARRIERS

However, this overview revealed that these benefits may only be experienced by certain populations with reported barriers in use of these systems associated with a user's socio-economic background (Thompson et al., 2016; Otte-Trojel et al., 2016; Goldzeig et al., 2013; Mold et al., 2015; Bush et al., 2015; Kruse et al., 2015a; Amante et al., 2014). The level of someone's education, IT literacy, health literacy, employment, and income as well as their age, gender and ethnicity all seem to impact the use of systems. The digital divide is often a factor when new systems are introduced and who can benefit from these systems. In this overview, users tended to be younger, of a majority, have as higher income and level of education attainment with higher health/computer literacy and with a chronic disease.

A similar study by Archer et al. (2011) conducted a scoping review of the literature on PHRs in order to describe the design, functionality, implementations, applications, outcomes, and perceived and real benefits of PHRs, which had a focus on use in Canada and the U.S. Included in the findings of the review were that people with a strong interest in maintaining healthy lifestyles, are more likely to adopt PHRs. It seems that those who are already have a level of empowerment and understanding of their health and technology will use the system. Whereas, those who may benefit more from use and are currently not empowered (have limited control of their health, not partaking in decision making and have less knowledge of conditions) are being left behind.

When it comes to access and providing equal access to all patients, those who use the system would potentially have greater access to their care provider than those who do not use the system as this overview identified that use improved communication with providers and increased access to health information and preventative care (Price et al., 2015; Mold et al., 2015). For current use of systems or for future implementations, it is vital that all users are able to access these systems and have the opportunity to benefit from use as otherwise as Gibbons (2011) identified, *"if the problems (associated with use) are of a nature such that one population benefits more than another from the technology, the adoption of health IT could actually increase or exacerbate existing healthcare disparities"* (p.4).

Other studies have noted that there limited research into the use of PHRs in particular by elderly users, low-income or minority populations and it is recommended that future research focus on use by users of different ages, education, SES and cultural backgrounds, and health and computer literacy levels (Kim and Nahm, 2012).

Providing access may not remove all barriers, as the motivation to use these systems may revolve around the beliefs or concerns an individual has around the system. This overview also captured components associated with the quality of the system and how the beliefs of both the patients and providers about the quality, value, benefits and usefulness of a system impacts its use (Thompson et al., 2016; Otte-Trojel et al., 2016; Goldzeig et al., 2013; Amante et al., 2014). The usefulness of a system may depend on whether it fits to needs of patients and providers. In this overview, systems that are both patient centered design, fit in with patient busy lives, can be personalized as well as being able to fit with provider's workflows were factors that impacted use (Otte-Trojel et al., 2016; Thompson et al., 2016; Bush et al., 2015; Amante et al., 2014). Other studies have highlighted that PHR systems in particular tend to be physician-oriented, and do not include patient-oriented functionalities and thus do not meet patient needs, furthermore most of the studies on the subject are oriented towards the care providers' points of view, indicating a lack of patient/user involvement in the design and study of PHRs (Pushpangadan and Seckman, 2015; Archer et al., 2011).

The integrity and complexity of data also impacted use highlighting the need for systems to ensure the data contained with the record is accurate, complete and understandable for the user (Thompson et al., 2016; Otte-Trojel et al., 2016; Amante et al., 2014; Bush et al., 2015; Kruse et al., 2015). Lastly, concerns around security were also identified in this overview as the level of security including encryption, firewalls and robust authentication a system has may impact the level of concern a user has about the security, privacy and confidentiality of their data stored in the systems. Concerns around security appears to be an ever pressing one referring to recent events around the world involving ransomware attacks, in particular attacks involving the National Health System in the UK where parts of the service were left paralyzed until the ransom is paid or a fix is found (BBC, 2017). A report by the Economist (2015) on data breaches in the U.S. states that the reports of hacking are on the rise and it is the medical sector that has reported the largest increase in thefts since 2010 with medical records accounting for 43% of all data stolen in 2014. Studies have highlighted concerns around security as a number of healthcare organizations have said to have found that the current encryption and security approaches for many mobile ehealth applications are inadequate at protecting the privacy and confidentiality of data (Househ et al., 2012; Huckvale et al., 2015), which is likely to raise concerns to users as more devices and applications connect and become integrated generating more data of which may be more detailed and personal (Huckvale et al., 2015; Varshney, 2009).

6.4 KEY ENABLERS

To overcome concerns of systems, the use of trials and demonstrations were identified as methods to enable use (Otte-Trojel et al., 2016; Bush et al., 2015). Other enablers included methods to enable use and improve access to systems such as providing users with training to assist those with lower IT literacy and/or providing onsite kiosks to improve access to the system for those whom may not have access to technology (Otte-Trojel et al., 2016). However, a key enabler identified was the influence or recommendations of family and friends (Amante et al., 2014) for patients or healthcare organizations for providers (Thompson et al., 2016). Furthermore, the findings from the reviews captured in the overview also identified that the level of provider encouragement, promotion, engagement or support to use system affected the likelihood of use by patients (Thompson et al., 2016; Amante et al., 2014; Otte-Trojel et al., 2016).

6.5 APPLYING THE ADAPTED CLINICAL ADOPTION FRAMEWORK

It is reported that there has been little work undertaken that has applied a theoretical framework to the study of adoption and use of PHRs (Emani et al., 2012). Other studies such as Nobin et al. (2013) and Emani et al. (2012) have applied theoretical models and concepts to understand PHR adoption such as the Technology Acceptance Model (Davis et al., 1989) and Roger's Diffusion of Innovation theory (Rogers, 2003) respectively. A study by Logue and Efffken (2012) developed a model specific to PHR adoption called the Personal Health Records Adoption Model (PHRAM). The PHRAM describes four factors that interact and influence a user's behaviour (using PHRs to self-manage chronic disease), which shares similar components as presented in the adapted version of the Clinical Adoption Framework, however the adapted CAF aims to capture not only factors of PHR use but also factors concerning Patient Portals as well. The 3 factors of the PRHAM; personal (People) factors (cognitive, affective, and biologic variables that may influence a person's behaviour or decision to change a behaviour), technology factors (how its characteristics influence self- management), and environmental factors (social and physical conditions that may influence a person's behaviour or decision to change a behaviour) are seen as the overarching factors of the adapted CAF. The fourth factor in the PRHAM, chronic disease (covering factors around the ability to self-manage), is seen as a separate entity, whereas in the adapted CAF, this factor could be captured under Personal or People as the specific factor Demographic/Health. How these factors impact behaviour is then captured as a specific outcome.

The development of the PRHAM was in response to the limited comprehensive model of personal health record adoption among older adults with chronic illness found in the literature. Similarly, to the adapted CAF, the purpose of the PHRAM was to capture the barriers and facilitators that could predict adoption of PHRs with the long-term goal of aiding in the development of interventions that increase PHR adoption and reduce barriers, but with the focus on older adults with chronic illness. The adapted CAF aims to take a broader view by not restricting the age of the user and also by capturing the perspectives of providers as well. As mentioned in the rationale of this overview, in order to fully comprehend potential barriers to adoption and utilization of PHRs and Portals and to explore the outcomes of use, an overview would need to capture factors impacting use which are associated with patients, caregivers, providers, the healthcare system, the system itself and the environment in which the system is being deployed. By combining these factors and showing how they interlink may shed light into the reasons as to why use is low and why there are currently inconclusive benefits from use. This is the aim of the adapted framework; to illustrate how different factors impact or influence each other at different levels.

The meso level of the adapted CAF including people factors and organization factors (including implementation) is said to have a direct effect on the micro level (Technology, Use/User Satisfaction and Outcomes) and the use of the system. Then as per the original CAF, the meso level is then affected by changes in the macro level, Environmental factors, in terms of standards, legislation, policy and governance, funding & incentives, and societal beliefs, preference and trends.

As mentioned in the methodology, a proposed example of an outcome of use would be where a system that has a high system, information and service quality is associated with more use and greater user satisfaction, which then potentially leads to a positive result or net benefit with the knowledge of success being fed back into the environment level and informing opinion and knowledge of system use. Whereas, a system with a negative net benefit could be as a result of a poor-quality system with greater dissatisfaction and less use and in turn, negatively affect the opinion of the systems in general (DeLone and McLean, 2003).

Using the Adapted CAF, a proposed scenario or interplay of factors from the findings of the overview could include an outcome, such as improved communication which may impact a decision or motivation by a health organisation to implement or use a system (Environment) thus impacting access for providers (Organisation) and patients (People) and/or support or incentives to providers to use these systems. The

use of the system may be affected by the providers' belief of the system such as impact of workload, which may then impact their level support provided to patients to use the system (Organisation, Technology and Use/User Satisfaction). Using the system could either affirm or allay concerns and beliefs and in turn impact further use, furthermore use may depend on ensuring all have equal access to these systems (People, Organisation, Technology, Use/User Satisfaction). As a result of use, it is observed that communication (Outcomes) has improved then knowledge of this outcome may flow back to influence the provider and patient's beliefs around value as well as to the environment and influence decision of organisations or health authorities.

This overview identified improved communication as an outcome, however, a negative or inconclusive outcome such as the ability of the systems to live up to the promise to empower patients leading to positive health outcomes may result in deterring organizations to invest and implement these systems. That being said this overview did identify a number of benefits from use and highlighted factors that may be impeding use and impacting the generation of further positive outcomes.

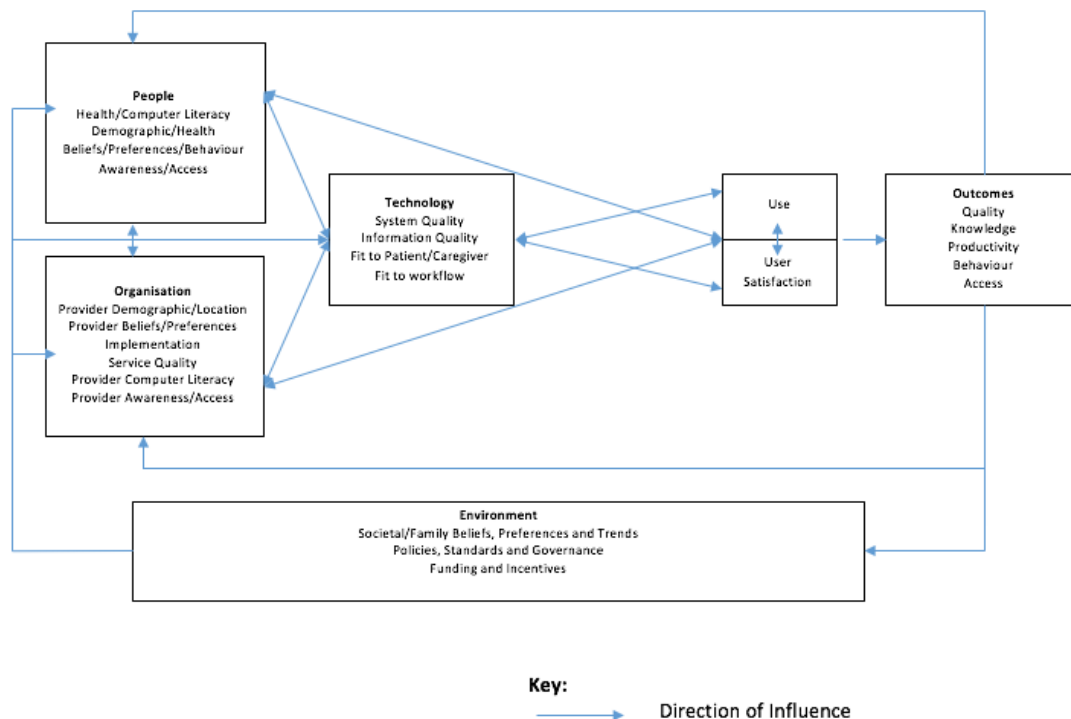


Figure 5: Adapted Clinical Adoption Framework

6.6 RECOMMENDATIONS

The following recommendations for future research and implementations of PHRs and Portals were derived from the findings of this overview:

1. Future research of PHRs and Portals should include identifying ways to improve access and use for those who are less empowered such as minorities, those with lower income and lower educational attainment, and those with less health literacy and computer literacy. Other studies have noted a shortfall in this reach area and have recommended that future research focus on the needs of users with different ages, level of education, SES and cultural backgrounds, and health and computer literacy levels (Kim and Nahm, 2012).
2. Within this research and also future development of systems, there should be a focus on patient-oriented functionalities as well as providers', this includes developing systems that fit in with patients' busy lives, can be personalized as well as being able to fit with providers' workflows (Otte-Trojel et al., 2016; Thompson et al., 2016; Bush et al., 2015; Amante et al., 2014; Pushpangadan and Seckman, 2015; Archer et al., 2011).
3. The use of trials and demonstrations may improve future implementations by helping to ensure that the system chosen meets the needs of all users (Otte-Trojel et al., 2016; Bush et al., 2015). Furthermore, once implemented, classes should be set up to teach users, particularly with lower IT literacy, to use these systems and onsite kiosks should be provided to improve access to the systems. (Otte-Trojel et al., 2016).
4. Finally, ensuring users are encouraged and supported to use these systems once implemented. This involves ensuring buy-in from providers as this overview revealed that providers can influence patient use. Linked to this would be ensuring that the systems meet providers' needs as mentioned above and also putting in place appropriate levels of incentives for providers to use them.

7.0 LIMITATIONS AND STUDY CHALLENGES

There a number of limitations to this overview that need to be acknowledged including confounding factors that may impact the findings. The restrictions in dates, availability of abstract and language in the search criteria may have resulted in excluding reviews relevant to this overview. Smith et al. (2011) states that although applying language restrictions is not recommended, it is likely unavoidable due to constraints such as a lack of access to translation services. It is advised reporting the difference between

searches with and without language restrictions may be beneficial in order to estimate the amount of citations that may have been excluded (Smith et al., 2011), however due to time restrictions for this overview this action was not possible. This approach could also be followed for identifying reviews that have been excluded due to not having an abstract and or fall outside the date period, but again due to time limitations this additional search was not performed. Further limitations in the selection of the reviews for this overview may be caused in the choice to include reviews that only identify themselves as systematic reviews which may have led to excluding papers which did undertake a systematic review methodology, but did not state this in the title of the article (Pare et al., 2015). By only including papers that identify as systematic reviews did provide a standardised process for selecting papers and decreases the potential of the author misinterpreting if a paper is truly is a systematic review or not. That being said, although a paper is identifying as a systematic review, this does not necessarily mean that it follows the systematic review methodology as mentioned in the article by Pare et al. (2015) which highlights inaccuracy or inconsistently in the titling of review studies.

The literature search and data extraction was conducted by just one author which opens the possibility for potential selection bias in terms of interpretation of relevance when selecting systematic reviews, assessing the quality of each review and extracting and coding the findings of each of the reviews. The standardised tool R-AMSTAR was used to assist with assessing the methodological quality of each review and to identify studies that may have a higher potential of bias. Excluding lesser quality papers would then improve the overall quality of the findings. No systematic reviews within this overview were excluded due to concerns around overall quality, which would suggest that the quality of the reviews was considered acceptable, however further caution is warranted as the use of the R-AMSTAR tool is not without limitations as well. As mentioned in the Methodology chapter, it has been suggested that the R-AMSTAR tool poses challenges for the user when assigning adequate weighting of items according to their importance of inclusion. Furthermore, the evaluation of each review is based on the user's interpretation of the reporting and if the information provided meets the criteria or not. It is possible that another user may interpret the quality of each paper differently and assign a different score. The use of a second evaluator who then compares scores may improve the accuracy of the reporting on quality.

It could be argued that the R-AMSTAR evaluates the reporting of each paper, and as Mohel et al. (2009) highlights, the absence of reporting one of the criteria such as a of publication bias, does not necessarily

indicate that it was not done. Furthermore, even if the possibility of publication bias is assessed, there is no guarantee that authors of the systematic reviews have assessed or interpreted it appropriately (Mohel et al., 2009). Secondly, the use of R-AMSTAR may show if a review reports accurately, but then does not identify if the results of the studies are interpreted correctly. As this is an overview of review, the author provides an interpretation of the findings of each systematic review with each systematic review having interpreted the findings of each of the primary studies. This may have resulted in errors in interpretation which are carried through each of the findings. An important factor in one of the primary studies may have been missed or misinterpreted, thus impacting the findings of the systematic review, and this overview of reviews. Only by re-analysing the findings of the individual primary studies included in the systematic reviews, would reduce the presence of publication bias and highlight any misinterpretation of the findings present in the systematic reviews.

