Conditions potentially sensitive to a Personal Health Record (PHR) intervention, a systematic review

Morgan Price\textsuperscript{1,2,3*}, Paule Bellwood\textsuperscript{2}, Nicole Kitson\textsuperscript{2}, Iryna Davies\textsuperscript{1}, Jens Weber\textsuperscript{1,2,3} and Francis Lau\textsuperscript{2}

**Abstract**

**Background:** Personal Health Records (PHRs) are electronic health records controlled, shared, or maintained by patients to support patient centered care. The potential for PHRs to transform health care is significant; however, PHRs do not always achieve their potential. One reason for this may be that not all health conditions are sensitive to the PHR as an intervention. The goal of this review was 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.

**Methods:** A systematic review of Medline and CINAHL was completed to find articles assessing PHR use and benefit from 2008 to 2014 in specific health conditions. Two researchers independently screened and coded articles. Health conditions with evidence of benefit from PHR use were identified from the included studies.

**Results:** 23 papers were included. Seven papers were RCTs. Ten health conditions were identified, seven of which had documented benefit associated with PHR use: asthma, diabetes, fertility, glaucoma, HIV, hyperlipidemia, and hypertension. Reported benefits were seen in terms of care quality, access, and productivity, although many benefits were measured by self-report through quasi-experimental studies. No study examined morbidity/mortality. No study reported harm from the PHR.

**Conclusion:** 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.

**Keywords:** Personal health records, Patient portals, Self-management, Systematic review, Chronic disease management

**Background**

**Personal health records**

Personal Health Records (PHRs) are electronic health records controlled, shared, or maintained by patients to support patient centered care [1]. While PHRs have variable designs and features, they share a similar goal of improving patient engagement in their care. PHR enabled management can include both self-management and communication with members of the patients’ circles of care. PHRs can be standalone or tethered to another clinical information system such as a hospital information system or part of a regional electronic health record. PHR features can range from administrative (e.g. booking appointments and paying bills) to more clinical features (e.g. reviewing information, communicating with the care team, documenting care activities/results/outcomes). The potential for PHRs to reduce care costs and increase access to care is significant and it has been suggested that PHRs will help enable and empower patients [2,3]. However, despite millions of dollars spent on PHRs, the published evidence and research on PHRs is relatively limited [4,5], and, compared to the promises, adoption rates continue to be lower than hoped [6].
The evidence for benefit of PHRs is mixed [7]. There has been early positive evidence as well as dramatic challenges in adoption of PHRs [8]. Potential benefits of PHRs include improvement in: quality, access, and costs [9]. Stakeholders (e.g. patients, providers, payers) will experience benefits differently [10]. Several reviews have looked at aspects of PHRs and PHR features such as: benefit of secure messaging [11], medication adherence reminders [12], or symptom reporting [13]. Others examined effect on chronic diseases [7] or mental health [14]. The challenges to achieving PHR benefits include: poor adoption rates [6], poor integration into care processes [15], and policy limitations [16]. More work is needed to understand how PHRs can be meaningfully used [5] and how PHRs can support select patient populations with specific conditions.

The variable benefits seen with PHRs are due to a number of factors. The PHR Adoption Model describes four factors that can influence behavior which may lead to outcome changes: personal factors, technology factors, environmental factors, and chronic disease factors [6]. It highlights chronic disease factors as an important aspect of adoption of PHRs. That is, the nature of the chronic condition the patient has impacts adoption and value of the PHR.

For this paper we sought to discover which health conditions have been assessed for improvements in outcomes that correlate with PHR use. There has been a recent review of PHRs and chronic disease [5] but there has not been a review to examine which conditions have evidence of benefit from PHR use. A condition is an aspect of a person’s health including a symptom, illness, diagnosis, or health goal. Benefits could be considered for the person, the care team (both formal and informal), or the overall healthcare system.

Objectives of this paper
The purpose of this paper is to add to our shared knowledge on PHRs by systematically reviewing the literature to develop an evidence-based list of conditions that have evidence of improvements that correlate with PHR use. We seek to answer the following questions:

1. What health conditions have evidence for benefits of PHR enabled self-management?
2. What are the common care activities related to these conditions that are supported through the use of PHR?
3. Can we use these characteristics to predict other potentially PHR sensitive conditions?

Methods
Evidence collection
Medline and CINAHL were searched for articles from 2008 to 2014. This focused findings on technically more modern PHRs (e.g. potential for mobile user experiences, more advanced web interactions). Search terms used: Personal Health Record or Patient Portal in the Title or Abstract. We limited our search to English language and abstract availability. Ethics was not required for this systematic review.

