

TITLE PAGE

1. Title

What do we know about developing patient portals? A review of the evidence

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ABSTRACT

Objective: Numerous articles have reported on the development of patient portals, including development problems and solutions. We review these articles to inform future patient portal development efforts and to provide a summary of the evidence base that can guide future research.

Materials and methods: Using a modified PRISMA checklist, we performed a systematic review of the relevant literature to answer five questions: (1) What categories of problems related to patient portal development have been defined?; (2) What causal factors have been identified by problem analysis and diagnosis? (3) What solutions have been proposed to ameliorate these causal factors?; (4) Which proposed solutions have been implemented and in which organizational contexts?; and (5) Have implemented solutions been evaluated and what learning has been generated? Through searches on PubMed, ScienceDirect and LISTA, we included 109 articles.

Results: We identified five main problem categories: achieving patient engagement, provider acceptance, appropriate data governance, secure infrastructure, and sustainable business model. Further, we identified key factors contributing to these problems and well as solutions proposed to ameliorate them. While about half (45) of the 109 articles proposed solutions, fewer than half of these solutions (18) were implemented, and even fewer (5) were evaluated to generate learning about their effects.

Discussion: Due to the lack of evidence on patient portal development processes, our review does not enable formulation of concrete suggestions to inform health care organizations about how to develop portals. However, our findings support a set of recommendations for how the evidence base can be advanced.

BACKGROUND AND SIGNIFICANCE

Patient portals give patients access to a personal health record (PHR) and enable an array of communication and administrative features.[1] For example, patients can use patient portals to email their providers, engage in self-management programs, seek information, handle insurance issues, book appointments, or request prescription refills.[2] Patient portals have been found to improve patient health and organizational performance as evidenced by better disease management, patient satisfaction, and enhanced administrative efficiency.[3-7] Up until recently, most patient portals were implemented and used within integrated care delivery systems[8], which have the structure and resources to support internal development and maintenance as well as continuing implementation and deployment efforts.[9] However, now, in response to the Meaningful Use (MU) program and similar national policy efforts to advance use of health information technology, patient portals are increasingly being implemented in a variety of healthcare delivery contexts, including accountable care organizations and multispecialty provider practices.[10-11]

An emerging evidence base provides insight into the problems associated with developing effective patient portals such as implementing required hardware and software, establishing portal content and capabilities, achieving physician commitment and patient engagement, interoperability across providers, regulatory compliance, and financial sustainability.[12-13] Numerous articles have addressed these and other problems that must be solved to develop portals and some have identified, implemented, and evaluated possible solutions. Due to the increasing interest in portals in various healthcare delivery contexts, the time is now ripe to review the evidence from these articles. Not only can such a review inform the development of new patient portals, it can also provide an account of the evidence base that can guide future research efforts.

OBJECTIVE

To organize and focus our review, we draw on principles in design science research.[14] Specifically, we use the generic problem solving cycle (Figure 1) to identify the problems that occur in the developmental process that underlies the creation of all patient portals, and to identify solutions aimed at ameliorating those problems. In practice, problem solving within the complex organizational contexts in which patient portals evolve typically takes a cyclic, iterative approach that continually takes into account changing demands imposed by the organizational context.[15] This development approach typically entails repeated execution of the Problem Solving Cycle depicted in figure 1. The problem Solving Cycle suggests that problems with portal development could arise at any of the five key steps in the developmental process.

Figure 1. The Problem Solving Cycle

Following the 'steps' of the problem solving cycle, we formulated five research questions to guide the review of scientific literature:

1. What categories of problems related to patient portal development have been defined?
2. What causal factors have been identified by problem analysis and diagnosis?
3. What solutions have been proposed to ameliorate these causal factors?
4. Which proposed solutions have been implemented and in which organizational contexts?
5. Have implemented solutions been evaluated and what learning has been generated?

MATERIALS AND METHODS

For our review, we followed a modified PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) checklist. The checklist was modified because the purpose of our review was not to compare and summarize effects of a specific intervention, but to systematically identify and

describe main development problems and solutions. Hence, several points on the checklist (points 12-16 and 19-23) were not relevant for this review.[16] For an overview of the effects of patient portals, we refer to several systematic reviews.[3-7].