Similarly, with the overlap and duplication of findings, without looking at the findings of each of the individual primary studies, it will likely not be possible to identify which finding has been reported more than once. Only by removing the duplicates and then performing a reanalysis of the data would allow for a truer representation of the findings and reduce the possibility that of some results having an overrepresentation and distorting the findings. To counter this weakness, a summary of the overlap was provided to give some indication of potential overlap of the findings. The benefit of the summary of overlap results were slightly impacted by not being able to identify the studies included in the systematic review of Otte-Trojel et al. (2016) which consisted of 109 studies. In the systematic review by Otte-Trojel et al. (2016), it mentions that the details of the included studies are available in an online supplementary file, however this author through consultation with the library of the University of Victoria, was unable to locate this supplementary file. This author also contacted the author of the said systematic review to see if the details of the primary studies could be provided, however received no response.

With the acknowledgment of potential bias in the findings and possibility of findings having overrepresentation, the findings of this review should be interpreted with some caution. Kruse et al. (2015a) criticizes a systematic review by Ammenwerth et al. (2012) who included PHRs in their search as the system is significantly different from a patient portal in terms of ownership and management. This overview also combines PHRs and Portals together and presenting the findings referring to the system which could be a PHR or Portal. It is noted that the majority of papers included in the overview do focus on portals and so the findings reported may reflect this.

By following the PRISMA statement, provided a standardised structure to help to improve the reporting

of this overview and increased the reliability and reproducibility of the overview process by providing comprehensive documentation of the literature search process, data extraction, coding and the analysis performed in the overview (Pare et al., 2015). These details were included using the Literature Search Flow Diagram and tables that details papers included and excluded with reason provided and tables that detail the findings of each review and how they were coded and incorporated into an adapted CAF.

8.0 CONCLUSION

The above overview of reviews presented the barriers, enablers and benefits of PHR and Portal use as identified in systematic reviews over the past 10 years. An adapted Clinical Adoption Framework was used to capture these findings and show how they interlink and influence each other. Although the methodological quality of the included 11 reviews were evaluated as satisfactory, this overview had a number of limitations as described above which mean that the findings of this review should be interpreted with some caution.

Several barriers to use were identified in this overview namely, the socio-economic background of users, the patient's and provider's beliefs of the system and the usability and usefulness of the systems. An enabler of use included encouragement from social supports and providers to use these systems. The use of PHRs and Portals do appear to produce some benefits such as improved communication, but the ability of these systems to empower patients leading to positive health outcomes remains to be confirmed with inconclusive results being reported for improvements in self-care and/or management or participation in care, and inconclusive results for improvements in disease/health outcomes.

Recommendations for future research and implementation of PHRs and Portals include improving access and use for those who are less empowered, developing systems to meet the needs of patient and providers, and ensuring users are encouraged and supported to use these systems once implemented.

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Appendix 1: Literature Search - Identification

| Search String | Criteria | Citations |
|---|---|-----------|
| (((systematic review [ti] OR meta-analysis [pt] OR meta-analysis [ti] OR systematic literature review [ti] OR this systematic review [tw] OR pooling project [tw] OR (systematic review [tiab] AND review [pt]) OR meta synthesis [ti] OR meta-analy*[ti] OR integrative review [tw] OR integrative research review [tw] OR rapid review [tw] OR umbrella review [tw] OR consensus development conference [pt] OR practice guideline [pt] OR drug class reviews [ti] OR cochrane database syst rev [ta] OR acp journal club [ta] OR health technol assess [ta] OR evid rep technol assess summ [ta] OR jbi database system rev implement rep [ta]) OR (clinical guideline [tw] AND management [tw]) OR ((evidence based[ti] OR evidence-based medicine [mh] OR best practice* [ti] OR evidence synthesis [tiab]) AND (review [pt] OR diseases category[mh] OR behavior and behavior mechanisms [mh] OR therapeutics [mh] OR evaluation studies[pt] OR validation studies[pt] OR guideline [pt] OR pmcbook)) OR ((systematic [tw] OR systematically [tw] OR critical [tiab] OR (study selection [tw]) OR (predetermined [tw] OR inclusion [tw] AND criteri* [tw]) OR exclusion criteri* [tw] OR main outcome measures [tw] OR standard of care [tw] OR standards of care [tw]) AND (survey [tiab] OR surveys [tiab] OR overview* [tw] OR review [tiab] OR reviews [tiab] OR search* [tw] OR handsearch [tw] OR analysis [ti] OR critique [tiab] OR appraisal [tw] OR (reduction [tw]AND (risk [mh] OR risk [tw]) AND (death OR recurrence))) AND (literature [tiab] OR articles [tiab] OR publications [tiab] OR publication [tiab] OR bibliography [tiab] OR bibliographies [tiab] OR published [tiab] OR pooled data [tw] OR unpublished [tw] OR citation [tw] OR citations [tw] OR database [tiab] OR internet [tiab] OR textbooks [tiab] OR references [tw] OR scales [tw] OR papers [tw] OR datasets [tw] OR trials [tiab] OR meta-analy* [tw] OR (clinical [tiab] AND studies [tiab]) OR treatment outcome [mh] OR treatment outcome [tw] OR pmcbook)) NOT (letter [pt] OR newspaper article [pt]))) AND ("Health Records, Personal"[Mesh] OR PHR[tiab] OR "patient portal"[tiab]) | Jan-2006 to Dec-2016 Abstract Available English | 410 |

Appendix 2: Literature Search - Screening

Included

| Author(s) | Year | Title | Reason For Inclusion |
|--------------------|------|--|---|
| Akhlaq et al. | 2015 | Barriers and facilitators to health information exchange in low- and middle-income country settings: a systematic review protocol. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available |
| Amante et al. | 2014 | A systematic review of electronic portal usage among patients with diabetes. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Ammenwerth et al. | 2011 | Patient empowerment by electronic health records: first results of a systematic review on the benefit of patient portals. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Ammenwerth et al. | 2012 | The impact of electronic patient portals on patient care: a systematic review of controlled trials. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Bush et al. | 2015 | Implementation of the Integrated Electronic Patient Portal in the Pediatric Population: A Systematic Review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Giardina et al. | 2014 | Patient access to medical records and healthcare outcomes: a systematic review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| De Lusignan et al. | 2014 | Patients' online access to their electronic health records and linked online services: a systematic interpretative review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |

| | | |
|--------------------|--|---|
| Goldzweig et al. | 2013 Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Kruse et al. | 2015 Patient and provider attitudes toward the use of patient portals for the management of chronic disease: a systematic review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Kruse et al. | 2015 The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Mair et al. | 2012 Factors that promote or inhibit the implementation of e-health systems: an explanatory systematic review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Mold et al. | 2015 Patients' online access to their electronic health records and linked online services: a systematic review in primary care. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Mold et al. | 2012 The provision and impact of online patient access to their electronic health records (EHR) and transactional services on the quality and safety of health care: systematic review protocol. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Otte-Trojel et al. | 2016 What do we know about developing patient portals? a systematic literature review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Prey et al. | 2014 Patient engagement in the inpatient setting: a systematic review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |

| | | |
|-----------------|--|---|
| Price et al. | 2015 Conditions potentially sensitive to a personal health record (PHR) intervention, a systematic review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Thompson et al. | 2016 Work system barriers to patient, provider, and caregiver use of personal health records: A systematic review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |
| Videl et al. | 2013 Health information technologies in geriatrics and gerontology: a mixed systematic review. | <ol style="list-style-type: none"> 1. Focused on use of an electronic PHR/Portal 2. English language 3. Abstract available 3. Published between Jan 2006 - Dec 2016 4. Included for further review |

Excluded

| Author(s) | Year | Title | Reason For Exclusion |
|--------------------|------|--|--|
| ? | 2015 | Progress in electronic medical record adoption in Canada. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Abdul Pari et al, | 2014 | Economic evaluations in bipolar disorder: a systematic review and critical appraisal. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Abhyankar et al. | 2014 | Combining structured and unstructured data to identify a cohort of ICU patients who received dialysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Abramson et al. | 2014 | Consumer perspectives on personal health records: a 4-community study. | 3. Not identified as a systematic review |
| Adelson et al. | 2014 | Implementation of electronic chemotherapy ordering: an opportunity to improve evidence-based oncology care. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Aghazadeh et al. | 2014 | The impact of software quality characteristics on healthcare outcome: a literature review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Aizpuru et al. | 2012 | Variability in the detection and monitoring of chronic patients in primary care according to what is registered in the electronic health record. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Al-Rawajfah et al. | 2015 | Use of Electronic Health-Related Datasets in Nursing and Health-Related Research. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Albu et al. | 2013 | Expansion of electronic health record-based screening, prevention, and management of diabetes in New York City. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Alkureishi et al. | 2016 | Impact of Electronic Medical Record Use on the Patient-Doctor Relationship and Communication: A Systematic Review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

| | | |
|-------------------|--|--|
| Alton et al. | 2015 Is there a difference in neurologic outcome in medical versus early operative management of cervical epidural abscesses? | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Andreasen et al. | 2012 Dental Trauma Guide: a source of evidence-based treatment guidelines for dental trauma. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
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| Joukes et al. | 2013 Composite quality of care scores, electronic health record maturity models, and their associations; preliminary literature review results. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kaferle & Wimsatt | 2012 A team-based approach to providing asthma action plans. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| Kahn et al. | 2014 Impact of nurse-led remote screening and prompting for evidence-based practices in the ICU*. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Karakulah et al. | 2012 A data-driven living review for pharmacogenomic decision support in cancer treatment. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Karlin--Zysman et al. | 2012 Struggling to bring clinical prediction rules to the point of care: missed opportunities to impact patient care. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kasarskis et al. | 2011 Integrative genomics strategies to elucidate the complexity of drug response. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kato-Lin | 2014 Does e-pain plan improve management of sickle cell disease associated vaso-occlusive pain crisis? a mixed methods evaluation. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kazmi | 2013 Effects of exam room EHR use on doctor-patient communication: a systematic literature review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Keijzers et al. | 2015 What is the effect of a formalised trauma tertiary survey procedure on missed injury rates in multi-trauma patients? Study protocol for a randomised controlled trial. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kelley et al. | 2011 Electronic nursing documentation as a strategy to improve quality of patient care. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Keltie et al. | 2014 Identifying complications of interventional procedures from UK routine healthcare databases: a systematic search for methods using clinical codes. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kim et al. | 2010 A physician's role following a breach of electronic health information. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kinder & Pettgrew | 2014 Improving primary care through information. A Wonca keynote paper. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Klan et al. | 2014 Decision support from local data: creating adaptive order menus from past clinician behavior. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Klatt & Hopp | 2012 Effect of a best-practice alert on the rate of influenza vaccination of pregnant women. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Ko et al. | 2010 Patient-held medical records for patients with chronic disease: a systematic review. | 2. Paper based record |
| Koch & Vimarlund | 2012 Critical advances in bridging personal health informatics and clinical informatics. | 3. Not identified as a systematic review |
| Kohane | 2015 An autism case history to review the systematic analysis of large-scale data to refine the diagnosis and treatment of neuropsychiatric disorders. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Koutkias & Thiessard | 2014 Big data - smart health strategies. Findings from the yearbook 2014 special theme. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| Krum et al. | 2014 The need for harmonized structured documentation and chances of secondary use - results of a systematic analysis with automated form comparison for prostate and breast cancer. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kruse et al. | 2015 Adoption factors associated with electronic health record among long-term care facilities: a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kuhn et al. | 2015 Clinical documentation in the 21st century: executive summary of a policy position paper from the American College of Physicians. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kushda et al. | 2012 Strategies for de-identification and anonymization of electronic health record data for use in multicenter research studies. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Kushniruk et al. | 2013 National efforts to improve health information system safety in Canada, the United States of America and England. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Lapane et al. | 2012 Tailored DVDs: a novel strategy for educating racially and ethnically diverse older adults about their medicines. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Large et al. | 2012 Meta-analysis of self-reported substance use compared with laboratory substance assay in general adult mental health settings. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Larun et al. | 2016 Use of forms for follow-up of diabetes in general practice. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Lau et al. | 2012 Impact of electronic medical record on physician practice in office settings: a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Lau et al. | 2010 A review on systematic reviews of health information system studies. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Ledwich et al. | 2009 Improved influenza and pneumococcal vaccination in rheumatology patients taking immunosuppressants using an electronic health record best practice alert. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Lehmann et al. | 2014 Assessing medication adherence: options to consider. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Leite et al. | 2016 Near real-time vaccine safety surveillance using electronic health records-a systematic review of the application of statistical methods. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Lepage et al. | 2012 Standardized Procedural Practices of the Ontario Prenatal Screening Program for aneuploidies and open neural tube defects. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Lessard et al. | 2015 Quality assessment of primary care for common mental disorders in isolated communities: Taking advantage of health records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Leventhal et al. | 2012 The patient-centered medical home and health information technology. | 3. Not identified as a systematic review |
| Lewis et al. | 2012 E-health in low- and middle-income countries: findings from the Center for Health Market Innovations. | 3. Not identified as a systematic review |