Study selection and inclusion/exclusion criteria
Inclusion criteria were:

1. Use of terms personal health record, patient-controlled electronic health record, or patient portal in the title or abstract; and
2. Conditions or self-care activities; and
3. Evidence of actual use of PHR in specific conditions
4. Use of PHR in outpatient environment
5. Only primary studies were included that assessed benefit of PHRs by patients for those chronic conditions.

As we were seeking to find empirical evidence of PHR use and benefit, we excluded studies that did not have patients using PHRs (e.g. surveys on intention to use) or studies that were based only on usability testing. Further studies that assessed training effectiveness, or studies that only measured PHR use without looking at impact were excluded. We excluded any opinion, commentary, reviews, or theoretical PHR papers. Papers that evaluated electronic health records without focusing on PHR were also excluded.

Article selection occurred in two passes. First, the Titles/Abstracts were screened; the full text papers were pulled for those that passed initial screening for full review. Both screening and full text review were completed independently by two of the authors.

Evidence synthesis
Two authors coded the included articles independently. The papers were graded using an extended evidence hierarchy based on Australia’s National Health and Medical Research Council (NHMRC) evidence hierarchy (Figure 1) [17]. Data was extracted from the papers including: type of PHR, patient population, health condition(s) examined, self-care activities, PHR features, and benefits observed (if any) as determined by the researcher. The codes were then compared. Consensus was reached on the coding for each characteristic. A third author was available for mediation if consensus could not be reached. The original authors, not the reviewers, determined benefits.

Results
Evidence of PHR benefit
Our search followed PRISMA guidelines (Figure 2) found 564 unique records, of which 23 met inclusion criteria.
and examined a specific health condition. Two papers [18,19] each examined three specific conditions and were included. Within the 23 studies, there were seven randomized control trials, the rest were quasi-experimental or observational studies. Most studies were small and/or of short duration with no prospective study lasting more than one year. The metrics examined varied between studies such that comparison was difficult. 12 studies looked at self-reported data alone, with six studies using at least one previously validated instrument. Nine of the included studies looked at condition specific indicators such as A1c, LDL, plasma HIV-1 RNA, and blood pressure. These were tracked through chart reviews or electronic record reporting tools. The included studies are summarized in Table 1.

Health conditions evaluated

Ten health conditions were found in the included studies (Table 1). Seven of these ten health conditions had at least one study reporting benefit from the use of a PHR: asthma, diabetes, fertility, glaucoma, HIV, hyperlipidemia, and hypertension. Diabetes was the most studied condition with eleven of twelve studies showing benefit. Three conditions had studies that met the criteria but did not show benefit of the PHR: cancer, idiopathic thrombocytopenic purpura (ITP), and multiple sclerosis.

PHR supported care activities and PHR characteristics

74% (17/23) studies used tethered PHRs, connected to regional electronic medical records/electronic health records. 76% (13/17) studies that used tethered PHRs reported benefit. In comparison, only 50% (3/6) studies that used standalone PHRs showed benefit.

Studies described a set of PHR supported care activities that included the following:

- Access Own Health Data – Using the PHR to access shared clinical records. This could include view only (e.g. lab results) or editing/annotating.
| Author                  | Conditions | Benefit | Level | # of patients | Study design and duration | Location | PHR type and features                                                                 | Evaluation methods                                                                 | Reported Benefits                      |
|-------------------------|------------|---------|-------|---------------|---------------------------|----------|--------------------------------------------------------------------------------------|----------------------------------------|----------------------------------------|
| Wiljer, 2010 [33]       | Cancer     | No      | IV    | 320 consented, 114 completed study | 6 weeks | Canada | Tethered PHR with access to personal health data (labs and diagnostic imaging), access to support groups and a virtual librarian. | State-Trait Anxiety Inventory; Stanford Self-Efficacy for Managing Chronic Disease | No change                             |
| Wade-Vuturo, 2013 [34] | Diabetes   | Yes     | IV    | 54 patients | Crossover-sectional: PHR use >1 year in 43 patients | USA      | Tethered Portal with secure messaging, access to medical records | Patient Self-Report; Chart review to assess glycemic control (A1c). | Improved Patient Satisfaction with Care; Improved Disease Control; More effective face-to-face visits; Better Pt-Provider Communication | |
| Urowitz, 2012 [21]     | Diabetes   | Yes     | IV    | 17 patients | Crossover-sectional, at least 6 months of access to PHR | Canada   | Standalone PHR with ability to record personal health information and see trends, can also look up health information references. | Patient Self-Report                   | Improved Access to own information; Improved access to pt information by provider; Improved ability to self manage; More Activated Patient |
| Tenforde, 2011 [35]    | Diabetes   | Yes     | IV    | 10,746 adult patients | Retrospective audit over 12 months | USA      | Tethered PHR with secure messaging and access to health record data, reminders for follow up and health information | Chart review for diabetes indicators (A1c, LDL-C, BP, BMI). | Improved Disease Control               |
| Wald, 2010 [36]        | Diabetes   | Yes     | II    | 2027 patients | Prompt 3 weeks prior to encounter. | USA      | Tethered PHR with secure messaging, access to health record data, Journal, and health information. | Patient and Provider Self Report       | Improved Patient Satisfaction with Care; Improved access to pt information by provider |
Table 1 Summary of included primary PHR studies that measured benefit from use of PHR by patients *(Continued)*