Search process

We searched in PubMed, ScienceDirect and LISTA in January 2015 using a combination of queries capturing articles about ‘patient portals’ and ‘electronic personal health records’. We included peer-reviewed articles written in the English language and published in the last 10 years. Table 1 shows the search queries.

Table 1: Search queries

Queries	Restrictions
<ul style="list-style-type: none"> • Patient portal* • Patient web portal* • Personal health record* AND electronic • Personal health record* AND online 	<ul style="list-style-type: none"> • Time period: 2005-2015 • Language: English • Type of publication: Peer-reviewed

Selection process

To be eligible for inclusion in the review, articles must concern patient portals that give patients access to their personal health records, must address a problem that must be solved to effectively develop a portal, and/or a concrete solution to a problem. We included both electronic health records (EHR) tethered portals and ‘universal PHRs’ as long as the PHRs were clinically integrated; i.e. received information that originated in one or more EHRs.[17] We use the term patient portals to also refer to such PHRs on the grounds that these are accessible through portals. The included articles were selected through two steps. First, each article’s title and abstract were reviewed and

articles excluded that did not meet the just-mentioned eligibility criteria. The primary reviewer (TOT) reviewed all articles, while the second reviewer (AdB) reviewed a random sample of 10%. The agreement rate was 88,6%, and disagreement was resolved through discussion. In the second step, the first reviewer read the full text and rejected articles did not comply with the criteria. The second reviewer received the list of rejected articles for validation. After reading these articles in full, the second concurred with 93,2% of the rejection decisions and the remaining were discussed until consensus was reached.

Data extraction and synthesis

We extracted information from the articles regarding each of the five steps of the problem solving cycle. The majority of the articles mentioned only one problem. However, some articles mentioned multiple problems in which case we extracted information about each of the addressed problems. Taking an abductive analysis approach [18] we then first combined information about problem definitions into 'problem categories'. This categorization was based on the problem definitions of the articles and informed by a framework on patient portal development [13] as well as previous work within our research team.[19]. Second, we combined information about factors causing each of the problems in the categories. Third, for each of the problem categories, we ordered information about proposed solutions into themes, each describing a type of solution. Fourth, for the solutions that had been implemented, we gathered information about the solution and the organizational context within which the solution was implemented, specifically the type of healthcare system setting. According to the problem solving framework, factors inherent to the organizational context profoundly affect the development process. Thus, we believed it was useful to understand, at a minimum, in which types of systems solutions were implemented. Fifth, for the implemented solutions that had been evaluated, we took note of evidence from the evaluations.

RESULTS

Study selection

The number of articles retrieved from the initial search was 441. The flow diagram displayed in figure 1 details the selection process, which resulted in 109 included articles.

Figure 2: Flow diagram

Study characteristics

61 of the articles presented primary research on actual patient portals, while 27 reported on primary research not specific to a portal such as population surveys and simulations. The remaining 21 articles conveyed secondary research such as reviews, commentaries and conceptual articles. The vast majority of authors were from the North America (#85) and Europe (#14), with only 10 from Asia, Australia and South America. 34 of the articles were published between 2005-2010, while 75 are from between 2011-2015, indicating a considerable increase in research on the topic in most recent years. The online supplementary file displays basic information of the articles¹.

Synthesis of results

Problem definition

Our categorization of data led to the identification of five main problem categories: achieving patient engagement, health service provider acceptance, appropriate data governance, a secure infrastructure, and a sustainable business model. These problems were defined in both primary and secondary research articles.

Problem analysis and diagnosis

¹ The numbering assigned to each article in the appendix is used in this text for referencing the articles.

For each of the identified problem categories, we provide an account of the factors causing the problems as they have been described in the included literature.

Patient engagement. Seventy-one articles addressed patients' use of patient portals, several of which remarked that use is generally low (#9,15,22,37,40,45,46,49,50,58,74,96). The articles placed in this problem category offered three explanations for this low use. First, as several articles noted, patient use is limited by patient concerns about confidentiality of their personal health data (#6,7,9,15,22,28,33,35,36,37,38,48,50,56,72,84,98,99). Second, some patients are unaware that they have access to a portal or do not recognize the usefulness of using one (#2,4,6,7,15,29,38,51,58,61, 95,108). Also, some patients have tried using a portal but have had negative experiences, perhaps due to lack of user friendliness (#2,22,33,84). Third, a major hindrance to engaging patients described in many articles is lack of digital access (#2,3,7,29,36, 38,41,45,51,55,58,99) and/or health literacy (#2,3,7,23,28,41,45,47,49,50,51,55,56,58,70,79,85, 90,91,109). Patients facing these constraints may not be able to access a patient portal or feel empowered to retrieve and apply information. A central topic in the literature is whether some patients, based on demographic and socio-economic characteristics, are less able and prone to use portals than others (#2,3,22,23,24, 28,29,38,40,42,44,49,52,53,54,66,67, 69,71,73,74,75,78,80,83, 85,86,94,98, 101,102,103, 104,106,107), generally associating use with being female, young, white, affluent, and having a chronic disease.