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| Li et al. | 2012 Integrating usability testing and think-aloud protocol analysis with "near-live" clinical simulations in evaluating clinical decision support. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Li et al. | 2013 Review of computerized physician handoff tools for improving the quality of patient care. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Liau et al. | 2015 The National Anesthesia Clinical Outcomes Registry. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Lindorfer & Manmann | 2015 A Comprehensive Assessment Tool for Patient Registry Software Systems: The CIPROS Checklist | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Lindorfer & Manmann | 2014 CIPROS--a checklist with items for a patient registry software system. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Liu et al. | 2013 An efficacy driven approach for medication recommendation in type 2 diabetes treatment using data mining techniques. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Liu et al. | 2013 Comparative analysis of pharmacovigilance methods in the detection of adverse drug reactions using electronic medical records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Long et al. | 2010 Evidence review of technology and dietary assessment. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Lowe et al. | 2013 Does incorporation of a clinical support template in the electronic medical record improve capture of wound care data in a cohort of veterans with diabetic foot ulcers? | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Lu | 2010 Electronic data-capturing technology for clinical trials: experience with a global postmarketing study. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Luna et al. | 2016 Cyber threats to health information systems: A systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Maehara et al. | 2014 Journal club: Renal masses detected at abdominal CT: radiologists' adherence to guidelines regarding management recommendations and communication of critical results. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Magee et al. | 2011 Identifying potentially eligible subjects for research: paper-based logs versus the hospital administrative database. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Maggio et al. | 2013 Evidence-based medicine training in undergraduate medical education: a review and critique of the literature published 2006-2011. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Malka et al. | 2015 Professional e-mail communication among health care providers: proposing evidence-based guidelines. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Mapp et al. | 2013 Prevention of unplanned intensive care unit admissions and hospital mortality by early warning systems. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Martin et al. | 2014 Clinical Pharmacogenetics Implementation Consortium Guidelines for HLA-B Genotype and Abacavir Dosing: 2014 update. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Mason-Blakley & Weber | 2013 A systems theory classification of EMR hazards: preliminary results. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| McAlearney et al. | 2014 Evidence-based management of ambulatory electronic health record system implementation: an assessment of conceptual support and qualitative evidence. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| McGinn et al. | 2013 Efficacy of an evidence-based clinical decision support in primary care practices: a randomized clinical trial. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| McGinn et al. | 2011 Comparison of user groups' perspectives of barriers and facilitators to implementing electronic health records: a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| McGinn et al. | 2012 Users' perspectives of key factors to implementing electronic health records in Canada: a Delphi study. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| McInnes et al. | 2010 Disparities in health-related internet use by US veterans: results from a national survey. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| McMahon et al. | 2015 Pediatric post-marketing safety systems in North America: assessment of the current status. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Meier | 2013 A role for data: an observation on empowering stakeholders. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Melton et al. | 2012 Social and behavioral history information in public health datasets. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Menaker & Miller | 2016 Best practice in unbilled account management: one medical center's story. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Menon et al. | 2016 Epidemiology of HPV Genotypes among HIV Positive Women in Kenya: A Systematic Review and Meta-Analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Meraji et al. | 2016 Applications of Information Technology in Nursing During 2005-15: Evidence from Iran. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Messner & Schnepf | 2014 Staff experiences within the implementation of computer-based nursing records in residential aged care facilities: a systematic review and synthesis of qualitative research. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Minard et al. | 2014 Development and implementation of an electronic asthma record for primary care: integrating guidelines into practice. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Minard et al. | 2010 Asthma electronic medical records in primary care: an integrative review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Minshall | 2013 A review of healthcare information system usability & safety. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Mohammed et al. | 2016 Creating a Patient-Centered Health Care Delivery System: A Systematic Review of Health Care Quality From the Patient Perspective. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Moja et al. | 2014 Effectiveness of computerized decision support systems linked to electronic health records: a systematic review and meta-analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Monsen et al. | 2012 Exploring the value of clinical data standards to predict hospitalization of home care patients. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Moore & Furberg | 2015 Electronic Health Data for Postmarket Surveillance: A Vision Not Realized. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| Moore et al. | 2016 Utility of plain radiographs and MRI in cervical spine clearance in symptomatic non-obtunded pediatric patients without high-impact trauma. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Moreno-Conde et al. | 2015 Clinical information modeling processes for semantic interoperability of electronic health records: systematic review and inductive analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Morgan et al. | 2015 Association of a Best-Practice Alert and Prenatal Administration With Tetanus Toxoid, Reduced Diphtheria Toxoid, and Acellular Pertussis Vaccination Rates. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Mykkannen et al. | 2016 Standardized Nursing Documentation Supports Evidence-Based Nursing Management | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Nagle et al. | 2015 Obesity and survival among women with ovarian cancer: results from the Ovarian Cancer Association Consortium. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Narra et al. | 2015 Clinical data warehousing for evidence based decision making. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Neff et al. | 2015 Stratification of children by medical complexity. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Nguyen et al. | 2014 Electronic health records implementation: an evaluation of information system impact and contingency factors. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Noren et al. | 2013 Empirical performance of the calibrated self-controlled cohort analysis within temporal pattern discovery: lessons for developing a risk identification and analysis system. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Norman et al. | 2011 Ethics and electronic health information technology: challenges for evidence-based medicine and the physician-patient relationship. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| O'Donnell et al. | 2011 Healthcare consumers' attitudes towards physician and personal use of health information exchange. | 3. Not identified as a systematic review |
| Orrico et al. | 2011 Assessment of the appropriateness of serum digoxin concentration measurement in a medical group setting. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Ouyang et al. | 2016 A design of experiments approach to validation sampling for logistic regression modeling with error-prone medical records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Ovretveit et al. | 2016 Comparing and improving chronic illness primary care in Sweden and the USA. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Pappas et al. | 2011 Computer-assisted history-taking systems (CAHTS) in health care: benefits, risks and potential for further development. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Park et al. | 2014 Applied nursing informatics research - state-of-the-art methodologies using electronic health record data. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Parker et al. | 2016 Health information exchanges--Unfulfilled promise as a data source for clinical research. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| Pasquali et al. | 2016 Report of the National Heart, Lung, and Blood Institute Working Group: An Integrated Network for Congenital Heart Disease Research. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Patel et al. | 2014 Spinal epidural abscesses: risk factors, medical versus surgical management, a retrospective review of 128 cases. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Paterson et al. | 2011 Electronic care plans and medicolegal liability. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Pathak et al. | 2011 Mapping clinical phenotype data elements to standardized metadata repositories and controlled terminologies: the eMERGE Network experience. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Paxton et al. | 2010 Kaiser Permanente National Total Joint Replacement Registry: aligning operations with information technology. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Peiris et al. | 2014 Use of mHealth systems and tools for non-communicable diseases in low- and middle-income countries: a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Peloquin et al. | 2016 Diagnostic and Therapeutic Yield of Endoscopy in Patients with Elevated INR and Gastrointestinal Bleeding. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Pereira et al. | 2013 A mapping of information security in health Information Systems in Latin America and Brazil. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Petersen et al. | 2016 Risks and benefits of psychotropic medication in pregnancy: cohort studies based on UK electronic primary care health records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Phansalkar et al. | 2013 Criteria for assessing high-priority drug-drug interactions for clinical decision support in electronic health records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Phansalkar et al. | 2012 High-priority drug-drug interactions for use in electronic health records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Pilgrim et al. | 2010 Administrative challenges to regionalization. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Pin et al. | 2011 Use of intrathecal baclofen therapy in ambulant children and adolescents with spasticity and dystonia of cerebral origin: a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Pivovarov & Elhadad | 2015 Automated methods for the summarization of electronic health records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Platt et al. | 2012 The U.S. Food and Drug Administration's Mini-Sentinel program: status and direction. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Plazzotta et al. | 2013 Natural language processing and inference rules as strategies for updating problem list in an electronic health record. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Poder et al. | 2011 Implementation of a multi-professional standardized care plan in electronic health records for the care of stroke patients. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Poe | 2011 Building nursing intellectual capital for safe use of information technology: a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| Police et al. | 2010 Adoption and use of health information technology in physician practice organisations: systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Polling et al. | 2015 Using routine clinical and administrative data to produce a dataset of attendances at Emergency Departments following self-harm. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Pons et al. | 2016 Natural Language Processing in Radiology: A Systematic Review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Porter et al. | 2014 Variability in date of prostate cancer diagnosis: a comparison of cancer registry, pathology report, and electronic health data sources. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Porto et al. | 2013 Stress cardiomyopathy (tako-tsubo) triggered by nervous system diseases: a systematic review of the reported cases. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Prins & Hasman | 2013 Appropriateness of ICD-coded diagnostic inpatient hospital discharge data for medical practice assessment. A systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Rahurkar et al. | 2015 Despite the spread of health information exchange, there is little evidence of its impact on cost, use, and quality of care. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Rajkumar et al. | 2015 Antiplatelet therapy as a modulator of stroke aetiology: a meta-analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Randell et al. | 2015 Electronic whiteboards: review of the literature. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Rangraz et al. | 2013 Evaluating the ability of hospital information systems to establish evidence-based medicine in Iran. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Raval et al. | 2016 Association between statins and clinical outcomes among men with prostate cancer: a systematic review and meta-analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Raval et al. | 2015 Impact of metformin on clinical outcomes among men with prostate cancer: a systematic review and meta-analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Remote Preconditioning | 2014 Remote preconditioning and major clinical complications following adult cardiovascular surgery: systematic review and meta-analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Rezaeibagha et al. | 2015 A systematic literature review on security and privacy of electronic health record systems: technical perspectives. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Richardson et al. | 2012 Bridging informatics and implementation science: evaluating a framework to assess electronic health record implementations in community settings. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Rischen et al. | 2013 Records needed for orthodontic diagnosis and treatment planning: a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Robinson et al. | 2016 Review of information technology for surgical patient care. | 3. Not identified as a systematic review |
| Ross et al. | 2014 "Big data" and the electronic health record. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| Rosenthal | 2014 The role of pragmatic clinical trials in the evolution of learning health systems. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Ross et al. | 2015 Exploring the challenges of implementing e-health: a protocol for an update of a systematic review of reviews. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Roumia & Steinhubl | 2014 Improving cardiovascular outcomes using electronic health records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Rubbo et al. | 2015 Use of electronic health records to ascertain, validate and phenotype acute myocardial infarction: A systematic review and recommendations. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Safran | 2014 Reuse of clinical data. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Sainato et al. | 2013 Management of infants born to women infected with hepatitis B in the military healthcare system. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Salahuddin & Ismail | 2015 Classification of antecedents towards safety use of health information technology: A systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Sartain et al. | 2015 Patients' views on the effectiveness of patient-held records: a systematic review and thematic synthesis of qualitative studies. | 2. Paper based record |
| Schickdanza | 2013 Access, interest, and attitudes toward electronic communication for health care among patients in the medical safety net. | 3. Not identified as a systematic review |
| Schoevers et al. | 2009 Patient-held records for undocumented immigrants: a blind spot. A systematic review of patient-held records. | 2. Paper based record |
| Schulz et al. | 2013 The use of best practice alerts with the development of an antimicrobial stewardship navigator to promote antibiotic de-escalation in the electronic medical record. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Schwartz et al. | 2014 Authentication systems for securing clinical documentation workflows. A systematic literature review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Schweitzer et al. | 2014 Structuring clinical workflows for diabetes care: an overview of the OntoHealth approach. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Shah et al. | 2011 Threshold haemoglobin levels and the prognosis of stable coronary disease: two new cohorts and a systematic review and meta-analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Shaha et al. | 2015 The Growing Gap in Electronic Medical Record Satisfaction Between Clinicians and Information Technology Professionals: Issues of Most Concern and Suggested Remediations. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Shahpori & Doig | 2010 Systematized Nomenclature of Medicine-Clinical Terms direction and its implications on criticalcare. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Shaikh et al. | 2015 Impact of electronic health record clinical decision support on the management of pediatric obesity. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| Shang et al. | 2015 Studies on nurse staffing and health care-associated infection: methodologic challenges and potential solutions. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Shen et al. | 2011 Mammography in 40-year-old women: what difference does it make? The potential impact of the U.S. Preventative Services Task Force (USPSTF) mammography guidelines. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Shivade et al. | 2014 A review of approaches to identifying patient phenotype cohorts using electronic health records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Shoenbill et al. | 2014 Genetic data and electronic health records: a discussion of ethical, logistical and technological considerations. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Shultz & Holmtrom | 2015 The use of medical scribes in health care settings: a systematic review and future directions. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Simons & Chung | 2014 Are high coronary risk patients missing out on lipid-lowering drugs in Australia? | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Simpao et al. | 2014 A review of analytics and clinical informatics in health care. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Skinner et al. | 2016 Development of the Parkland-UT Southwestern Colonoscopy Reporting System (CoRS) for evidence-based colon cancer surveillance recommendations. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Skinner et al. | 2014 Realist review to inform development of the electronic advance care plan for the personally controlled electronic health record in Australia. | 3. Not identified as a systematic review |
| Solar et al. | 2015 Evidence-based rules from family practice to inform family practice; the learning healthcare system case study on urinary tract infections. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Son et al. | 2015 Visualization of e-Health Research Topics and Current Trends Using Social Network Analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Song et al. | 2015 Evaluation of Evidence-based Nursing Pain Management Practice. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Song et al. | 2013 Reusing electronic patient data for dental clinical research: a review of current status. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Spyropoulos et al. | 2015 Features of electronic health records necessary for the delivery of optimized anticoagulant therapy: consensus of the EHR Task Force of the New York State Anticoagulation Coalition | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| St Peter | 2010 Improving medication safety in chronic kidney disease patients on dialysis through medication reconciliation. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Staccini et al. | 2013 Evidence-based Practice. Findings from the Section on Education and Consumer Health Informatics. | 3. Not identified as a systematic review |
| Stavropoulou et al. | 2015 How Effective Are Incident-Reporting Systems for Improving Patient Safety? A Systematic Literature Review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| Stevenson et al. | 2010 Nurses' experience of using electronic patient records in everyday practice in acute/inpatient ward settings: A literature review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Stockwell et al. | 2016 Development of an Electronic Pediatric All-Cause Harm Measurement Tool Using a Modified Delphi Method. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Strudwick & Eyasu | 2015 Electronic health record use by nurses in mental health settings: a literature review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Studený & Coustasse | 2014 Personal health records: is rapid adoption hindering interoperability? | 3. Not identified as a systematic review |
| Sun et al. | 2014 Association of MDR1 gene C3435T polymorphism with childhood intractable epilepsy: a meta-analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Thomas et al. | 2014 Systematic review of methods for individual patient data meta- analysis with binary outcomes. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Thompson et al. | 2015 Impact of the Electronic Medical Record on Mortality, Length of Stay, and Cost in the Hospital and ICU: A Systematic Review and Metaanalysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Topaz et al. | 2014 The Omaha System: a systematic review of the recent literature. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Trigo et al. | 2012 A review on digital ECG formats and the relationships between them. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Trinanes et al. | 2015 Development and impact of computerised decision support systems for clinical management of depression: A systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Uzuner et al | 2012 Evaluating the state of the art in coreference resolution for electronic medical records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Van Staa et al. | 2014 The opportunities and challenges of pragmatic point-of-care randomised trials using routinely collected electronic records: evaluations of two exemplar trials. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Van Staa et al. | 2014 Use of electronic healthcare records in large-scale simple randomized trials at the point of care for the documentation of value-based medicine. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Varela-lema et al. | 2012 Observation of health technologies after their introduction into clinical practice: a systematic review on data collection instruments. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Venkatesan et al. | 2015 Development of processes allowing near real-time refinement and validation of triage tools during the early stage of an outbreak in readiness for surge: the FLU-CATs Study. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Vesely et al. | 2016 Obesity Treatment at HealthPartners: Adaptation of Clinical Guidelines into Systems for Practice Operations. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| Vest et al. | 2015 Image Sharing Technologies and Reduction of Imaging Utilization: A Systematic Review and Meta-analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Vigen et al. | 2016 Validation of self-reported comorbidity status of breast cancer patients with medical records: the California Breast Cancer Survivorship Consortium (CBCSC). | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Villarreal-Garza | 2014 Platinum-based chemotherapy in triple-negative advanced breast cancer. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Vimalananda et al. | 2015 Electronic consultations (e-consults) to improve access to specialty care: a systematic review and narrative synthesis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Virginio & Ricarte | 2015 Identification of Patient Safety Risks Associated with Electronic Health Records: A Software Quality Perspective. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Vuokko et al. | 2015 Secondary use of structured patient data: interim results of a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Walker et al. | 2016 Computer-assisted expert case definition in electronic health records. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Walsh et al. | 2013 Provider-to-provider electronic communication in the era of meaningful use: a review of the evidence. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Walsh et al. | 2012 Lack of association between electronic health record systems and improvement in use of evidence-based heart failure therapies in outpatient cardiology practices. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Walsh et al. | 2010 Electronic health records and quality of care for heart failure | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Warner & Alterovitz | 2012 Phenome based analysis as a means for discovering context dependent clinical reference ranges. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Weber & Kohane | 2013 Extracting physician group intelligence from electronic health records to support evidence based medicine. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Weinberg et al. | 2016 Are Readmissions After THA Preventable? | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Welch et al. | 2014 Technical desiderata for the integration of genomic data with clinical decision support. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Welden | 2013 Electronic Health Record: Driving Evidence-Based Catheter-Associated Urinary Tract Infections (CAUTI) Care Practices | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Wells et al. | 2010 Implementing an electronic point-of-care medical record at an organized athletic event: challenges, pitfalls, and lessons learned. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| West et al. | 2015 Innovative information visualization of electronic health record data: a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Westra et al. | 2015 A national action plan for sharable and comparable nursing data to support practice and translational research for transforming health care. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Wexler et al. | 2016 Incidence of adult Huntington's disease in the UK: a UK-based primary care study and a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

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| Wollersheim et al. | 2009 Archetype-based electronic health records: a literature review and evaluation of their applicability to health data interoperability and access. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Wood et al. | 2012 An electronic health record-enabled obesity database. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Woodfield et al. | 2015 Accuracy of Electronic Health Record Data for Identifying Stroke Cases in Large-Scale Epidemiological Studies: A Systematic Review from the UK Biobank Stroke Outcomes Group. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Wu et al. | 2016 Improving an electronic system for measuring PROs in routine oncology practice. | 3. Not identified as a systematic review |
| Wu et al. | 2015 CD44 family proteins in gastric cancer: a meta-analysis and narrative review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Ye et al. | 2015 Associations between statin use and non-Hodgkin lymphoma (NHL) risk and survival: a meta-analysis. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Yeh et al. | 2011 Intravenous bisphosphonates for post-menopausal osteoporosis: adherence to a network guideline. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Young | 2015 Increasing Diagnosis and Treatment of Overweight and Obese Pediatric Patients. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Zahabi et al. | 2015 Usability and Safety in Electronic Medical Records Interface Design: A Review of Recent Literature and Guideline Formulation. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Zaslavsky et al. | 2012 The role of emerging information technologies in frailty assessment. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Zhang et al. | 2015 Data-driven CT protocol review and management—experience from a large academic hospital. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Zhong et al. | 2015 Cost-utility analyses in diabetes: a systematic review and implications from real-world evidence. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Zhou et al. | 2010 Development of traditional Chinese medicine clinical data warehouse for medical knowledge discovery and decision support. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Patterson | 2012 Technology support of the handover: promoting observability, flexibility and efficiency. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Radadhan et al. | 2012 Understanding unintended consequences for EMR: a literature review. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Silow-Carroll et al | 2012 Using electronic health records to improve quality and efficiency: the experiences of leading hospitals. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Trussler & Tabbal | 2012 Patient safety in plastic surgery. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Van Der Vaart et al. | 2013 Need for online information and support of patients with systemic sclerosis. | 3. Not identified as a systematic review |