| Study | Condition | Intervention | Sample | Study design | Setting | PHR characteristics | Benefit | Additional details |
|-------|-----------|--------------|--------|--------------|---------|---------------------|---------|---------------------|
| Hess, 2014 [37] | Diabetes (able to extract from paper) | Yes | IV | 504 patients | Pre post, one year | USA | Tethered PHR with reminders for preventive care | Improved Disease Control | Patient documentation of care received |
| Fonda, 2009 [38] | Diabetes | Yes | II | 104 patients | RCT, 52 weeks | USA | Tethered PHR with secure messaging, access to personal health data, educational materials. | Decreased Patient Distress | Problem Areas in Diabetes (PAID) validated survey |
| Lau, 2014 [39] | Diabetes | Yes | III-3 | 50 users and 107 non-users | 6-24 months | Canada | Standalone PHR with health information, journaling, entering health data, secure messaging with providers | Improved Disease Control | Chart review to monitor A1c control |
| Sarkar, 2014 [40] | Diabetes | Yes | III-3 | 8705 users with 9055 matched reference group | Observational cohort study, 1 year | USA | Tethered PHR with access to record, secure messaging, renewal requests, and online scheduling. | Improved Disease Control | Measured renewal rates for statins over 1 year based on chart data |
| Wald, 2009 [41] | Diabetes | Yes | IV | 37 patients | 2 week follow up, patients were already using the general PHR as part of inclusion. | USA | Tethered PHR with secure messaging, access to personal health data, decision support, ability to annotate their health record, care plan. | Improved access to pt information by provider | Self Report |
| Grant, 2008 [20] | Diabetes | No | II | 244 patients | RCT, use of PHR 52 weeks | USA | Tethered PHR with access to personal health data, decision support, care plans | No change | DM indicators: BP control, A1c, LDL-C # of primary care visits. |
| van Empel, 2011 [42] | Fertility | Yes | IV | 369 couples | Cross sectional survey | Netherlands | Tethered PHR with secure messaging, access to personal health data, social support/forums. | Improved Continuity | Patient Self-Report, Partner Self-Report |
| Boland, 2014 [43] | Glaucoma | Yes | II | 38 intervention; 32 control | RCT, 3 months | USA | PHR that could record patient information and medications; daily reminders by text/phone to intervention group to take medication | Improved access to health knowledge | Adherence monitoring with medication smart cap, patient surveys. |
| Crouch, 2014 [44] | HIV | Yes | III-3 | Cross sectional | USA | PHR that could record patient information and medications; daily reminders by text/phone to intervention group to take medication | Improved medication management | | |
| Study, Year | Condition | HIV Status | Study Design | Sample Size (Users) | Sample Description | Measurements | Country | PHR Access | PHR Features | Patient Activation Measure | PhD Intervention | Findings |
|-------------|-----------|------------|--------------|--------------------|-------------------|--------------|---------|------------|-------------|--------------------------|----------------|----------|
| Gordon, 2012 [45] | HIV | No | IV | 40 (20 users, 20 non-users) | Tethered PHR with access to labs, notes, secure communication and medication renewal. | Patient Activation Measure | USA | Tethered PHR with access to labs, notes, secure communication and medication renewal. | Patient Self-Report | Improved Disease Control |
| Kahn, 2010 [46] | HIV | Yes | IV | 112 active users | Tethered PHR viewer with access to personal health data. | Patient Self-Report | USA | Tethered PHR with access to personal health data, ability to record own health data, access health information | Chart review, survey data from Veterans Aging Cohort Study | Improved ability to self manage |
| McInnes, 2013 [47] | HIV | Yes | IV | 221 users registered | Tethered PHR with access to personal health data, request medication renewal, reminders for preventive care, scheduling appointments, secure messaging. | Chart review | USA | Tethered PHR with access to personal health data, request medication renewal, reminders for preventive care, scheduling appointments, secure messaging. | Improved ability to self manage |
| Shade, 2014 [48] | HIV | Yes | IV | Unclear at site using PHR | Standalone PHR with continuity of care patient summaries including HIV results; secure provider communication. | Chart review | USA | Standalone PHR with continuity of care patient summaries including HIV results; secure provider communication. | Chart review | Improved ability to self manage |
| Wagner, 2012 [49] | Hypertension | No | II | 453 users | Tethered PHR with secure messaging, access to personal health data, track personal health data, access to health information, care plan goal setting. | Patient Self-Report, Chart review for blood pressure | USA | Tethered PHR with secure messaging, access to personal health data, track personal health data, access to health information, care plan goal setting. | No change |
| Chiche, 2012 [50] | Idiopathic thrombocytopenic purpura (ITP) | No | III-2 | 43 patients | Standalone PHR with ability to record personal health data | ITP patient assessment questionnaire | France | Standalone PHR with ability to record personal health data | No change |
| Miller, 2011 [51] | Multiple Sclerosis | No | II | 204 patients recruited | Standalone PHR with ability to record personal health data and receive decision support (through MS Quality of Life Inventory) | Sickness Impact Profile, MS Functional Composite, Control Subscale of the MS Self-Efficacy Scale | USA | Standalone PHR with ability to record personal health data and receive decision support (through MS Quality of Life Inventory) | No change |
Table 1 Summary of included primary PHR studies that measured benefit from use of PHR by patients (Continued)