Health service provider acceptance. Twenty-two articles described concerns held by providers that hinder them from adopting or using a portal. An often-mentioned aspect is providers' fear that use of portal features, especially secure email, will increase their workload and disrupt their workflow (#20,21,27,43,63,65,92,97,102)², especially in light of inadequate compensation (#7,21). A related

² This is despite a recent study, which found that, on average, secure e-mailing with patients has not substantially impacted primary care provider workloads [20]

concern among providers, as expressed in these and other articles, is that they do not possess the skills and capacities to adjust to new processes and work requirements induced by electronic means of interacting with patients (#7,21,56,75,76). A third aspect revolved around liability in case of breached privacy or harmful patient behavior (#7,16,39,62,64,65,92,97,105); for instance, providers could fail to respond in a timely way to patient inquiries or be required to base clinical decision-making on patient-entered data, which they cannot be sure is accurate or complete. Further, some patients may not be able to interpret clinical content, leading to anxiety, confusion and perhaps inappropriate or harmful behavior. Lastly, two articles note that some providers are hesitant to give up autonomy, a consequence of giving patients control over activities traditionally arranged by the providers such as booking appointments (#82,92).

Secure infrastructure. Twenty articles touched upon the challenge of establishing secure and stable technical infrastructures on which portals can operate. Two articles made explicit that this problem should be seen in light of non-standardized technical and semantic language and rules for setting up and managing health information system infrastructures (#41,57). To avoid portals becoming ‘information islands’, it was explicitly recognized in four articles that patient portals should be able to receive and transmit data to and from several EHRs (#23,32,41,92). Thus, an important problem is achieving data exchange, especially in contexts with non-interoperable EHR systems (#38,92,41). The data exchange problem also extends to establishing bi-directional flow of data between the EHR and the portal as well as between the portal and external web sources (#5,32,92). For systems to exchange data, they must be able to identify and verify the owners of data and corresponding records, making the establishment of robust authentication mechanisms a focus of several articles (#37,48,57,75,81,89,92). Another aspect, which was described in two articles, is the importance of protecting against security breaches from, for instance, hacking or inappropriate system use (#18,38,68). At the same time, five articles noted that ramping up security measures typically lowers the flexibility and friendliness of use (#7,17,37,75,92).

Data governance. Appropriate data protecting and handling was the focus of 16 articles. A notion in some of these was that national data regulations (such as the HIPAA in the United States) do not cover patient portal developers and the hosting organization, causing uncertainty about appropriate data governance (#38,41,64,77). This uncertainty centered on three main aspects. The first is data transparency; that is, what data (such as clinical notes, test result, and problems lists) should be included in the PHR, when to make these data available, and in what way to convey them (#7,13,19,32,26). This problem is augmented by the fact that data have traditionally been recorded for an expert audience as opposed to lay people (#26). A second aspect of uncertainty concerned authorization/privacy control; who should have access to records and who should be able to determine such access rights (#13,16,19,26,32,38,77). Examples are whether minors should have access to portals and whether patients should be able to assign proxy access to their informal caregivers. Several of the articles point out that, in situations where patients can choose to extent access to other people, some patients may not be able to properly manage the activities of the people to whom they have extended access (#16,77). A third aspect is how to guarantee data integrity; that is, the accuracy and completeness of data (#16,19,57,87). The question often raised was that when data in the record can be altered and complemented, how well such revisions would be visible in the record.

Sustainable business model. Nine articles concerned the problem of developing a sufficiently sound business model for patient portals. Two main topics were discussed under this problem category. First, there are inadequate and often contradictory reimbursement structures for services provided electronically (#19,21,22,36,38,60,93). Even with the MU program, the incentives are often too modest (and the thresholds too high) to create an adequate business case (#60). The second issue

is the lack of documented cost-savings from using patient portals, attainable for example through better-managed patients or administrative efficiencies (#7,19,38,59).