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| Vines & Dean | 2012 Technology implementation impacting the outcomes of patients with CAP. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Weiskopf & Wong | 2013 Methods and dimensions of electronic health record data quality assessment: enabling reuse for clinical research. | 1. Off topic/not relevant - does not focus on PHR/Portals. |
| Zipkin et al. | 2012 Evidence-based medicine and primary care: keeping up is hard to do. | 1. Off topic/not relevant - does not focus on PHR/Portals. |

Appendix 3: Literature Search - Eligibility

Included

| Author(s) | Year | Title | Reason For Inclusion | Full text |
|--------------------|------|--|--|-----------|
| Thompson et al. | 2016 | Work system barriers to patient, provider, and caregiver use of personal health records: A systematic review. | 1. Focused on use of an electronic PHR/Portal. 2. A systematic review | Yes |
| Otte-Trojel et al. | 2016 | What do we know about developing patient portals? a systematic literature review. | 1. Focused on use of an electronic PHR/Portal. 2. A systematic review | Yes |
| Mold et al. | 2015 | Patients' online access to their electronic health records and linked online services: a systematic review in primary care. | 1. Focused on use of an electronic PHR/Portal. 2. A systematic review | Yes |
| Bush et al. | 2015 | Implementation of the Integrated Electronic Patient Portal in the Pediatric Population: A Systematic Review. | 1. Focused on use of an electronic PHR/Portal. 2. A systematic review | Yes |
| Kruse et al. | 2015 | Patient and provider attitudes toward the use of patient portals for the management of chronic disease: a systematic review. | 1. Focused on use of an electronic PHR/Portal. 2. A systematic review | Yes |
| Kruse et al. | 2015 | The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. | 1. Focused on use of an electronic PHR/Portal. 2. A systematic review | Yes |
| Giardina et al. | 2014 | Patient access to medical records and healthcare outcomes: a systematic review. | 1. Focused on use of an electronic PHR/Portal. 2. A systematic review | Yes |
| Amante et al. | 2014 | A systematic review of electronic portal usage among patients with diabetes. | 1. Focused on use of an electronic PHR/Portal. 2. A systematic review | Yes |
| Goldzweig et al. | 2013 | Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. | 1. Focused on use of an electronic PHR/Portal. 2. A systematic review | Yes |
| Ammenwerth et al. | 2012 | The impact of electronic patient portals on patient care: a systematic review of controlled trials. | 1. Focused on use of an electronic PHR/Portal. 2. A systematic review | Yes |

Excluded

| Author(s) | Year | Title | Primary Reason For Exclusion | Full text |
|-------------------|------|---|------------------------------|-----------|
| Ammenwerth et al. | 2011 | Patient empowerment by electronic health records: first results of a systematic review on the benefit of patient portals. | 5. Duplicate | Yes |

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|--------------------|------|---|--|-----|
| Mair et al. | 2012 | Factors that promote or inhibit the implementation of e-health systems: an explanatory systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. | Yes |
| Mold et al. | 2012 | The provision and impact of online patient access to their electronic health records (EHR) and transactional services on the quality and safety of health care: systematic review protocol. | 5. Duplicate | Yes |
| Videl et al. | 2013 | Health information technologies in geriatrics and gerontology: a mixed systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. | Yes |
| De Lusignan et al. | 2014 | Patients' online access to their electronic health records and linked online services: a systematic interpretative review. | 5. Duplicate | Yes |
| Prey et al. | 2014 | Patient engagement in the inpatient setting: a systematic review. | 1. Off topic/not relevant - does not focus on PHR/Portals. | Yes |
| Akhlaq et al. | 2015 | Barriers and facilitators to health information exchange in low- and middle-income country settings: a systematic review protocol. | 1. Off topic/not relevant - does not focus on PHR/Portals. | Yes |

Appendix 4: Literature Search - Evaluation (R-AMSTAR Scores)

| Study | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | Total (44) |
|---------------------------|---|---|---|---|---|---|---|---|---|----|----|------------|
| Ammenwerth et al. (2012) | 3 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 2 | 3 | 3 | 38 |
| Mold et al. (2015) | 4 | 4 | 4 | 4 | 2 | 2 | 3 | 2 | 3 | 4 | 3 | 35 |
| Giardina et al. (2014) | 3 | 4 | 3 | 3 | 3 | 3 | 2 | 2 | 2 | 2 | 3 | 30 |
| Amante et al. (2014) | 3 | 1 | 4 | 2 | 3 | 4 | 2 | 1 | 2 | 2 | 2 | 26 |
| Bush et al. (2015) | 3 | 4 | 4 | 2 | 3 | 4 | 1 | 1 | 2 | 2 | 3 | 29 |
| Goldzweig et al. (2013) | 3 | 4 | 4 | 2 | 2 | 4 | 2 | 2 | 2 | 1 | 3 | 29 |
| Kruse et al. (2015) | 3 | 2 | 4 | 2 | 3 | 2 | 1 | 1 | 1 | 1 | 3 | 23 |
| Kruse et al. (2015a) | 3 | 4 | 4 | 2 | 3 | 4 | 1 | 1 | 1 | 2 | 3 | 28 |
| Otte-Trojel et al. (2016) | 3 | 4 | 3 | 2 | 3 | 1 | 1 | 1 | 1 | 2 | 3 | 24 |
| Price et al. (2015) | 3 | 4 | 3 | 2 | 3 | 4 | 2 | 2 | 2 | 1 | 3 | 29 |
| Thompson et al. (2016) | 3 | 4 | 3 | 2 | 3 | 4 | 1 | 1 | 3 | 2 | 2 | 28 |

[Appendix 5: Literature Search - Evaluation \(Comparison of R-AMSTAR Scores\)](#)

| Study | Total (44) | Grade |
|---------------------------|------------|-------|
| Ammenwerth et al. (2012) | 38 | A |
| Mold et al. (2015) | 35 | A |
| Giardina et al. (2014) | 30 | B |
| Amante et al. (2014) | 26 | C |
| Bush et al. (2015) | 29 | C |
| Goldzweig et al. (2013) | 29 | C |
| Kruse et al. (2015) | 23 | C |
| Kruse et al. (2015a) | 28 | C |
| Otte-Trojel et al. (2016) | 24 | C |
| Price et al. (2015) | 29 | C |
| Thompson et al. (2016) | 28 | C |

| Percentile | |
|------------|----|
| 90th | 35 |
| 80th | 30 |
| 70th | 29 |

Appendix 6: Literature Search - Included

| Author(s) | Year | Title |
|--------------------|-------|--|
| Kruse et al. | 2015a | The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. |
| Otte-Trojel et al. | 2016 | What do we know about developing patient portals? a systematic literature review. |
| Thompson et al. | 2016 | Work system barriers to patient, provider, and caregiver use of personal health records: A systematic review. |
| Bush et al. | 2015 | Implementation of the Integrated Electronic Patient Portal in the Pediatric Population: A Systematic Review. |
| Kruse et al. | 2015 | Patient and provider attitudes toward the use of patient portals for the management of chronic disease: a systematic review. |
| Mold et al. | 2015 | Patients' online access to their electronic health records and linked online services: a systematic review in primary care. |
| Price et al. | 2015 | Conditions potentially sensitive to a personal health record (PHR) intervention, a systematic review. |
| Amante et al. | 2014 | A systematic review of electronic portal usage among patients with diabetes. |
| Giardina et al. | 2014 | Patient access to medical records and healthcare outcomes: a systematic review. |
| Goldzweig et al. | 2013 | Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. |
| Ammenwerth et al. | 2012 | The impact of electronic patient portals on patient care: a systematic review of controlled trials. |

Appendix 7: Characteristics of Included Reviews

| Author(s)/Year | Aim/Objective | Time Period & No. of studies included | No. of Participants | Population | Origin of Primary Studies/ Language | R-AMSTAR Grade | Conclusions |
|--------------------------|---|---------------------------------------|---------------------|---|---|----------------|---|
| Thompson et al., 2016 | To apply a human factors/ergonomics (HF/E) paradigm to assess individual, work system/unit, organization, and external environment factors generating barriers to patient, provider, and informal caregiver personal health record (PHR) use. | Jan 2000-Oct 2013. 60. | 377,970 | Patients, provider and caregivers - no specified care area, demographic or medical condition. | No restriction on origin. English language | | C The study used the HF/E paradigm to frame an assessment of factors creating barriers to PHR use. A majority of the articles found barriers related to individual factors and work system/unit factors; however, less than half found barriers related to organization factors and external environment factors. Few studies examined caregiver barriers, despite growing recognition of the critical role these individuals play. Although all 3 users may benefit from use, this review demonstrates that each group has unique roles and is embedded in a different context. Results indicate that design efforts should address literacy, interoperability, access to health information, and secure messaging. A deeper understanding of the interactions between work systems and the role of organization and external environment factors is required. |
| Otte-Trojel et al., 2016 | To review articles on portal development to inform future patient portal development efforts and to provide a summary of the evidence base that can guide future research. The problem-solving cycle is used to address the problems encountered in patient portal development. | Jan 2005-Jan 2015. 109. | ? No specified | No specified care area, demographic or medical condition. | No restriction on origin. English language | | C Five problem categories were identified: achieving patient engagement, provider engagement, appropriate data governance, security and interoperability, and a sustainable business model. Key factors contributing to these problems as well as solutions proposed to ameliorate them were identified. Few studies systematically report on the patient portal development processes and so, the review does not provide an evidence base for portal development. The findings support a set of recommendations for advancement of the evidence base. |

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| Mold et al., 2015 | To assess the impact of providing patients with access to their general practice electronic health records (EHR) and other EHR-linked online services on the provision, quality, and safety of health care. | 1999-Sep 2012. 17. | ? Defined as users or non-users of online record access and remote contact services, including both patients (including carers and children) and clinicians/support staff in primary care. | No restriction on origin. No restriction on language. | A While the Risk of Bias scores suggest many of the studies were of low quality, patients using online services reported increased convenience and satisfaction. These services positively impacted on patient safety, although there were variations of record access and use by specific ethnic and socioeconomic groups. Professional concerns about privacy were unrealised and those about workload were only partly so. |
| Bush et al., 2015 | To study was to systematically review existing research on the state of the science, describe the way others have defined the patient portal, and examine pediatric patient portal utilization. | 1992-2014. 11. | 104,789 Pediatric population (including perspectives from caregivers/parents). | No restriction on origin. English language | C Reflecting the additional considerations of pediatric proxy access and fewer chronically ill patients, pediatric medicine has yet to use patient portal as a modality for outcomes measurement. Given the paucity of studies within this age group, it is difficult to measure outcome improvements or the effect of patient record access on healthcare behaviors. This systematic review presents innovative research on the general acceptance of the patient portal among parents and highlights that the implementation of the portal is still in its early stages and has yet to be used widely in diverse populations or studies in a longitudinal manner. Further studies should confirm that protected access to health information and secure communication and information sharing with healthcare providers have an impact in the pediatric population on healthcare outcomes. |

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| Kruse et al., 2015 | To identify the shared characteristics of portals that receive favorable responses from patients and providers and to identify the elements that patients and providers believe need improvement | Jan 2004- July 2014. 27 (+8 added in Peer-review process = 35). | ? Patients with chronic diseases and providers. | No restriction on origin. English language | C This systematic review revealed mixed attitudes from patients and their providers regarding the use of patient portals to manage their chronic disease. The authors suggest that a standard patient portal design providing patients with the resources to understand and manage their chronic conditions will promote the adoption of patient portals in health care organizations |
| Kruse et al., 2015a | To outline and summarize study results on the effect of patient portals on quality, or chronic-condition outcomes as defined by the Agency for Healthcare Research and Quality, and its implications to Meaningful Use since the beginning of 2011. This review updates and builds on the work by Ammenwerth, Schnell-Inderst, and Hoerbst. | Jan 2011 - Aug 2014. 27. | 1,325,781 (of those chronic reported) diseases | No restriction on origin. No listed restriction on language. | C The results of this review demonstrate that more healthcare organizations today offer features of a patient portal than in the review published in 2011. Articles reviewed rarely analyzed a full patient portal but instead analyzed features of a portal such as secure messaging, as well as disease management and monitoring. The ability of patients to be able to view their health information electronically meets the intent of Meaningful Use, Stage 2 requirements, but the ability to transmit to a third party was not found in the review. |
| Price et al., 2015 | To to discover which conditions were potentially sensitive to the PHR as an intervention, that is, what conditions have empirical evidence of benefit from PHR-enabled management. | 2008-2014. 23. | 44,852 (of those conditions - reported) no specified care area, demographic | No restriction on origin. English language | C There is a small body of condition specific evidence that has been published. Conditions with evidence of benefit when using PHRs tended to be chronic conditions with a feedback loop between monitoring in the PHR and direct behaviours that could be self-managed. These findings can point to other potentially PHR sensitive health conditions and guide PHR designers, implementers, and researchers. More research is needed to link PHR design, features, adoption and health outcomes to better understand how and if PHRs are making a difference to health outcomes. |

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|-----------------------|---|-----------------------------------|---|--|--|
| Giardina et al., 2014 | To determine the effect of providing patients access to their medical records (electronic or paper-based) on healthcare quality, as defined by measures of safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity. | 27. | 181,141 Adult patients - no specified care area or medical condition. | No restriction on origin. English language | B Although few positive findings generally favored patient access, the literature is unclear on whether providing patients access to their medical records improves quality. |
| Amante et al., 2014 | To examine characteristics associated with enrollment in and utilization of portals among patients with diabetes and to identify barriers and facilitators of portal enrollment and utilization. | Feb 1, 2005 - Jan 1, 2014. 16. | 73,579 Patients with diabetes. | USA English language | C This review shows that patients with diabetes won't enroll in portals if they lack the skills, desire, and/or knowledge of them. Even after patients have enrolled, they won't use the portals if they experience difficulty accessing and/or using the technology, or if they or their providers don't buy into the potential benefits. To increase portal utilization among those who could benefit most, the technology needs to be accessible, easy to use, and secure, and both patients and providers need to believe in the portal's benefits. Provider and family encouragement to utilize portals are major facilitators to portal enrollment and utilization by patients with diabetes. Patients, their family members, and providers all need to be educated how to use the technology and be informed about the potential benefits. For providers to buy into the use of portals, they need to be educated on the benefits and may require compensation for time spent interacting with patients through the portal. |

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|-------------------------|---|---|--|---|--|
| Goldzweig et al., 2013 | To systematically review the literature reporting the effect of patient portals on clinical care. | Jan 1, 1990 to Jan 24, 2013. 46. | 790,578 Patients - no specified care area, demographic or medical condition. | Focus on USA English Language | C Evidence that patient portals improve health outcomes, cost, or utilization is insufficient. Patient attitudes are generally positive, but more widespread use may require efforts to overcome racial, ethnic, and literacy barriers. Portals represent a new technology with benefits that are still unclear. Better understanding requires studies that include details about context, implementation factors, and cost. |
| Ammenwerth et al., 2012 | To systematically review the impact of electronic patient portals on patient care by analyzing controlled studies on the use of patient portals | 1990-2011. 5 (including 1 duplicate study). | 7137 (of those reported) care area, demographic or medical condition. | No restriction on origin. English, French and German language | A The number of available controlled studies with regard to patient portals is low. Even when patient portals are often discussed as a way to empower patients and improve quality of care, there is insufficient evidence to support this assumption. |