| Study                | Condition(s)          | Intervention                          | Setting               | Outcomes                                           |
|----------------------|-----------------------|---------------------------------------|-----------------------|----------------------------------------------------|
| Solomon, 2012 [18]   | Asthma, Hypertension, Diabetes | Tethered PHR with secure messaging and targeted health education weekly training modules. | USA                   | Euro-Quality of Life 5 Patient Activation Measure 13 (PAM-13) Improved ability to self manage |
| Sobko, 2011 [19]     | Diabetes, hypertension, lipids | Tethered PHR with access to health record, secure communication, decision support, medication renewal | USA                   | Chart review: medication possession rates; A1c, blood pressure, lipids Improved ability to self manage Improved Disease Control |
- Access Health Information – Using the PHR to access handouts, protocol information or other self-management information in a linked or embedded knowledge base.
- Record Personal Health Data – Using the PHR to record and track subjective experience data or objective data related to the condition over time.
- Receive Personal Decision Support – Using the PHR health data to drive evidence-based reminders and alerts to the user to support self-management.
- Plan Care – Using the PHR to proactively set personal goals, targets and tasks related to health and care. For example: set weight or blood glucose targets.
- Self-Manage Care – Using the PHR to make day-to-day decisions about care management, such as medication dosing, food choice.
- Communicate with Care Team – Using the PHR to engage with and support members of the circle of care. This can be virtual and/or face-to-face. This includes direct communication (e.g. secure messaging) or sharing of data in a shared repository.
- Communicate with Support Group – Using the PHR platform to securely engage in communication with informal members of the care team or members of a community for support. Using a secure forum to discuss health related issues.

Table 2 highlights the types of PHR features that were reported by the conditions in studies where benefits were reported. Most reported using PHRs that provided patients with access to general health information (5/6 conditions) and improved communication with their provider(s) (4/6 conditions). Access to personal health data and ability to record or annotate against that data were supported for 3/6 conditions.

No study described a PHR platform that included all eight features. Both positive and negative PHR studies described PHR platforms with various combinations of these features (see Table 1). It was not clear from many of the papers how these features were designed or implemented in the context of the healthcare system.

**Benefits and harm of PHR use**

70% of studies (16/23) reported benefits associated with PHR use. Of the 16 studies that reported benefit, six were based only on self-reported data (or provider or partner reported) and not on objective data or a validated reporting tool. Of the six studies that relied on non-validated self-report, 83% reported benefit (5/6). By contrast, only 50% (5/10) of studies that used validated/objective data reported benefit. 57% (4/7) of Randomized Control Trials (RCTs) reported benefits although one of the RCTs used self-report data only.

The studies looked at a range of metrics that covered several domains of benefit from disease specific measures to validated surveys to custom surveys. Disease specific outcomes included primarily indicators for diabetes (A1c, LDL, blood pressure, and Body Mass Index) and one for blood pressure in a hypertension study.

One diabetes RCT [20] measured number of primary visits and saw no change with the PHR. Ten validated survey instruments were used across the 23 studies. Five validated survey instruments used were not specific to the health condition being assessed: the Patient Activation Measure, the State-Trait Anxiety Inventory, the Stanford Self-Efficacy for Managing Chronic Disease, Seniors’ General Satisfaction, Physician Quality of Care, and the Euro-Quality of Life 5. Five tools were health condition specific: Problem Areas in Diabetes (PAID) Survey (Fonda), ITP patient assessment questionnaire, Sickness Impact Profile, MS Functional Composite, and the Control Subscale of the MS Self-Efficacy Scale. Several studies used non-validated tools to gather targeted self-report data from their participants. Custom surveys examined a range of concepts, including: assessing the PHR components, patient satisfaction, improvements in self-management, access to care, access to information, and sense of control.