Design of solutions

Forty-five articles reporting on both primary and secondary research proposed solutions to ameliorate these problems.

Patient engagement. Seventeen articles discussed how to better engage patients to use patient portals, the majority of which mentioned using participatory design approaches (#12,23,31,33, 36,46,52,70, 72,75,84,88,100,108). Designing portals to meet needs defined by patients' characteristics, preferences, and capacities, as opposed to the most easily operationalized features of the technology, is believed to result in portals with high patient-perceived usefulness and usability. One example is translation of content to minority languages (#36). As described in many of these articles, such patient-centered designs are achieved through patient interviews, surveys and focus groups or through actual usability testing where patients are observed while using the portal. A second way to engage patients, with particular emphasis on those lacking access and skills, is via training these patients in the use of portals (#2,26,33,47,55,67) or providing access through, for example, onsite kiosks (#2). Three articles reported on actual training programs offered to patients, and especially to vulnerable patients with low Internet skills (#47,55,67). Lastly, a couple of articles mentioned promotion initiatives as helpful to attracting patient attention and increasing awareness. This can be either through encouragement by providers (#2,52), through providing written or visual materials (#33,46,61,102), or follow up registration reminders (#29).

Health service provider acceptance. Ten articles suggested ways to enhance provider acceptance by improving their attitudes toward patient portals. Four articles suggested providing communication

and practical training to providers to equip them to handle technical, interpersonal, and workflow aspects related to using electronic means of communicating (#20,26,56,92). Three out of four suggested introducing information about the use EHRs and PHRs into the medical and nursing school curricula (#20,56,92). Another proposed way to mitigate provider concern is through workflow engineering; three articles described how mirroring current workflow and capitalizing on existing provider roles can inform minimal burden workflow revisions (#11,30,34). As a concrete example, one article explained how completed care plans were not transmitted to a relevant provider until two weeks prior to scheduled visit (#3). Two articles made explicit that involving providers in this process is important to fully understand their work environment and tasks (#11,75). Ways to appease providers' liability-related concerns were addressed in two articles. One suggested notifying providers if patients had not opened an email, while the other proposed designing the system to detect messages that signal medical urgency [62,64].

Secure infrastructure. Thirteen articles suggested ways to improve the infrastructure for patient portals. Of these, several discussed the feasibility of setting up various types of authentication mechanisms (#17,25,48,57,75,81,89), such as the so-called Public Key Infrastructures³ (PKIs). Three articles expressed the importance of standardizing interoperability guidelines to allow for data exchange among organization, such as the international HL7 standard (#7,8,68). Two articles proposed achieving data exchange by setting up (Regional) Health Information Exchanges that can standardize data and facilitate exchange among different organizations (#23,38). One article suggested circumventing the need for inter-organizational data exchange by letting patients act as mediators (#39). A few articles discussed ways to improve system security through encryption tools, firewall, and audits of adherence to security protocols (#17,75).

³ Public Key Infrastructures are sets of hardware, software, people, policies, and procedures needed to create, manage, distribute, use, store, and revoke digital certificates.[21]

Data governance. Nine articles suggested solutions to data governance problems. Of these, the majority addressed policies for data availability and timing (#10,13,26,30,32,64), four of which described actual policies defined in organizations that have implemented portals (#10,30,32,64). In these cases, as much data as possible (except for test results prohibited by state laws such as for cancer and HIV) were made available to patients. In at least two of these organizations, the timing of certain test results was tuned to provider workflow to allow for quick provider follow-up. Four articles suggested ways to authorize patients to view data (#8,16,32,64). In most cases, patients had to provide proof of identify in person before gaining access to a portal, while an electronically signed user agreement sufficed in others. One article explicitly mentioned that patients were allowed to delegate access to one proxy (#64). Lastly, with regards to data integrity, three articles commented that systematic use of electronic signatures could be a viable way to clearly determine who had revised the records (#1,8,57).

Sustainable business model. Two articles addressed solutions to ensure a sustainable business model. One article advised organizations to negotiate a trial period before committing to purchasing a portal. This would allow organizations to test usability and be better able to estimate financial and organizational effects of using a portal (#59). The other article was committed to developing and testing reimbursement criteria for secure messaging, which could be used by payers to determine whether and by how much to reimburse an online encounter (#93).