Appendix 8: Summary of Findings

| Author(s)/Year | Barriers | Description | A-CAF Factor |
|-----------------------|--|--|---|
| Thompson et al., 2016 | Patient use: skills, employment, knowledge, training, and education. | Patient use impacted by a user's understanding, such as awareness of system functions and computer literacy which were identified as barriers to use. Those with a lower educational attainment were found more likely to never have logged on. | People Factors |
| | Patient use: age, gender, ethnicity, language and marital status | Patient use reflected demographic groups. There were noted ethnicity differences in use. | People Factors |
| | Patient use: needs, biases, beliefs, and mood | Patient use reflected user's mindset and focused on perceived value of system, degree of need or existence of alternative technologies, and communication preferences. | People Factors |
| | Patient use: behaviour. | Patient use reflected users' actions including health service utilization, practice of a healthy lifestyle, and norms for technology use and communication - example using email already set up and in use. | People Factors |
| | Patient use: task demands, complexity and difficulty | Patient use reflected users' ability to complete related work and related to issues encountered when using the system, such as unintuitive navigation, password recovery and understanding terminology. | Technology Factors People Factors |
| | Patient use: time and sequence demands | Patient use reflected the temporal length and order of completing related work and focused on provider and system response times and the systems' fit with patients' everyday routines. Patients expressed dissatisfaction with response time from provider, not meeting expectations so reverted to previous methods. | Organization Factors Use/User Satisfaction Technology Factors |
| | Patient use: availability of usable technology | Patient use reflected users' access to electronic resources including Internet, computer, and smartphone. Lack of access is described as a barrier to use. | People Factors |
| | Patient use: technology functions and features | Patient use reflected characteristics of the electronic resources and included posed barriers to patients because of challenging content (e.g., difficult terminology), inadequate privacy and security settings, missing functionality, and limited technology platform options) | Technology Factors |
| | Patient use: physical layout and geography | Patient use reflected users' location and focused on the location where the patient lived and whether the patient used the system while hospitalized or after discharge. A study showed greater use when admitted. | People Factors |
| | Patient use: organizational policy/priorities | Focused on whether members of their home and community (e.g., family, friends) would have access to patients' PHRs. | Environment Factors |

| | | |
|---|---|---|
| Patient use: organizational structure | Patient use reflected home and community members' structure and participation. Home and community members' presence at doctors' appointments and in the household, was identified as a barrier. | Environment Factors |
| Patient use: financial resources | Patient use reflected available financial resources within the home and community including household income, insurance, and willingness to pay for PHR service. Users were more likely to have higher incomes and be privately insured. | People Factors |
| Patient use: staffing levels | Patient use reflected the availability of home and community members and the availability of home and community members to assist patients with using system. | Organization Factors Environment Factors |
| Patient use: social climate/ culture. | Patient use reflected home and community members' values, experiences, and practices and focused on home and community members' support, health status, and education. Study showed that users were younger, more likely to have insurance, identify as Caucasian, have higher household incomes, and live in a region with higher rates of high school completion. | Environment Factors |
| Patient use: extra-organizational rules, standards, legislation enforcement | Patient use reflected policies surrounding the healthcare system such as 3rd party access, interoperability with EHRs, and the ability/inability to contact multiple providers, which were recognized as barriers. | Environment Factors Technology Factors |
| Patient use: industry social influences | Patient use reflected users' interactions with providers and focused on patient provider relationships and the value of the system to providers. Study identified that there was a fear of losing relationships as some participants valued choice in how to communicate, and were concerned that the system might cause them to lose those choices. | People Factors Organization Factors |
| Patient use: industry workforce characteristics | Patient use reflected aspects of providers' work such as the degree of involvement from the healthcare team and issues related to provider work (e.g., difficulty responding to patient inquiries, inconsistencies in provider notes, and un-availability of clinical support), which also presented barriers to patients. | Organization Factors |
| Provider use: skills, employment, knowledge, training, and education. | Providers' use reflected their understanding which included the awareness of system and provider specialty, which were described as barriers to providers' use. Limited knowledge of system limits providers' ability to endorse patient use, or to integrate use of features within the clinical practice setting. | People Factors Organization Factors |
| Provider use: age, gender, ethnicity, language and marital status | Providers' use reflected demographic groups. Male physicians disclosed greater use than female. | Organization Factors |

| | | |
|---|--|---|
| Provider use: needs, biases, beliefs, and mood | Providers' use reflected individuals' mindset, such as perceived system value, degree to which an alternative technology solution was perceived as feasible or appropriate, and beliefs regarding patient self-care, which were described as barriers. Believing that system is more beneficial for patients than providers such as for education. | Organization Factors |
| Provider use: behaviour. | Providers' use reflected individuals' actions including use of EHRs, degree of engagement with system, and prior use of alternative forms of technology, which were recognized as a barrier. | Organization Factors |
| Provider use: task demands, complexity and difficulty | Providers' use reflected individuals' ability to complete related work and focused on concerns regarding patients' expectations and issues encountered while using the system (e.g., cumbersome system interface and navigation) | Organization Factors Technology Factors |
| Provider use: time and sequence demands | Providers' use reflected the temporal length and order of completing related work such as time allotted to patient care, workload, timing of information access, and time required to use and learn the system, which were identified as barriers. | Technology Factors |
| Provider use: availability of usable technology | Providers' use reflected individuals' access to electronic resources, specifically the lack of patient- accessible computers in waiting rooms, posed barriers to providers. | Organization Factors |
| Provider use: technology functions and features | Providers' use reflected characteristics of the electronic resources including accuracy of and patient access to sensitive information, missing functions, privacy, awkward security procedures, and general technical issues, which were described as barriers. | Technology Factors |
| Provider use: physical layout and geography | Providers' use reflected location and focused on the clinic setting (e.g., rural or urban settings). Users were more often urban, in group practices or hospital employed, and in none primary care specialties | Organization Factors |
| Provider use: organizational policy/priorities | Providers' use reflected established practices for healthcare institutions' system use such as sensitive information permissions and lack of alignment with workflow, which were recognized as barriers to providers' use. | Environment Factors Technology Factors |
| Provider use: financial resources | Providers' use reflected available financial resources within the healthcare institution and focused on the cost-benefit of using the system. | Environment Factors |
| Provider use: rewards structure | Providers' use reflected healthcare institutions' incentives for use and providers had concerns whether or not they would be appropriately reimbursed for time spent reviewing PHRs. | Environment Factors Organization Factors |
| Provider use: training provided | Providers' use reflected healthcare institutions' instruction in PHR use and inadequate training provided to healthcare institution staff and patients posed barriers to providers. More training and improved usability testing were said to be needed for the system to be used more effectively. | Environment Factors Organization Factors |

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| Provider use: staffing levels | Providers' use reflected the availability of healthcare institution staff or the availability of healthcare institution staff to work with patients on system, which was described as a barrier. | Organization Factors |
| Provider use: social norms and pressures | Providers' use reflected the healthcare institutions' technology use norms. Using alternative tools and resources with little incentive to change. | Environment Factors |
| Provider use: extra-organizational rules, standards, legislation enforcement | Providers' use reflected the policies surrounding the larger healthcare system, such as patient access to provider entered data and provider liability for all information within a patient's PHR, which posed barriers to providers' use. Other concerns included unintentional and intentional data inaccuracies in these records. | Environment Factors Technology Factors |
| Provider use: industry social influences | Providers' use reflected individuals' interactions with patients and focused on the amount of time spent with patients and patients' expectations and assumptions. System seen as increasing workload and decreasing time spent on patient in the office. | Organization Factors |
| Caregiver use: skills, knowledge, training, education | Caregivers' use reflected individuals' understanding including system awareness and experience using the Internet, were recognized as barriers to caregivers' use. Users were those with college degree and insurance for child. | People Factors |
| Caregiver use: needs, biases, beliefs, mood | Caregivers' use reflected individuals' mindset including the perceived system value, degree of need, comfort sharing medical information on the Internet, and communication preferences, which posed barriers. Preferences to have some information directly from provider or sometimes saw information that scared them. | People Factors |
| Caregiver use: behavior | Caregivers' use reflected individuals' actions and included the likelihood of receiving information from other sources which was described as a barrier. | People Factors |
| Caregiver use: task demands, complexity difficulty | Caregivers' use reflected individuals' ability to complete related work, such as the ease with which caregivers could access and use the system, were recognized as barriers. | Technology Factors |
| Caregiver use: time and sequence demands | Caregivers' use reflected the temporal length and order of completing related work and focused on provider and system response times, Internet speed, and general time constraints. | Organization Factors Technology Factors |
| Caregiver use: availability of usable technology | Caregivers' use reflected individuals' access to electronic resources which including computer and Internet access, which posed barriers to caregivers | People Factors |
| Caregiver use: technology functions/features | Caregivers' use reflected characteristics of the electronic resources and were described as barriers due to the lack of specific functions or features and concerns such as accessing frightening information, including new information which had previously been disclosed to patient. | Technology Factors People Factors |

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| | Caregiver use: financial resources | Caregivers' use reflected available monetary resources within the home and community and included the type of insurance caregivers have for their child, were recognized as barriers to caregivers. Users had higher education. | People Factors |
| | Caregiver use: extra-organizational rules, standards, legislation enforcement | Caregivers' use reflected policies surrounding the healthcare system including the sharing of data with external parties (e.g., government agencies, outside providers), which posed barriers to caregivers. Included concerns with sharing data with insurance companies and the potential for discrimination. | Environment Factors People Factors |
| Otte-Trojel et al., 2016 | Patient engagement: Privacy and confidentiality concerns | Low use associated with patient concerns about confidentiality of their personal health data. | People Factors Technology Factors |
| | Patient engagement: Awareness | Low use associated with being unaware of having access to a portal. | People Factors |
| | Patient engagement: Usefulness and usability | Low use associated with not recognizing the usefulness of using a portal or had poor experience using one | People Factors |
| | Patient engagement: Digital access | Low use associated with limited digital access | People Factors |
| | Patient engagement: Health literacy | Low use associated with level of health literacy | People Factors |
| | Patient engagement: Socio-economic disparities | Low use associated with demographic and socio-economic characteristics - generally use was associated with being female, young, white, affluent, and having a chronic disease. | People Factors |
| | Health service provider engagement: Workload and workflow | Providers' fears that use of system features would increase workload and disrupt workflow, especially in light of inadequate compensation. | Organization Factors Environment Factors |
| | Health service provider engagement: Skills and capacities | Concern among providers that they did not possess the skills and capacities to adjust to technical requirements and new models of patient care induced by electronic means of interacting with patients, which would give patients more control as well as responsibility. | Organization Factors |
| | Health service provider engagement: Liability | Concerns around liability in case of breached privacy or harmful patient behavior, e.g., providers could fail to respond in a timely way to patient inquiries or be required to base decision making on patient-entered data, that may not be accurate or complete. Concerns about their possible liability related to patients who may not be able to interpret clinical content and the resulting anxiety, confusion, and perhaps inappropriate or harmful behavior. | Organization Factors Technology Factors |
| | Health service provider engagement: Autonomy | Provider concerns around giving up autonomy, a consequence of giving patients control over activities traditionally arranged by the providers, such as booking appointments. | Organization Factors |
| | Security and interoperability: Data exchange | Problems of use associated with having no standardized technical and semantic language and rules for setting up and managing health information system infrastructures. Also includes existence of non-interoperable systems i.e. stand alone. | Environment Factors Technology Factors |

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| | Security and interoperability: Authentication | For systems to exchange data, they must be able to identify and verify the owners of the data and corresponding records, requiring robust authentication mechanisms. | Technology Factors |
| | Security and interoperability: System robustness | For use, systems need to protect against security breaches from, for instance, hacking or inappropriate system use, although noted that ramping up security measures typically lowers the flexibility and friendliness of use. | Technology Factors |
| | Data governance: Data transparency | Problems around uncertainty with what data should be included in the PHR, when to make these data available, and in what way to convey them. Data have traditionally been recorded for an expert audience as opposed to lay people. | Technology Factors |
| | Data governance: Authorization/ privacy control | Concerns around who should have access to records and who should be able to determine such access rights e.g. minors should have access to portals and whether patients should be able to assign proxy access to their informal caregivers. Concerns around patients not being able to properly manage the activities of the people to whom they have extended access to. | Environment Factors |
| | Data governance: Data integrity | Concerns around how to guarantee the accuracy and completeness of data and whether data in the record could be altered and complemented and how revisions would be visible in the record. | Technology Factors |
| | Financial sustainability: Inadequate reimbursements | Concerns around inadequate and often contradictory reimbursement structures for services provided electronically such as incentives that are too modest and the thresholds too high. | Environment Factors Organization Factors |
| | Financial sustainability: Uncertainty about cost savings | Concerns with lack of documented cost savings from using system, attainable, for example, through better-managed patients or administrative efficiencies. | Organization Factors |
| Mold et al., 2015 | Users of these services were more likely to be female, middle aged or older, with much greater morbidity than non-users | Socio-economic factors impacting use. | People Factors |
| | People with Medicaid cover were less likely to use these services than people with commercial insurance | Financial status/resources impacting use. | People Factors |
| | African-American, other non-white ethnicities, and females with lower socioeconomic classification were less likely to use the services | Disparity in who accesses online records and services, with people of non-white ethnicities and those from lower socioeconomic groups potentially being disadvantaged. | People Factors |

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| | About half of US patients were willing to pay for online access, and 21% were unwilling. Of those who were willing, the median value assigned was \$2 per message | Many patients would not be willing to pay for, or only placed a low value on, online services, such as online communication with clinicians. Those who had communicated with their clinician electronically for at least a year had a lower willingness to pay than those who did not have access. Future research is said to be needed as research presented here is either unclear or at high risk of bias. | People Factors |
| | 1–8% of patients say that viewing their record online caused confusion, worry, or offence | 1–8% of patients stated that viewing consultation notes caused confusion, worry, or felt offended with note comments. Similarly, clinicians had fears about potentially offending or worrying patients. | People Factors Organization Factors |
| | Clinicians had concerns about the additional burden and workload from online access. | | Organization Factors |
| Bush et al., 2015 | Reported utilization of the patient portal was generally low, especially in light of the cross-sectional nature of most of the studies, which did not follow adherence over time. | | Use/User Satisfaction |
| | Difficulty in graphing and interpreting data, the need for more explanation of test results, and understanding medical terminology | | Technology Factors People Factors |
| | Dislike of having separate accounts for each child and the lack of a symptom checker. | | Technology Factors |
| | Logistical reasons included being too busy and forgetting the login/password for the system. | | People Factors |
| | Concerns about confidentiality, especially among teenagers and their parents, are also seen as a barrier to use | | People Factors |
| | Found that use of the portal was higher for children with autism and those who had more conditions listed on the medical report problem list. | | People Factors |
| | Individuals of color and those with Medicaid or who were low income were less likely to obtain a portal account. Users were likely to have more education and commercial insurance versus nonusers. Adolescents are also less likely to activate the patient portal | | People Factors |
| Kruse et al., 2015 | Security | Even though patients and providers view secure messaging capabilities in system as a beneficial attribute, 11 of the 27 articles (41%) stated that there was insufficient security in the design | Technology Factors |

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| | User friendliness | 11 of 27 articles, patients did not perceive the system as user-friendly and had difficulty navigating Web applications due to a lack of patient technical support, education, and access to the Internet. | Technology Factors Use/User Satisfaction |
| | Secure messaging | Combination with time management as providers expressed frustration that they would not have sufficient time to take care of business that is reimbursable. | Organization Factors |
| | Time management | Time management was most often mentioned by providers as an expression of frustration that they would not have sufficient time to take care of business that is reimbursable | Organization Factors |
| | Cost | 3 in 27 articles (11%) identified cost as a concern. | Organization Factors Environment Factors |
| | Educational resources | Although patients value the educational resources provided in their patient portal, in 3 articles, many patients reported difficulty understanding and navigating interactive resources such as health libraries in their patient portal. | People Factors Technology Factors |
| Kruse et al., 2015a | Portal users tend to be female, Caucasian, under 65 years old, well educated, and prefer electronic means of communication | | People Factors |
| | Sociodemographic disparities exist for portal use, and users need to improve their health literacy in order to better interpret the medical information they are viewing | | People Factors |
| | Providers who offer the portals will not be able to capitalize on the Meaningful Use, stage 2 incentive due to lack of awareness of the patient portal service. | | People Factors |
| Amante et al., 2014 | Portal enrollment - Lack of capacity: Lack of computer skills | | People Factors |
| | Portal enrollment - Lack of capacity: No computer/internet access | | People Factors |
| | Portal enrollment - Lack of capacity: Don't want to spend time learning system | | People Factors |
| | Portal enrollment - Lack of desire: Already satisfied with provider relationship | | People Factors |
| | Portal enrollment - Lack of desire: Already email provider directly without portal | | People Factors |
| | Portal enrollment - Lack of desire: Don't want to spend time on the computer | | People Factors |
| | Portal enrollment - Lack of awareness: Unaware of portal | | People Factors |

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| Portal enrollment - Lack of awareness: Unaware of portal features | | People Factors |
| Portal utilization - patient barrier: Too busy/not enough time | | People Factors |
| Portal utilization - patient barrier: No computer/internet access | | People Factors |
| Portal utilization - patient barrier: Low knowledge/technical literacy | | People Factors |
| Portal utilization - patient barrier: Unaware of portal/portal features | | People Factors |
| Portal utilization - patient barrier: Doubts about technology and reliability of message exchange, security concerns, or prefer traditional communication | | People Factors Technology Factors |
| Portal utilization - patient barrier: Don't believe in benefits. | | People Factors |
| Portal utilization - provider barrier: Provider instructed patient not to use | | Organization Factors |
| Portal utilization - provider barrier: Provider less engaged in portal use | | Organization Factors |
| Portal utilization - provider barrier: Patient assumptions of provider engagement, interruptions, or reimbursement. | | Organization Factors |
| Portal utilization - usability barrier: Lost/unknown user name/passwords. | | People Factors |
| Portal utilization - usability barrier: Negative experience using portal. | | People Factors |
| Portal utilization - usability barrier: Can't directly message all providers | | Technology Factors |
| Portal utilization - usability barrier: No reminders sent | | Technology Factors |
| Portal utilization - usability barrier: Inaccurate patient information on portal | | Technology Factors |
| Portal utilization - usability barrier: Slow response from secure messages | | Organization Factors People Factors Use/User satisfaction |
| Patient enrollment demographic factors: Higher education, younger age, higher income, private health insurance, and non-Hispanic/ non-black race | | People Factors |