The benefits are summarized in Table 3, based on the descriptions by the original authors. The counts exceed the number of studies as studies often assessed and reported on multiple benefits. Most commonly reported benefits included more activated patients, improved ability

**Table 2 Summary of reported PHR features by condition**

| PHR Feature                          | Asthma | Diabetes | Fertility | Glaucoma | HIV | Hypertension |
|--------------------------------------|--------|----------|-----------|----------|-----|--------------|
| Access Medical/Health Record         | X      |          |           |          |     |              |
| Access Health Information            |        | X        |           |          | X   |              |
| Record Personal Health Data          |        | X        |           |          | X   |              |
| Annotate Medical/Health Record       | X      |          |           |          |     |              |
| Receive Personal Decision Support    | X      |          |           |          |     |              |
| Develop/Manage Care plans            | X      |          |           |          |     |              |
| Communicate with Provider            | X      | X        |           |          | X   |              |
| Communicate with Support Group       |        |          |           |          |     | X            |

| Price et al. BMC Medical Informatics and Decision Making (2015) 15:32 Page 8 of 12 |
to self-manage, and improved communication with providers.

No study reported on harm from using the PHR. Providers in one study voiced concern that patients assumed the providers were monitoring the PHR constantly and patients may not report a change in health status as they may assume the provider is aware through the PHR [21].

Discussion

The intention of this systematic review was to discover from the literature a set of health conditions that were potentially “sensitive” to a PHR as a health intervention. That is, which conditions had empirical evidence that associated PHR use with improved health outcomes. While we found 70% of the 23 included studies reported benefit, the literature base is still small, with most of the PHR research focusing on intention to use, usability, and use characteristics. Most of the included studies in this review that focused on outcomes were quasi-experimental and focused on shorter-term or self-reported benefits. No study examined morbidity or mortality. Thus, there is a gap in high quality primary PHR research that focuses on longer-term outcome measures. This is somewhat expected, as electronic PHRs are still a relatively new and are rapidly changing. Research is needed to better understand the features of the PHRs and how they are used so that benefits are seen. Additional research is also needed to explore unintended consequences of PHR. None of the included studies assessed potential harms and, as we know from other literature, there can be unintended consequences when using health information systems. This is consistent with Health Information Systems research in general [22,23] and speaks to a greater need in health informatics research. PHRs are socio-technical systems that can change many aspects of care processes as well as care outcomes. Multi-methods research is needed to understand PHR impact and capture some of these unintended consequences. Larger studies are needed that assess sustained benefits of PHRs and impact on morbidity, mortality, and cost, and use multiple and mixed methods to better understand the impact of PHRs as health information systems [24].

Potentially PHR sensitive conditions

From this review, there is early evidence that highlights a small group of conditions that have evidence of benefit to using a PHR as a health intervention. These conditions include: diabetes, hypertension, asthma, HIV, fertility management, glaucoma, and hyperlipidemia. Benefits were seen in care quality, access, and/or productivity. These conditions share several common characteristics: Each of these conditions is chronic. They have a significant benefit from self-management through behavioural changes. Many have an aspect of monitoring, either from the clinician or the patient (self-monitoring). Self-management is present in all. The seven conditions were conditions where the self-management behaviours could be suitably tracked in a PHR and were tightly linked to the feedback of monitoring/self-monitoring of indicators (Figure 3). For example, self-monitoring blood pressure in hypertension or glucose levels in diabetes allowed for more specific and direct feedback to patients using a PHR.

Given the early state of the evidence for PHRs, it is not possible to exclude other conditions from this list and, indeed, many of the other conditions that have been evaluated but did not show benefit (e.g. Cancer) have several similar traits to the other conditions that have supporting evidence. It is expected that the PHR design, implementation of the PHR in the context of those patients or the design of the study had an impact on discovering benefits. That is, if the patient or the health condition was not as well supported by the particular

Table 3 Summary of reported benefits of PHR for each condition

| Reported Benefit                                | Asthma | Diabetes | Fertility | Glaucoma | HIV | Hypertension |
|-------------------------------------------------|--------|----------|-----------|----------|-----|--------------|
| Improved Patient Satisfaction with Care         | 2      |          |           |          |     |              |
| Improved Disease Control                        | 5      |          | 1         |          |     |              |
| Decreased Patient Distress                      | 1      |          |           |          |     |              |
| Improved Continuity                             | 1      | 1        | 1         |          |     |              |
| Improved medication management                  | 1      | 1        | 1         |          |     |              |
| Improved Access to own information              |       |          |           | 1        |     |              |
| Improved access to health knowledge             | 3      |          |           |          |     |              |
| Improved access to patient information by provider | 3      |          |           |          |     |              |
| More effective face-to-face visits              | 3      |          |           |          |     |              |
| Better Patient-Provider Communication           | 2      | 1        | 1         |          |     |              |
| Improved ability to self manage                 | 1      | 1        | 3         | 1        |     |              |
| More Activated Patient                          | 1      | 2        | 1         |          |     |              |

Cell numbers indicate number of studies that measured benefit in that area by health condition.
PHR or the implementation was different, benefits may not have been seen. Further, other health conditions could benefit from PHRs that have not been examined in studies included in this review. For example, obesity was not found in this this review but has significant prevalence [25,26] and results in elevated risk for specific conditions and morbidity [27,28]. Measurements such as body size measurements (e.g. waist size) and fat mass measurements can be used to monitor the impact of behavioural changes on obesity. It could benefit from PHR support. Indeed, there are several self-management applications that are providing tools for weight management such as: SapoFit [29] and over 200 smart phone apps [30].

**Contribution to knowledge**

This work expands on Logue’s PHR adoption model, providing additional information on the chronic disease factors that influence PHR adoption [6]. The PHR activities list (Table 2) can serve as a model that can be mapped back to the management of other chronic conditions to help in the design and use of PHRs in the future. PHRs today have a range of features/value propositions [10].

For PHR designers and implementers, this condition list can serve as optional target populations (Figure 3) and can be used when considering PHR features. Designers can consider specific feedback loops for health conditions and consider how specific PHRs support PHR enabled care activities such as accessing health information, communicating with providers, and accessing and recording personal health information. Implementers can use the same model when considering how to implement a PHR within a healthcare system.

**Study limitations**

Electronic PHRs are new and thus the evidence base is also new, with few studies and no large, long-term studies.

Also, PHRs are different and changing, and new features, such as mobile devices and various environmental and personal sensors, are rapidly evolving. These features may well change the value propositions of PHRs. This review may have missed some studies that were not found through its search strategy. For example, there have been PHR related papers published prior to 2008 that were not included. Earlier reviews suggested that PHRs were limited in functionality [31] and we chose to focus on newer studies that may examine more robust PHRs that leverage Internet and mobile technologies. Quality of studies was graded but papers were not excluded based on quality. The studies focused on different aspects of benefit, limiting between-study meta-analysis. Application of a common evaluation framework in future primary studies would help build a common knowledgebase related to PHRs. PHR features and usability of the PHR were not always clear from the published studies, but we know that this will effect the realization of benefits [32]. It is expected that the variability in PHR design of features changes value [10]. Much of this information was not available in the studies. Finally, as a review, the list of conditions is limited to what has been studied and included in the search.

**Conclusion**

While many factors can influence the impact of a PHR such as the PHR’s function and design, how it is implemented by the patient and by the healthcare system, we discovered some early evidence of benefit for seven health conditions: asthma, diabetes, fertility, glaucoma, HIV, hyperlipidemia, and hypertension. Each of these conditions are chronic in nature and tend to have clear feedback loops of behaviours resulting in changes in indicators that can be better self-monitored through the PHR. However, the current body of evidence for PHRs is small, with studies limited to assessing perceptions of benefit or early indicators. There is a need to continue research into how PHRs are designed, what features they have, how they are adopted as well as studies that assess PHR impact on health outcomes. Longer term and more robust studies are needed, and our current knowledge can guide future research to potentially PHR sensitive conditions.

**Competing interests**

The authors declare that they have no competing interests.

**Authors’ contributions**

MP was primary author of the paper, developing the initial idea, was a primary reviewer of the literature, and led the draft writing. He also acted as a mediator during the review and is the lead researcher on the overall Alberta Personal Health Portal evaluation. NK was one of the three primary reviewers of the literature, summarizing the data from the included papers. PB completed the primary reviewers of the literature, summarizing the data from the included papers. JW confirmed approach and provided editorial support on the internal drafts of the paper. FL was the senior author,
confirmed approach and provided editorial support on the internal drafts of the paper. FL is also the senior researcher on the overall PHP evaluation. All authors read and approved the final manuscript.

Acknowledgments
We would like to thank Alberta Health and the Personal Health Portal (PHP) program who supported our group in evaluating the design and implementation of the PHP and whose funding permitted the research analyst time to complete this review.

Funding
This work is funded, in part, through the Alberta Health’s Personal Health Portal program.

Author details
1Department of Family Practice, University of British Columbia, Vancouver, B.C., Canada. 2Health Information Science, University of Victoria, Victoria, B.C., Canada. 3Department of Computer Science, University of Victoria, Victoria, B.C., Canada.