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| | Psychosocial and disease knowledge enrollment factors: higher self-efficacy, more diabetes and insulin-related knowledge, higher health literacy, greater trust in the Internet as a health information source, better-controlled diabetes, nonsmoker and having higher morbidity burden. | | People Factors |
| | Provider enrollment factors: Provider engaged in use, better provider quality measures, greater trust in providers and better communication with provider | | Organization Factors |
| | Patient utilization demographic factors: Higher education, younger age, higher income, and non-Hispanic, non-black race. | | People Factors |
| | Patient utilization diabetes factors: Patients utilized portals more if they had better controlled diabetes and reported less self-perceived diabetes distress and severity. Patients with greater morbidity burden or high use of clinical services were more likely to utilize portals. One article found that using insulin was associated with higher portal utilization. | Findings for diabetes-related factors were mixed. | People Factors |
| Goldzeig et al., 2013 | Patient-specific factors with lower use by racial and ethnic minorities, lower use with lower education level or literacy, and greater use with increased numbers of medical problems. | | People Factors |
| | Barriers including instances of suboptimal patient attitudes of system worth | | People Factors |

| Author(s)/Year | Enablers | Description | CAF Factor |
|--------------------------|-------------------------|---|----------------------|
| Otte-Trojel et al., 2016 | Patient-centered design | Designing systems to meet needs defined by patients' characteristics, preferences, and capacities, as opposed to the most easily operationalized features of the technology - results in systems with high patient-perceived usefulness and usability. Achieved through patient interviews, surveys, focus groups and usability testing | Technology Factors |
| | Training and education | Providing training to users who lack skills in the use of system and improve access by providing for example, onsite kiosks. | Organization Factors |

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| Promotional initiatives | Promotion initiatives for attracting patient attention and increasing awareness such as through encouragement by providers, through providing written or visual materials or follow-up registration reminders. | Organization Factors |
| Workflow engineering | Using workflow engineering to mirror current workflow and capitalizing on existing provider roles could inform minimal burden workflow revisions (involving providers in the process). | Organization Factors |
| Workflow training | To improve provider engagement, provide communication and practical training to providers to equip them to handle technical, interpersonal, and workflow aspects of system use. | Organization Factors |
| Notification and signaling of urgency | To counter providers' liability-related concerns by notifying providers if patients had not opened an email and designing the system to detect messages that signal medical urgency. | Technology Factors |
| International Communication Standards | Standardizing interoperability guidelines to allow for data exchange among organizations such as the international Health Level 7 (HL7) standard. | Environment Factors |
| Access control mechanisms | Setting up authentication mechanisms such as Public Key. | Technology Factors |
| Encryption , internet firewalls, audits | Improve system security through encryption tools, firewalls, and audits of adherence to security protocol. | Technology Factors |
| Health information exchanges | Setting up (Regional) Health Information Exchanges that can standardize data and facilitate ex- change among different organizations. | Environment Factors |
| Policies for data availability and timing | Setting up policies for data viability and timing in order to improve data governance. | Environment Factors |
| In-person authorization/user agreements | Patients to show identification in person before gaining access to a portal or using an electronically signed user agreement. | Environment Factors Technology Factors |
| Provider and patient electronic signatures | Using electronic signatures to determine who had revised the records in order to improve data integrity. | Technology Factors |
| Trial period to establish business case | Trial period before committing to purchasing a system to allow organizations to test usability and be better able to estimate financial and organizational effects of use. | Organization Factors |
| Appropriate reimbursement criteria | Developing and testing reimbursement criteria for secure messaging that could be used by payers to determine whether and by how much to reimburse an online encounter. | Environment Factors |
| Bush et al., 2015 | Following a demonstration of the portal to parents in an academic practice waiting room, 92% thought the patient portal was easy to use, and they planned to view medical records and laboratory results in the future. | Organization Factors |
| Price et al., 2015 | 76% (13/17) studies that used tethered PHR reported benefit. In comparison, only 50% (3/6) studies that used standalone PHRs showed benefit. | Technology Factors |

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| Giardina et al., 2014 | Usage of PHR - access to personalized medical information. | 3 RCT compared usage of informational resources when given computer access to either personalized medical information or general health information, and found that access to personalized information increased the likelihood of usage. | Technology Factors |
| | Perceived usefulness of access to medical records | One trial randomly assigned pregnant patients to use an internet-based pregnancy resource either with or without additional access to personal antenatal health records. Although both groups found the information easy to access and useful, there was no significant difference in perceived usefulness. | Use/User Satisfaction |
| Amante et al., 2014 | Portal enrollment - facilitator: Family recommended/supported | | Environment Factors |
| | Portal enrollment - facilitator: Provider recommended | | Organization Factors |
| | Portal enrollment - facilitator: Dissatisfied with provider-patient relationship | | Organization Factors |
| | Portal utilization - facilitator: Family recommended/provided support. | | Environment Factors |
| | Portal utilization - facilitator: Provider instructed patients to use | | Organization Factors |
| | Provider utilization factors: Provider engaged in use, encourage use, patients reporting greater trust in their providers and better quality measures for their care | | Organization Factors |
| | Portal enrollment - facilitator: Experienced difficulty obtaining medical information. | | Organization Factors |
| Kruse et al., 2015 | User-friendliness | Seven out of 27 articles (26%) reported from both patients and providers of the ease of navigation and user-friendliness of the system | Technology Use/User Satisfaction |
| | Secure messaging | Ten of 27 articles (37%) reported a positive association with the secure messaging offered by the system | Technology Use/User Satisfaction |

| Author(s)/Year | Benefits | Description | CAF Factor |
|-------------------|--|---|------------|
| Mold et al., 2015 | 70% of clinicians felt that online access strengthened relationships, enhanced trust, and improved decision making | | Outcomes |
| | Patients who used online access to test results were more satisfied than those who did not | Patient satisfaction improved through enabling better self-care. The introduction of a system which enabled patients to view their test results, manage their medication list, and have secure messaging with their practice, resulted in responders saying the system facilitated their participation in their own care and another post-intervention survey found that patients felt more in control of their care. | Outcomes |

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| | Use of a secure messaging tool improved patient satisfaction with care | Patient satisfaction improved through enabling better self-care. Several trials showed that online access to records and services improved communication. | Outcomes |
| | Patients felt themselves better able to express their concerns in writing (34%), to communicate about difficult topics (36%), and to send psychosocial information when using online tools versus telephone. | Several trials showed that online access to records and services improved communication. | Outcomes |
| | Online systems saved patients time, telephone calls, and clinic visits | | Outcomes |
| | Patients given online access to their records identified more than twice as many medication list discrepancies with potential for severe harm than those who did not | Patient safety was largely improved through patients identifying errors in their medication list. Online access to consultation notes was also found to increase reported medication adherence. | Outcomes |
| | Users of online services received 84% of preventive care services compared with 68% of controls, including influenza vaccine (22% versus 14%) and mammography (49% versus 30%); children whose parents used online services received 96% of immunizations versus 87% in controls. Online services also facilitated health maintenance/appointment reminders | Online services facilitated uptake of preventive care services by providing prevention or health maintenance reminders. Online access to consultation notes was also found to increase reported medication adherence. | Outcomes |
| | Clinicians had concerns about the additional burden and workload from online access but found their fears only partly realized | Clinicians thought e-mail was useful for answering patients' non-urgent medical questions and helpful in managing patients' administrative concerns. However, a few intervention clinicians felt that e-mails were too lengthy or were concerned about incomplete information. | Outcomes |
| | 1–8% of patients say that viewing their record online caused confusion, worry, or offence | Only 1–8% of patients stated that viewing consultation notes caused confusion, worry, or felt offended with note comments. Similarly, clinicians had fears about potentially offending or worrying patients; however, these concerns did not materialize in practice. | Outcomes |
| | The impact of online record access on patient use of face-to-face services and telephone calls was unclear | Online access has an inconsistent effect on face-to-face consultations, which increased in some studies and went down in others. | Outcomes |
| Bush et al. 2015 | Parents of chronically ill children (diabetes mellitus, cystic fibrosis, and juvenile idiopathic arthritis) reported that the portal was accurate and timely, helping them to communicate with their children's care providers | | Outcomes |

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| | The portal helped to manage and understand child's condition, reducing anxiety and offering reassurance. | | Outcomes |
| | Parents of both healthy and chronically ill children like the concept of the patient portal. | Parents of chronically ill children (diabetes mellitus, cystic fibrosis, and juvenile idiopathic arthritis) reported that the portal was accurate and timely, helping them to communicate with their children's care providers. | Outcomes |
| | Portal use was statistically significant predictor of glycosylated hemoglobin level but not of low-density lipoprotein and total cholesterol levels. | | Outcomes |
| Kruse et al., 2015 | Patient-provider communication | A total of 11 out of 27 articles (41%) reported an improvement of patient-provider communication as a result of using the system | Outcomes |
| | Quality of care | Ten out of 27 articles (37%) mentioned improvements in quality of care as reported by both patient and provider | Outcomes |
| | Disease outcomes | Ten of 27 articles (37%) reported an increase in disease outcomes as a result of using the system. Only two of 27 articles (7%) reported negative medical outcomes as a result of use. | Outcomes |
| | Educational resources | Nine out of 21 articles (33%) attributed greater self-management of chronic conditions through the presence of educational resources presented through a patient portal | Outcomes |
| | Time | Example: Using the mobile monitoring apps allow patients to access their patient portal at their own convenience | Outcomes |
| Kruse et al., 2015a | The use of the patient portals in this review illustrates a higher retention rate of patient loyalty | | Outcomes |
| | Lower appointment no-show rates | | Outcomes |
| | Studies documented a high rate of patient satisfaction with the portal, which enables patients to take a more active role in medical decision making | | Outcomes |
| | Portal use also seems to increase patient-to-provider communication with only a slight increase in workload or office visits | | Outcomes |
| | Results varied on improved outcomes | | Outcomes |
| Price et al., 2015 | Improved patient satisfaction with care | | Outcomes |
| | Improved disease control | PHR sensitive conditions identified included: diabetes, hypertension, asthma, HIV, fertility management, glaucoma, and hyperlipidemia. These conditions share several common characteristics: Each of these conditions is chronic. | Outcomes |
| | Decreased patient distress | | Outcomes |
| | improved continuity | | Outcomes |

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| | Improved medication management | | Outcomes |
| | Improved access to own information | | Outcomes |
| | Improved access to health knowledge | | Outcomes |
| | Improved access to patient information by provider | | Outcomes |
| | More effective face-to-face visits | | Outcomes |
| | Better patient-provider communication | | Outcomes |
| | Improved ability to self manage | Significant benefit from self-management through behavioural changes. | Outcomes |
| | More activated patient | | Outcomes |
| Giardina et al., 2014 | Physical health outcomes | Mixed findings for biological outcomes such as laboratory values, body mass index, and blood pressure. Found no current evidence to substantiate any negative patient outcomes resulting from access to health information | Outcomes |
| | Psychosocial health outcomes | Five studies addressed psychosocial variables including depression, anxiety, contentment, and quality of life. Three studies found no significant differences in anxiety between groups, while two studies found that anxiety decreased with access to medical information. Two studies evaluated self-reported depression and contentment in patients and found no significant differences between the intervention and control groups. Found no current evidence to substantiate any negative patient outcomes resulting from access to health information. Access to medical information did not increase patient anxiety. | Outcomes |
| | Health behaviors and adherence outcomes | Four studies included measures of patient health behaviors, and outcomes were mixed. | Outcomes |
| | Recall of medical information | Two studies addressed patient recall of medical information as an outcome of patient access to medical records, and the results were mixed. | Outcomes |
| | Accuracy of the medical record | One uncontrolled observational study evaluated the influence of a secure web-based patient portal on the accuracy of medication lists in the electronic health record, and found no significant differences. | Outcomes |
| | Patient satisfaction | Limited evidence suggests that patients with access to medical records have improved levels of satisfaction | Outcomes |
| | Informed patient | Three studies measured pregnant women's perceptions of being informed when provided with access to their medical records of which two found a significant effect | Outcomes |
| | Patient involvement in care | Mixed findings around self-efficacy, control and empowerment. | Outcomes |
| | Studies of efficiency | Mixed finding with impact on office visits and telephone calls. PHR users as a group had significantly more after-hours clinic visits, emergency department visits, and hospital visit | Outcomes |

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| Goldzweig et al., 2013 | Improved outcomes for patients with chronic conditions | Identified examples in which portal use was associated with improved outcomes for patients with chronic diseases, such as diabetes, hypertension, and depression, but these studies generally used the portal in conjunction with case management. | Outcomes |
| Ammenwerth et al., 2012 | Quicker decrease in office visit rates and slower increase in telephone contacts | | Outcomes |
| | Increase in number of messages sent | A study mentions that a quarter of portal users indicated they would have scheduled an appointment in lieu of electronic messaging; so there seems to be a possibility of saving resources by a portal with electronic messaging but there is not sufficient data to decide conclusively on this. | Outcomes |
| | Changes of the medication regimen | | Outcomes |
| | Better adherence to treatment | It seems plausible that better-informed patients show higher adherence to treatment or to clinical advices, but there is not sufficient evidence to support this assumption. | Outcomes |

Appendix 9: Synthesis of Results

Environment Factors

| Societal/Family Beliefs, Preferences and Trends | Reference |
|--|---|
| Social climate/culture (home and community members' values, experiences, practices, support, health status, and education) | Thompson et al. (2016) |
| Recommendation or support from family | Amante et al. (2014) |
| Healthcare social norms and pressures (technology use norms, instructions to use, incentive to change) | Thompson et al. (2016) |
| Policies, Standards and Governance | Reference |
| Policy, priorities and privacy controls (who has access to system/data-patients and caregivers) | Thompson et al. (2016); Otte-Trojel et al. (2016) |
| Rules, standards, and legislation (3rd party access, interoperability, ability/inability to contact multiple providers and provider liability concerning data) | Thompson et al. (2016) |
| Standardized technical and semantic language -allow for data exchange. | Otte-Trojel et al. (2016) |
| Funding and Incentives | Reference |
| Practice/Health organization's financial resources (including cost-benefit of system) | Thompson et al. (2016); Kruse et al. (2015) |
| Level/amount of incentives to use (rewards structure) | Thompson et al. (2016); Otte-Trojel et al. (2016) |

People Factors

| Health/Computer Literacy | Reference |
|--|---|
| Level of computer skills/literacy (experience of using the internet) | Thompson et al. (2016); Amante et al. (2014) |
| Level of health literacy (understanding terminology) | Otte-Trojel et al. (2016); Thompson et al. (2016); Bush et al. (2015); Kruse et al. (2015); Kruse et al. (2015a); Amante et al. (2014) |
| Demographic/Health | Reference |
| Level of education + training | Thompson et al. (2016); Bush et al. (2015); Kruse et al. (2015a); Goldzeig et al. (2013); Amante et al. (2014) |
| Level of employment | Thompson et al. (2016) |
| Age | Thompson et al. (2016); Otte-Trojel et al. (2016); Mold et al. (2015); Bush et al. (2015); Kruse et al. (2015a); Amante et al. (2014) |
| Gender | Thompson et al. (2016); Otte-Trojel et al. (2016); Mold et al. (2015); Kruse et al. (2015a) |
| Ethnicity (minority) | Thompson et al. (2016); Otte-Trojel et al. (2016); Mold et al. (2015); Bush et al. (2015); Kruse et al. (2015a); Goldzeig et al. (2013); Amante et al. (2014) |
| Language | Thompson et al. (2016) |
| Financial resources (income, private insurance , ability to pay for system access) | Thompson et al. (2016); Otte-Trojel et al. (2016); Mold et al. (2015); Bush et al. (2015); Amante et al. (2014) |