Received: 24 October 2014 Accepted: 15 April 2015 Published online: 18 April 2015

References
1. Archer N, Fevrier-Thomas U, Lokker C, McKibbon KA, Straus SE. Personal health records: a scoping review. J Am Med Inform Assoc. 2011;18:515–22.
2. Agarwal G. Personal health records–an overview of the changing face of family practice. Fam Pract. 2013;30:363–4.
3. Ball MJ, Smith C, Bakalar RS. Personal health records: empowering consumers. J Healthc Inform Manag. 2007;21:76–86.
4. Kaelber DC, Jha AK, Johnston D, Middleton B, Bates DW. A research agenda for personal health records (PHRs). J Am Med Inform Assoc. 2008;15:229–36.
5. Tenforde M, Jain A, Hickner J. The value of personal health records for chronic disease management: what do we know? Fam Med. 2011;43:351.
6. Logue MD, Effken JA. Modeling factors that influence personal health records adoption. Comput Inform Nurs. 2012;30(7):354–62.
7. Ko H, Turner T, Jones C, Hill C. Patient-held medical records for patients with chronic disease: a systematic review. BMJ Qual Saf. 2010;19:441–1.
8. Greenhalgh T, Hinder S, Stramer K, Buxton E, Russell J. Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. BML. 2010;34:518–3111.
9. Tang P, An J, Bates D, Overhage J, Sands D. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. Adv Physio Educ. 2006;10:121–6.
10. Johnston D, Kaelber D, Pan EC, Bu D, Shah S, Hook JM, et al. A framework and approach for assessing the value of personal health records (PHRs). AMIA Annu Symp Proc. 2007:374–378.
11. Goldzweig CL, Towfigh AA, Paige NM, Orshansky G, Haggstrom DA, Beroes JM, et al. Systematic Review: Secure Messaging Between Providers and Patients, and Patients’ Access to Their Own Medical Record: Evidence on Health Outcomes, Satisfaction, Efficiency and Attitudes. Washington (DC): Department of Veterans Affairs (US); 2012.
12. Saberi P, Johnson KB. Personal health records: evaluation of functionality and consumer adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. BML. 2010;34:518–3111.
13. Ennis L, Vimarlund V. Critical advances in bridging personal health information and clinical informatics. Yearb Med Inform. 2012;3:348–55.
14. Hordern A, Georgiou A, Whetton S, Prgomet M. Consumer e-health: an overview of research evidence and implications for future policy. HIM J. 2011;406–14.
15. Merlin T, Weston A, Tooher R. Extending an evidence hierarchy to include topics other than treatment: revising the Australian ‘levels of evidence’. BMC Med Res Methodol. 2009;9:34.
16. Solomon M, Wagner SL, Goes J. Effects of a web-based intervention for adults with chronic conditions on patient activation: online randomized controlled trial. J Med Internet Res. 2012;14:e32.
17. Sobko H. Associations Among Measures Of Engagement With Kp.Org And Clinical Outcomes. Birmingham: University of Alabama; 2011. p. 1–239.
18. Grant RW, Wald JS, Schnipper JL, Gandhi TK, Poon EG, Orai EJ, et al. Practice-linked online personal health records for type 2 diabetes mellitus: a randomized controlled trial. Arch Intern Med. 2008;168:1776–82.
19. Uwoszit S, Wiljer D, Dupak K, Kuehner Z, Leonard K, Lovrics E, et al. Improving diabetes management with a patient portal: a qualitative study of diabetes self-management portal. J Med Internet Res. 2012;14:e158.
20. Black AO, Car J, Pagliari C, Anandani C, Cresswell K, Bokun T, et al. The impact of eHealth on the quality and safety of health care: a systematic overview. PLoS Med. 2011;8:e1000387.
21. Lau F, Kuziemsky C, Price M, Gardner J. A review on systematic reviews of health information system studies. J Am Med Inform Assoc. 2010;17:637–45.
22. Kaplan B. Evaluating informatics applications-some alternative approaches: theory, social interactionism, and call for methodological pluralism. Int J Med Inform. 2001;64:39–56.
23. Ogden CL, Carroll MD, Curtin LR, McDowell MA, Tabak CJ, Flegal KM. Prevalence of overweight and obesity in the United States, 1999–2004. JAMA. 2006;295:1549–55.
24. Flegal KM, Carroll MD, Kit BK, Ogden CL. Prevalence of obesity and trends in the distribution of body mass index among US adults, 1999–2010. JAMA. 2012;307:497–1.
25. Matthews Lenz TRM. The morbidity and mortality associated with overweight and obesity in adulthood: a systematic review. Dtsch Arztebl Int. 2009;106:641.
26. Reilly JJ, Kelly J. Long-term impact of overweight and obesity in childhood and adolescence on morbidity and premature mortality in adulthood: systematic review. Int J Obes Relat Metab Disord. 2010;35:891–8.
27. Rodrigues JPC, Lopes BMC, Silva BMC, de Torre I L. A new mobile ubiquitous computing application to control obesity: SapoFit. Inform Health Soc Care. 2013;38:373–37.
28. Brøn EF, Fuemmeler BF, Abrams LC. Weight loss—there is an app for that
But does it adhere to evidence-informed practices? Behav Med Pract Policy Res. 2011;1:523–9.
29. Kim Mi, Johnson KB. Personal health records: evaluation of functionality and utility. J Am Med Inform Assoc. 2002;9:171–80.
30. Lau F, Hagens S, Muttitt S. A proposed benefits evaluation framework for health information systems in Canada. Healthc Q. 2007;10:112-6-118.
31. Wiljer D, Leonard KJ, Uwoszit S, Apatu E, Massey C, Querrey N, et al. The anxious wait: assessing the impact of patient accessible EHRs for breast cancer patients. BMC Med Inform Decis Mak. 2010;10:46.
32. Wade-Vuturo AE, Maybery LS, Osborn CY. Secure messaging and diabetes management: experiences and perspectives of patient portal users. J Am Med Inform Assoc. 2013;20:519–25.
33. Tenforde M, Nowacki A, Jain A, Hickner J. The association between personal health record use and diabetes quality measures. J Gen Intern Med. 2011;27:1942–4.
34. Wald JS, Businger A, Gandhi TK, Grant RW, Poon EG, Schnipper JL, et al. Implementing practice-linked pre-visit electronic journals in primary care: patient and physician use and satisfaction. J Am Med Inform Assoc. 2010;17:502–6.
35. Hess R, Fischer GS, Sullivan SM, Dong X, Weimer M, Zeith C, et al. Patterns of response to patient-centered decision support through a personal health record. Telemed e Health. 2014;20:984–9.
36. Fonda SJ, Mcmahon GT, Gomes HE. Changes in diabetes distress related to participation in an internet-based diabetes care management program and glycemic control. J Diabet Sci Technol. 2009;3:1117–24.
37. Lau M, Campbell H, Tang T, Thompson DJS, Elliott T. Impact of patient use of an online patient portal on diabetes outcomes. Can J Diabetes. 2014;38:171–2.
38. Sarker U, Lyles CR, Parker MM, Allen J, Nguyen R, Moffet HH, et al. Use of the refill function through an online patient portal is associated with improved adherence to statins in an integrated health system. Med Care. 2014;52:194–201.
39. Wald JS, Grant RW, Schnipper JL, Gandhi TK, Poon EG, Businger AC, et al. Survey analysis of patient experience using a practice-linked PHR for type 2 diabetes mellitus. AMIA Annu Symp Proc. 2009;2009:678–82.
40. van Empel IWH, Hermens RPMG, Akkermans RP, Hollandar KWP, Nelen WLM, Kremer JAM. Organizational determinants of patient-centered fertility care: a multilevel analysis. Fertil Steril. 2011;95:513–9.
43. Boland MV, Chang DS, Frazier T, Plyler R, Jefferys JL, Friedman DS. Automated telecommunication-based reminders and adherence with once-daily glaucoma medication dosing: the automated dosing reminder study. JAMA Ophthalmol. 2014;132:845–50.