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| Chronic disease/ greater morbidity | Otte-Trojel et al. (2016); Mold et al. (2015); Goldzeig et al. (2013); Amante et al. (2014); Bush et al. (2015) |
| Location (admitted vs community) | Thompson et al. (2016) |
| Socio economic status | Mold et al. (2015); Kruse et al. (2015a); Otte-Trojel et al. (2016) |
| Beliefs/Preferences/Behaviour | Reference |
| Preference for existing methods for communication, sharing and accessing information (including receiving new/concerning information from provider directly) | Thompson et al. (2016); Amante et al. (2014) |
| Preferences for existing/alternative technology | Thompson et al. (2016); Amante et al. (2014) |
| Beliefs of value, use and usefulness of system (including prior experience of using one) | Thompson et al. (2016); Otte-Trojel et al. (2016); Goldzeig et al. (2013); Amante et al. (2014) |
| Behaviour (health service utilization, practice of a healthy lifestyle, and norms for technology use and communication) | Thompson et al. (2016); Kruse et al. (2015a); Amante et al. (2014) |
| Security, Privacy and Confidentiality concerns (including impact of sharing data on insurance and discrimination) | Thompson et al. (2016); Otte-Trojel et al. (2016); Bush et al. (2015); Amante et al. (2014) |
| Willingness to pay for system/access/service | Thompson et al. (2016); Mold et al. (2015) |
| Concerns with not understanding, becoming worried or being offended by information accessed through system. | Thompson et al. (2016); Mold et al. (2015) |
| Willingness to learn system or use system | Amante et al. (2014) |
| Awareness/Access | Reference |
| Level of awareness of system/access and functions | Thompson et al. (2016); Otte-Trojel et al. (2016); Kruse et al. (2015a); Amante et al. (2014) |
| Access or availability of technology (Internet, computer, and smartphone) | Thompson et al. (2016); Otte-Trojel et al. (2016); Kruse et al. (2015); Amante et al. (2014) |
| Remembering passwords | Bush et al. (2015); Amante et al. (2014) |

Organization Factors

| | |
|---|--|
| Provider Demographic/Location | Reference |
| Age | Thompson et al. (2016) |
| Gender | Thompson et al. (2016) |
| Ethnicity | Thompson et al. (2016) |
| Language | Thompson et al. (2016) |
| Location (clinic setting rural vs urban) | Thompson et al. (2016) |
| Provider's Beliefs/Preferences | Reference |
| Preference for existing methods for communication | Thompson et al. (2016) |
| Preferences for existing/alternative technology | Thompson et al. (2016) |
| Beliefs (expectations/assumptions from patients, time to learn system, impact on time with patients) | Thompson et al. (2016); Amante et al. (2014) |
| Beliefs of value and benefits of system (including cost benefit) | Thompson et al. (2016); Kruse et al. (2015); Otte-Trojel et al. (2016) |
| Concerns with liability (data breaches, decision making with inaccuracy data entered by patients) | Thompson et al. (2016); Otte-Trojel et al. (2016) |
| Concerns with patients not understanding data or information entered causes stress or harmful behaviour | Otte-Trojel et al. (2016); Mold et al. (2015) |

| | |
|---|--|
| Concerns with autonomy (giving up autonomy and consequences of allowing patients more control of provider activities) | Otte-Trojel et al. (2016) |
| Concerns with amount/lack of reimbursement with use | Thompson et al. (2016); Otte-Trojel et al. (2016); Kruse et al. (2015); Amante et al. (2014) |
| Concerns with impact on workload/workflow with use | Thompson et al. (2016); Otte-Trojel et al. (2016); Mold et al. (2015); Kruse et al. (2015); Amante et al. (2014) |
| Behaviour (norms for technology use and communication) | Thompson et al. (2016) |
| Implementation | Reference |
| Provider's training | Thompson et al. (2016); Otte-Trojel et al. (2016) |
| Patient/caregiver training | Otte-Trojel et al. (2016) |
| Providing access to Patient/caregiver (onsite kiosk) | Otte-Trojel et al. (2016) |
| Workflow engineering (involving providers) | Otte-Trojel et al. (2016) |
| Trial period and demonstrations | Otte-Trojel et al. (2016); Bush et al. (2015) |
| Service Quality | Reference |
| Response time from provider | Thompson et al. (2016); Amante et al. (2014) |
| Level of support for patients using system (staffing levels) | Thompson et al. (2016); Kruse et al. (2015) |
| Level of provider encouragement, promotion, engagement or support to use system (industry influence) | Thompson et al. (2016); Amante et al. (2014); Otte-Trojel et al. (2016) |
| Patient's trust and satisfaction with provider (high and low satisfaction led to use) | Amante et al. (2014); Otte-Trojel et al. (2016) |
| Provider Skills/Computer Literacy | Reference |
| Provider's skills and knowledge of understanding and using system | Thompson et al. (2016); Otte-Trojel et al. (2016) |
| Provider Awareness/Access | Reference |
| Provider's level of awareness of system and functions | Thompson et al. (2016) |
| Provider's patients level of access/availability of usable technology | Thompson et al. (2016) |

Technology Factors

| | |
|--|---|
| System Quality | Reference |
| Usability (access, task demands, complexity, difficulty & response time) | Thompson et al. (2016); Bush et al. (2015); Amante et al. (2014); Kruse et al. (2015) |
| Functions and features (missing functionality) | Thompson et al. (2016); Bush et al. (2015); Amante et al. (2014) |
| Level of security(encryption firewalls)/confidentiality (robust authentication) | Thompson et al. (2016); Otte-Trojel et al. (2016); Kruse et al. (2015) |
| Patient centered design/personalization | Otte-Trojel et al. (2016) |
| Interoperability (tethered vs standalone) | Price et al. (2015); Thompson et al. (2016); Otte-Trojel et al. (2016) |
| Notifications (to counter liability and assist with signaling urgency) | Otte-Trojel et al. (2016) |
| Information Quality | Reference |
| Complexity of data/terminology | Thompson et al. (2016); Bush et al. (2015); Kruse et al. (2015) |
| Data integrity (accuracy and completeness of data, use of provider and patient electronic signatures) | Thompson et al. (2016); Otte-Trojel et al. (2016); Amante et al. (2014) |

| | |
|---|--|
| Personalized information | Giardina et al. (2014) |
| Data transparency (what data should be included - for the expert or lay people?) | Otte-Trojel et al. (2016) |
| Fit to Patient/Caregiver | Reference |
| Fit to everyday routines and time constraints (time and sequence demands, not enough time to use system) | Thompson et al. (2016); Bush et al. (2015); Amante et al. (2014) |
| Fit to Workflow | Reference |
| Fit to Workflow (time and sequence demands - time taken to complete related work, access information and to use and learn the system) | Thompson et al. (2016) |

Use/User Satisfaction

| | |
|--|--|
| User/User Satisfaction | Reference |
| Response time from provider not meeting expectations | Thompson et al. (2016); Amante et al. (2014) |
| Low use | Bush et al. (2015) |
| Usability/usefulness (mixed) | Kruse et al. (2015); Giardina et al. (2014) |

Outcomes

| | |
|---|---|
| Quality | Reference |
| Enhanced trust | Mold et al. (2015) |
| Strengthened relationships | Mold et al. (2015) |
| Patient satisfaction (with care) | Mold et al. (2015); Kruse et al. (2015); Kruse et al. (2015a); Price et al. (2015); Giardina et al. (2014) |
| Provider satisfaction (with care) | Kruse et al., (2015) |
| Improved communication (patient-provider) | Mold et al. (2015); Bush et al. (2015); Kruse et al. (2015); Kruse et al., (2015a); Price et al. (2015); Ammenwerth et al. (2012) |
| Improved patient safety | Mold et al. (2015) |
| Improvements on disease/health outcomes (mixed) | Kruse et al. (2015); Kruse et al, (2015a); Giardina et al, (2014); Goldzweig et al. (2013) |
| Accuracy of the medical record (no Significant differences) | Giardina et al. (2014); Bush et al. (2015) |
| Knowledge | Reference |
| Improved decision making | Mold et al. (2015) |
| Improved understanding of condition | Bush et al. (2015); Giardina et al. (2014) |
| Recall of medical information (mixed) | Giardina et al. (2014) |
| Productivity | Reference |
| Saved patients time, decreased telephone calls, and clinic visits (mixed results) | Mold et al. (2015); Giardina et al. (2014); Ammenwerth et al. (2012) |
| Decreased no shows | Kruse et al. (2015a) |
| Concerns re: increased workload only partly realized | Mold et al. (2015); Kruse et al. (2015a) |
| Improved continuity | Price et al. (2015) |
| More effective face-to-face visits | Price et al. (2015) |
| Behaviour | Reference |

| | |
|--|--|
| Improved self care and/or management and participation in care (adherence to medication) (mixed results) | Mold et al. (2015); Bush et al. (2015); Kruse et al. (2015); Kruse et al. (2015a); Price et al. (2015); Giardina et al. (2014); Ammenwerth et al. (2012) |
| Reduced anxiety/distress (or did not increase anxiety) | Bush et al. (2015); Price et al. (2015); Giardina et al. (2014) |
| Higher retention rate of patient loyalty | Kruse et al. (2015a) |
| Access | Reference |
| Improved access to preventative care | Mold et al. (2015) |
| Allowed patients to access system at own convenience | Kruse et al. (2015) |
| Improved access to information by patient | Price et al. (2015) |
| Improved access to information by provider | Price et al. (2015) |
| Improved access to health knowledge | Price et al. (2015) |

Appendix 10: Overlap of Primary Studies Included in Reviews

| Primary Study | Year | Title | Thompson et al. (2016) | Otte-Trojel et al. (2016) | Bush et al. (2015) | Kruse et al. (2015) | Kruse et al. (2015a) | Mold et al. (2015) | Price et al. (2015) | Amante et al. (2014) | Giardina et al. (2014) | Goldzweig et al. (2013) | Ammenwerth et al. (2012) | Total |
|----------------------|------|--|------------------------|---------------------------|--------------------|---------------------|----------------------|--------------------|---------------------|----------------------|------------------------|-------------------------|--------------------------|-------|
| deSchmidt and Nguyen | 2013 | Parent intention to use a patient portal as related to their children following a facilitated demonstration | | | x | | | | | | | | | 1 |
| Ammenwerth et al | 2012 | The impact of electronic patient portals on patient care: a systematic review of controlled trials | | | | x | | | | | | | | 1 |
| Ancker et al | 2011 | Use of an electronic patient portal among disadvantaged populations | x | | | | | | | | | | | 1 |
| Banet and Felchla | 1997 | The potential utility of a shared medical record in a "first-time" stroke population | | | | | | | | | x | | | 1 |
| Beaudoin et al | 2005 | Enhancing access to patient education information: a pilot usability study | | | | x | | | | | | | | 1 |
| Bergman et al | 2008 | Teen use of a patient portal: a qualitative study of parent and teen attitudes | | | x | | | | | | | | | 1 |
| Bergmo and Wangberg | 2007 | Patients' willingness to pay for electronic communication with their general practitioner | | | | | | x | | | | | | 1 |
| Bergmo et al | 2005 | Electronic patient-provider communication: will it offset office visits and telephone consultations in primary care? | | | | | | x | | | | | | 1 |

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|------------------|------|--|---|--|---|---|--|--|---|---|--|--|---|--|---|
| Boland et al | 2014 | Automated telecommunication-based reminders and adherence with once-daily glaucoma medication dosing: the automated dosing reminder study. | | | | | | | x | | | | | | 1 |
| Bredfeldt et al | 2011 | Effects of between visit physician-patient communication on Diabetes Recognition Program scores | | | | | | | | x | | | | | 1 |
| Britto et al | 2009 | Usability testing finds problems for novice users of pediatric portals | | | x | x | | | | | | | | | 2 |
| Britto et al | 2013 | Parents' perceptions of a patient portal for managing their child's chronic illness | x | | x | x | | | | | | | | | 3 |
| Burke et al | 2010 | Transforming patient and family access to medical information: Utilization patterns of a patient-accessible electronic health record | x | | | | | | | | | | x | | 2 |
| Byczkowski et al | 2011 | Variation in use of Internet-based patient portals by parents of children with chronic disease | | | x | x | | | | | | | | | 2 |
| Byczkowski et al | 2014 | Family perceptions of the usability and value of chronic disease web-based patient portals | x | | x | x | | | | | | | | | 3 |
| Chiche et al | 2012 | Evaluation of a prototype electronic personal health record for patients with idiopathic thrombocytopenic purpura | | | | | | | x | | | | | | 1 |
| Cho et al | 2010 | Do diabetic veterans use the Internet? Self-reported usage, skills, and interest in using My HealtheVet Web portal | | | | | | | | x | | | x | | 2 |

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|----------------|------|--|---|--|--|---|---|--|--|---|---|---|---|--|--|---|
| Hassol et al | 2004 | Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging. | | | | | | | | | | | x | | | 1 |
| Haun et al | 2014 | Evaluating user experiences of the secure messaging tool on the Veterans Affairs' patient portal system | | | | x | x | | | | | | | | | 2 |
| Hess et al | 2007 | Exploring challenges and potentials of personal health records in diabetes self-management: implementation and initial assessment. | x | | | | | | | | x | | x | | | 3 |
| Hess et al | 2014 | Patterns of response to patient-centered decision support through a personal health record | | | | | | | | x | | | | | | 1 |
| Hogan et al | 2014 | Technology-assisted patient access to clinical information: an evaluation framework for blue button | | | | x | x | | | | | | | | | 2 |
| Homer et al | 1999 | The introduction of a woman-held record into a hospital antenatal clinic: the bring your own records study | | | | | | | | | | | x | | | 1 |
| Horvath et al | 2011 | Impact of health portal enrollment with email reminders on adherence to clinic appointments: a pilot study. | | | | x | x | | | | | | | | | 2 |
| Jethwani et al | 2012 | Diabetes connect: an evaluation of patient adoption and engagement in a web-based remote glucose monitoring program | | | | | | | | | x | | | | | 1 |
| Jones et al | 1999 | Randomised trial of personalised computer based information for cancer patients. | | | | | | | | | | x | | | | 1 |
| Jung et al | 2011 | Who are portal users vs. early E-Visit adopters? A preliminary analysis | x | | | | | | | | | | x | | | 2 |

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|----------------|-------|--|---|--|--|---|---|--|---|---|---|---|--|--|---|
| Lam et al | 2013 | Older adult consumers' attitudes and preferences on electronic patient-physician messaging | | | | | x | | | | | | | | 1 |
| Lau et al | 2014 | Impact of patient use of an online patient portal on diabetes outcomes | | | | x | | | | x | | | | | 2 |
| Lau et al | 2013a | Consumers' online social Network topologies and health behaviors | x | | | | | | | | | | | | 1 |
| Lau et al | 2013b | Social and self-reflective use of a web-based personally controlled health management system | x | | | | | | | | | | | | 1 |
| Lau et al | 2013c | Which bundles of features in a web-based personally controlled health management system are associated with consumer help-seeking behaviors for physical and emotional well-being? | x | | | | | | | | | | | | 1 |
| Leveille et al | 2009 | Health coaching via an internet portal for primary care patients with chronic conditions: a randomized controlled trial | | | | | x | | | | | | | | 1 |
| Liaw et al | 1998 | The impact of a computer generated patient held health record | | | | | | | | | x | | | | 1 |
| Liaw et al | 1996 | The effect of a computer-generated patient-held medical record summary and/or a written personal health record on patients' attitudes, knowledge and behaviour concerning health promotion | | | | | | | | | x | | | | 1 |
| Lin et al | 2005 | An Internet-based patient-provider communication system: randomized controlled trial | x | | | | | | x | | | x | | | 3 |

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|----------------|------|---|---|--|--|---|---|--|---|---|---|---|--|--|---|
| Liss et al | 2014 | Changes in office visit use associated with electronic messaging and telephone encounters among patients with diabetes in the PCMH | | | | | x | | | | | | | | 1 |
| Lober et al | 2006 | An internet-based patient-provider communication system: Randomized controlled trial | x | | | | | | | | | | | | 1 |
| Lovell et al | 1987 | Tomas's Hospital maternity case notes study: a randomised controlled trial to assess the effects of giving expectant mothers their own maternity case notes | | | | | | | | | x | | | | 1 |
| Luzio et al | 2007 | Results of the pilot study of DIADEM: a comprehensive disease management programme for type 2 diabetes | | | | x | | | | | | | | | 1 |
| Lyles et al | 2013 | Patient-provider communication and trust in relation to use of an online patient portal among diabetes patients: The Diabetes and Aging Study | | | | x | x | | | x | | | | | 3 |
| Lyles et al | 2012 | Patient race/ethnicity and shared medical record use among diabetes patients | | | | | | | | x | | x | | | 2 |
| Maly et al | 1999 | A randomized controlled trial of facilitating information giving to patients with chronic medical conditions: effects on outcomes of care. | | | | | | | | | x | | | | 1 |
| Matheny et al | 2007 | Impact of an automated test results management system on patients' satisfaction about test result communication | | | | | | | x | | | | | | 1 |
| Mayberry et al | 2011 | Bridging the digital divide in diabetes: family support and implications for health literacy | x | | | | | | | | x | | | | 2 |

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|-----------------|------|--|---|--|--|--|---|---|---|--|---|---|--|--|---|
| McCarrier et al | 2009 | Web-based collaborative care for type 1 diabetes: a pilot randomized trial. | | | | | | | | | x | x | | | 2 |
| McInnes et al | 2013 | Personal health record use and its association with antiretroviral adherence: survey and medical record data from 1871 US veterans infected with HIV | | | | | | | x | | | x | | | 2 |
| McInnes et al | 2013 | Development and evaluation of an internet and personal health record training program for low-income patients with HIV or hepatitis C | x | | | | | | | | | | | | 1 |
| Miller et al | 2011 | Web-based self-management for patients with multiple sclerosis: a practical, randomized trial | | | | | | | x | | | | | | 1 |
| Miller et al | 2007 | Determinants of personal health record use | x | | | | | | | | | | | | 1 |
| Nagykaldi et al | 2012 | Impact of a Wellness Portal on the delivery of patient-centered preventive care. | x | | | | | x | | | | | | | 2 |
| Nazi | 2010 | Veterans' voices: use of the American Customer Satisfaction Index (ACSI) Survey to identify My HealtheVet personal health record users' characteristics, needs, and preference | x | | | | | | | | | | | | 1 |
| Nazi | 2013 | The personal health record paradox: Healthcare professionals' perspectives and the information ecology of personal health record systems in organizational and clinical settings | x | | | | | | | | | | | | 1 |
| Nazi et al | 2013 | Evaluating patient access to electronic health records results from a survey of veterans | x | | | | x | | | | | | | | 2 |

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|------------------------|------|--|---|--|--|---|---|---|--|---|---|---|--|--|---|
| Neuner et al | 2014 | Meaningful Use and the Patient Portal: Patient Enrollment, Use, and Satisfaction With Patient Portals at a Later-Adopting Center | | | | | x | | | | | | | | 1 |
| Nielsen et al | 2012 | Internet portal use in an academic multiple sclerosis center | x | | | | | | | | | | | | 1 |
| Nijland et al | 2011 | Factors influencing the use of a Web-based application for supporting the self-care of patients with type 2 diabetes: a longitudinal study | | | | x | x | | | | | | | | 2 |
| North et al | 2011 | Patient portal doldrums: does an exam room promotional video during an office visit increase patient portal registrations and portal use? | | | | | | x | | | | | | | 1 |
| North et al | 2013 | Patient-generated secure messages and eVisits on a patient portal: are patients at risk? | | | | x | | | | | | | | | 1 |
| f National Coordinator | 2014 | What is a patient portal? | | | | x | | | | | | | | | 1 |
| Or et al | 2014 | Does the use of consumer health information technology improve outcomes in the patient self-management of diabetes? A meta-analysis and narrative review of randomized controlled trials | | | | x | | | | | | | | | 1 |
| Orsborn et al | 2010 | Patient web portals to improve diabetes outcomes: a systematic review | | | | x | | | | | | | | | 1 |
| Osborn et al. | 2013 | Understanding patient portal use: implications for medication management | x | | | x | x | | | x | | | | | 4 |
| Palen et al | 2012 | Association of online patient access to clinicians and medical records with use of clinical services | | | | | x | x | | | x | x | | | 4 |

| | | | | | | | | | | | | | | | |
|-------------------|------|---|---|--|--|---|---|---|---|---|---|---|---|--|---|
| Sarker et al | 2010 | The literacy divide: health literacy and the use of an internet-based patient portal in an integrated health system—results from the Diabetes Study of Northern California (DISTANCE) | x | | | x | | | | x | | x | | | 4 |
| Sarker et al | 2011 | Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. | x | | | | | | | x | | | | | 2 |
| Sarker et al. | 2014 | Use of the refill function through an online patient portal is associated with improved adherence to statins in an integrated health system | | | | | | | x | | | | | | 1 |
| Saunders et al | 2003 | Does receiving a copy of correspondence improve patients' satisfaction with their out-patient consultation? | | | | | | | | | x | | | | 1 |
| Schnipper et al | 2012 | Effects of an online personal health record on medication accuracy and safety: a cluster randomized trial | | | | | | x | | | | | x | | 2 |
| Schnipper et al | 2008 | Design and implementation of a web-based patient portal linked to an electronic health record designed to improve medication safety: the Patient Gateway medications module | x | | | | | | | | | | x | | 2 |
| Schprechman et al | 2013 | Health Literacy and Global Cognitive Function Predict E-Mail but Not Internet Use in Heart Failure Patients. | | | | | x | | | | | | | | 1 |

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|--------------------|------|--|---|--|---|---|---|--|---|---|---|---|---|--|---|
| Tang et al | 2013 | Online disease management of diabetes: engaging and motivating patients online with enhanced resources-diabetes (EMPOWER-D), a randomized controlled trial | | | | | | | | | | x | | | 1 |
| Tenforde et al | 2012 | The association between personal health record use and diabetes quality measures | x | | | | | | x | x | x | x | | | 5 |
| Tjora et al | 2005 | Privacy vs. usability: A qualitative exploration of patients' experiences with secure internet communication with their general practitioner | x | | | | | | | | | | | | 1 |
| Tom et al | 2012 | Integrated personal health record use: association with parent-reported care experiences | x | | x | | | | | | | x | | | 3 |
| Tsai and Rosenheck | 2012 | Use of the internet and an online personal health record system by US veterans: comparison of Veterans Affairs mental health service users and other veterans nationally | x | | | | | | | | | x | | | 2 |
| Tuil et al | 2007 | Empowering patients undergoing in vitro fertilization by providing Internet access to medical data | | | | | | | | | x | x | x | | 3 |
| Tuli et al | 2006 | Patient-centered care: using online personal medical records in IVF practice | x | | | | | | | | | | | | 1 |
| Turvey et al | 2014 | Blue Button use by patients to access and share health record information using the Department of Veterans Affairs' online patient portal | | | | | x | | | | | | | | 1 |
| Urowitz et al | 2012 | Improving diabetes management with a patient portal: a qualitative study of diabetes self-management portal | x | | | x | x | | x | | | | | | 4 |

| | | | | | | | | | | | | | | | |
|----------------|------|--|---|--|--|--|--|--|---|---|---|---|--|--|---|
| Wald et al | 2010 | Implementing practice-linked pre-visit electronic journals in primary care: patient and physician use and satisfaction | x | | | | | | x | | | x | | | 3 |
| Wald et al | 2010 | Variations in patient portal adoption in four primary care practices. | | | | | | | | | | x | | | 1 |
| Wald et al | 2009 | Survey analysis of patient experience using a practice-linked PHR for type 2 diabetes mellitus | x | | | | | | x | | | x | | | 3 |
| Wang et al | 2004 | Personal health information management system and its application in referral management | x | | | | | | | | | | | | 1 |
| Weingart et al | 2006 | Who uses the patient internet portal? The PatientSite experience | x | | | | | | | | | | | | 1 |
| Weitzman et al | 2012 | Willingness to share personal health record data for care improvement and public health: a survey of experienced personal health record users | x | | | | | | | | | | | | 1 |
| Wen et al | 2010 | Consumers' perceptions about and use of the internet for personal health records and health information exchange: Analysis of the 2007 Health Information National Trends Survey | x | | | | | | | | | | | | 1 |
| Weppner et al | 2010 | Use of a shared medical record with secure messaging by older patients with diabetes | | | | | | | | x | | x | | | 2 |
| Wiljer et al | 2010 | The anxious wait: assessing the impact of patient accessible EHRs for breast cancer patients | x | | | | | | x | | x | x | | | 4 |

1. Was an 'a priori' design provided?

If it satisfies 3 of the criteria →4

If it satisfies 2 of the criteria →3

If it satisfies 1 of the criteria →2

If it satisfies 0 of the criteria →1

Criteria:

| |
|---|
| (A) 'a priori' design |
| (B) statement of inclusion criteria |
| (C) PICO/PIPO research question (population, intervention, comparison, prediction, outcome) |

2. Was there duplicate study selection and data extraction?

If it satisfies 3 of the criteria →4

If it satisfies 2 of the criteria →3

If it satisfies 1 of the criteria →2

If it satisfies 0 of the criteria →1

Criteria:

| |
|--|
| (A) There should be <u>at least two</u> independent data extractors as stated or implied. |
| (B) Statement of recognition or awareness of <u>consensus procedure</u> for disagreements. |
| (C) Disagreements among extractors resolved properly as stated or implied |

3. Was a comprehensive literature search performed?

If it satisfies 4 or 5 of the criteria → 4

If it satisfies 3 of the criteria → 3

If it satisfies 2 of the criteria → 2

If it satisfies 1 or 0 of the criteria → 1

Criteria:

| |
|--|
| (A) At least two electronic sources should be searched. |
| (B) The report must include years and databases used (e.g. Central, EMBASE, and MEDLINE). |
| (C) Key words and/or MESH terms must be stated AND where feasible the search strategy outline should be provided such that one can trace the filtering process of the included articles. |
| (D) In addition to the electronic databases (PubMed, EMBASE, Medline), all searches should be supplemented by consulting current contents, reviews, textbooks, specialized registers, or experts in the particular field of study, and by reviewing the references in the studies found. |
| (E) Journals were "hand-searched" or "manual searched" (i.e. identifying highly relevant journals and conducting a manual, page-by-page search of their entire contents looking for potentially eligible studies) |

4. Was the status of publication (i.e. grey literature) used as an inclusion criterion?

(Grey literature is literature produced at all levels of government, academia, business and industry in print and electronic formats, but is not controlled by commercial publishers. Examples can be but not limited to dissertations, conference proceedings.)

Here is an extra description of what grey literature is.

If it satisfies 3 of the criteria → 4

If it satisfies 2 of the criteria → 3

If it satisfies 1 of the criteria → 2

If it satisfies 0 of the criteria → 1

Criteria:

| |
|--|
| (A) The authors should state that they searched for reports regardless of their publication type. |
| (B) The authors should state whether or not they excluded any reports (from the systematic review), based on their publication status, language etc. |
| (C) "Non-English papers were translated" or readers sufficiently trained in foreign language |
| (D) No language restriction or recognition of non-English articles |

5. Was a list of studies (included and excluded) provided?

If it satisfies 4 of the criteria →4

If it satisfies 3 of the criteria →3

If it satisfies 2 of the criteria →2

If it satisfies 1 or 0 of the criteria → 1

Criteria:

| |
|---|
| (A) Table/list/or figure of included studies, a reference list does not suffice. |
| (B) Table/list/figure of excluded studies ¹ either in the article or in a supplemental source (i.e. online). (Excluded studies refers to those studies seriously considered on the basis of title and/or abstract, but rejected after reading the body of the text) |
| (C) Author satisfactorily/sufficiently stated the reason for exclusion of the seriously considered studies. |
| (D) Reader is able to retrace the included and the excluded studies anywhere in the article bibliography, reference, or supplemental source |

6. Were the characteristics of the included studies provided?

If it satisfies 3 of the criteria →4

If it satisfies 2 of the criteria →3

If it satisfies 1 of the criteria →2

If it satisfies 0 criteria → 1

Criteria:

| |
|--|
| (A) In an aggregated form such as a table, data from the original studies should be provided on the participants, interventions AND outcomes. |
| (B) Provide the ranges of relevant characteristics in the studies analyzed (e.g. age, race, sex, relevant socioeconomic data, disease status, duration, severity, or other diseases should be reported.) |
| (C) The information provided appears to be complete and accurate (i.e. there is a tolerable range of subjectivity here. Is the reader left wondering? If so, state the needed information and the reasoning). |

7. Was the scientific quality of the included studies assessed and documented?

If it satisfies 4 of the criteria →4

If it satisfies 3 of the criteria →3

If it satisfies 2 of the criteria →2

If it satisfies 1 or 0 of the criteria → 1

Criteria:

| |
|--|
| (A) 'A priori' methods of assessment should be provided (e.g., for effectiveness studies if the author(s) chose to include only randomized, double-blind, placebo controlled studies, or allocation concealment as inclusion criteria); for other types of studies alternative items will be relevant. |
| (B) The scientific quality of the included studies <u>appears to be meaningful</u> . |
| (C) Discussion/recognition/awareness of level of evidence |
| (D) Quality of evidence should be rated/ranked based on characterized instruments. (Characterized instrument is a created instrument that ranks the level of evidence, e.g. GRADE[Grading of Recommendations Assessment, Development and Evaluation.] |

8. Was the scientific quality of the included studies used appropriately in formulating conclusions?

If it satisfies 4 of the criteria →4

If it satisfies 3 of the criteria →3

If it satisfies 2 of the criteria →2

If it satisfies 1 or 0 of the criteria → 1

Criteria:

| |
|---|
| (A) The results of the methodological rigor and scientific quality should be considered in the analysis and the conclusions of the review |
| (B) The results of the methodological rigor and scientific quality are <u>explicitly stated</u> in formulating recommendations. |
| (C) To have conclusions integrated/drives towards a clinical consensus statement |
| (D) This clinical consensus statement drives toward revision or confirmation of clinical practice guidelines |

9. Were the methods used to combine the findings of studies appropriate?

If it satisfy 4 of the criteria → 4

If it satisfy 3 of the criteria → 3

If it satisfy 2 of the criteria → 2

If it satisfy 1 or 0 of the following criteria → 1

Criteria:

| |
|--|
| (A) Statement of criteria that were used to decide that the studies analyzed were similar enough to be pooled? |
| (B) For the pooled results, a test should be done to ensure the studies were combinable, to assess their homogeneity (i.e. Chi-squared test for homogeneity, I ²). |
| (C) Is there a recognition of heterogeneity or lack of thereof |
| (D) If heterogeneity exists a “random effects model” should be used and/or the rationale (i.e. clinical appropriateness) of combining should be taken into consideration (i.e. is it sensible to combine?), or stated explicitly |
| (E) If homogeneity exists, author should state a rationale or a statistical test |

10. Was the likelihood of publication bias (a.k.a. “file drawer” effect) assessed?

If it satisfies 3 of the criteria →4

If it satisfies 2 of the criteria →3

If it satisfies 1 of the criteria →2

If it satisfies 0 of the criteria →1

Criteria:

| |
|--|
| (A) Recognition of publication bias or file-drawer effect |
| (B) An assessment of publication bias should include graphical aids (e.g., funnel plot, other available tests) |
| (C) Statistical tests (e.g., Egger regression test). |

11. Was the conflict of interest stated?

If it satisfies 3 of the criteria →4

If it satisfies 2 of the criteria →3

If it satisfies 1 of the criteria →2

If it satisfies 0 of the criteria →1

Criteria:

| |
|---|
| (A) Statement of sources of support |
| (B) No conflict of interest. This is subjective and may require some deduction or searching. |
| (C) An awareness/statement of support or conflict of interest in the <u>primary</u> inclusion studies |

[Appendix 12: Documentation of Research Approval from the University of Victoria's Research Ethics Board](#)

Dear Steve Denman,

Thank you for this information.

Given that there are no participants for this study, and data collection will only involve document review from publically available sources, research ethics approval is not required.

When we write these emails we also include the following caveats:

Please note that this decision does not release the researchers from any other applicable legal obligations, ethical oversight, or conforming to professional or occupational codes of ethics where applicable, such as obtaining data sharing agreements when necessary, etc.

Please note that this decision has been made without precedent and cannot be applied to other, seemingly similar, situations.

Please contact me if you have any questions or concerns.

Kind regards,

Kenna



Ethics going online:

<http://www.uvic.ca/research/conduct/home/forms/rais/index.php>

Kenna Miskelly, B.Sc., M.A.

Human Research Ethics Facilitator | Office of Research Services | University of Victoria | Room B233, Administrative Services Building

3800 Finnerty Road | PO Box 1700 STN CSC | Victoria, BC | V8W 2Y2 Canada

Phone (250) 472-5555 | Fax (250) 721-8960 | Email hre@uvic.ca

We are in the Administrative Services Building on Ring Road

<http://www.uvic.ca/buildings/ssb.html>

Our Website, forms, and guidelines are located on:

<http://www.uvic.ca/research/conduct/home/regapproval/humanethics/index.php>

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