44. Crouch P-C. Patient Activation in HIV-Infected Veterans Who Use Electronic Personal Health Records. San Francisco: University of California; 2014. p. 1–77.

45. Gordon P, Camhi E, Hesse R, Odlum M, Schnall R, Rodriguez M, et al. Processes and outcomes of developing a continuity of care document for use as a personal health record by people living with HIV/AIDS in New York City. Int J Med Inform. 2012;81:e63–73.

46. Kahn JS, Hilton JF, Van Nunnery T, Leasure S, Bryant KM, Hare CB, et al. Personal health record in a public hospital: experience at the HIV/AIDS clinic at San Francisco General Hospital. J Am Med Inform Assoc. 2010;17:224–8.

47. McInnes DK, Shimada SL, Rao SR, Quill A, Duggal M, Gifford AL, et al. Personal health record use and its association with antiretroviral adherence: survey and medical record data from 1871 US veterans infected with HIV. AIDS Behav. 2013;17:3091–100.

48. Shade SB, Steward WT, Koester KA, Chakravarty D, Myers JJ. Health information technology interventions enhance care completion, engagement in HIV care and treatment, and viral suppression among HIV-infected patients in publicly funded settings. J Am Med Inform Assoc. 2014.

49. Wagner PJ, Dias J, Howard S, Kintziger KW, Hudson MF, Seol Y-H, et al. Personal health records and hypertension control: a randomized trial. J Am Med Inform Assoc. 2012;19:e26–34.

50. Chiche L, Brescianini A, Mancini J, Servy H, Durand J-M. Evaluation of a prototype electronic personal health record for patients with idiopathic thrombocytopenic purpura. Patient Preference and Adherence. 2012;6:725–34.

51. Miller DM, Moore SM, Fox RJ, Atreja A, Fu AZ, Lee J-C, et al. Web-based self-management for patients with multiple sclerosis: a practical, randomized trial. Telemed e Health. 2011;17:5–13.