Implementation of solutions

Eighteen of the proposed solutions reported above had been implemented in an actual patient portal (#5,8,10,11,12,20,30,32,39,46,55,61,64,67,70,88,100,102). The most commonly

implemented solutions were aimed at solving problems in the patient engagement category, followed by solutions in the provider acceptance, data governance and secure infrastructure categories. There were none in the sustainable business case category. Interestingly, in terms of the organizational context, 14 of the solutions were implemented in portals within single organizations or organized care delivery systems, while four of the portals were provided in collaboration between individual organizations.

Evaluation of solutions

Of the 18 solutions implemented in actual portals reported above, five (#20,46,55,61,67) had been evaluated to determine their effects. All of these were in the patient engagement and provider acceptance categories. These five evaluations collected data on implementation of secure messaging curricula in residency training (#20), strategies to promote portals to patients (#46,61), and patient training and guidance (#55,67] and demonstrated that these solutions can ameliorate problems of achieving patient engagement and health service provider acceptance.

Table 2 summarizes the findings of the review.

Table 2: Summary of review findings

Development problems	Solutions
Patient engagement <ul style="list-style-type: none"> • Privacy and confidentiality concerns • Awareness • Usefulness and usability • Digital access • Health literacy • Socio-economic disparities 	<ul style="list-style-type: none"> • Patient centered design • Training and education* • Promotional initiatives*
Health service provider acceptance <ul style="list-style-type: none"> • Workload and workflow • Skills and capacities • Liability • Autonomy 	<ul style="list-style-type: none"> • Workflow engineering • Workflow training* • Notifications and signaling of urgency

Secure infrastructure <ul style="list-style-type: none"> • Data exchange • Authentication • System robustness 	<ul style="list-style-type: none"> • International standards, such as HL7 • Access control mechanisms • Encryption, internet firewalls, audits • Health information exchanges
Data governance <ul style="list-style-type: none"> • Data transparency • Authorization/privacy control • Data integrity 	<ul style="list-style-type: none"> • Policies for data availability and timing • In person authorization /user agreements • Provider and patient signatures
Financial sustainability <ul style="list-style-type: none"> • Inadequate reimbursements • Uncertainty about cost savings 	<ul style="list-style-type: none"> • Trial period to establish business case • Appropriate reimbursement criteria

** Effect of solution has been evaluated*

DISCUSSION

The review provides valuable insights into problems, diagnosis, and possible solutions described in an emerging field of research. Held up against the problem solving cycle, we note that of the 109 articles, 45 reported to have made it past the problem analysis and diagnosis to propose solutions. Of these, eighteen reported implementation, of which five reported evaluation, thus evidencing to have gone “full circle” at least once. None of these articles described the problem solving process in enough detail for the reader to understand the iterations and dynamics of the process. This does not necessarily mean that the problem solving process was not completed. The stages not reported, may simply have been disregarded in the publication. Yet, in view of the modest number of implemented, and, especially, evaluated designs, we cannot provide concrete suggestions to inform developers and health care organizations about how to develop portals. That being said, it does provide the basis for further reflection on the nature of the evidence base and recommendations for how it can best be advanced to inform practice.

Further reflection on the evidence base

There appears to be a great deal of attention on patient engagement in the scientific literature. Especially, we note that a large proportion of articles are dedicated to examining socio-economic

factors associated with portal use. Fewer, but still a considerable number of articles, address problems and solutions related to securing provider acceptance, appropriate data governance, and a secure infrastructure. In comparison, few articles deal with the financial sustainability of patient portals. Furthermore, aside from patient engagement and provider acceptance, we have noted no evaluated solutions in the other categories. The uneven nature of the evidence-base hinders portal developers from comprehending and solving for all problems that affect patient portal development, problems that may be interrelated; for example, lack of financial sustainability will likely hinder provider acceptance, even if providers think positively about using a portal. As such, it appears that the current evidence base informs only part of an effective development process.

Further, according to the problem-solving framework, the development process is affected by the organizational context. For instance, it is likely that implementing solutions in portal developments within fragmented care delivery contexts is most difficult, since several organizations typically must join forces to develop a comprehensive portal; while achieving patient engagement, health service provider acceptance, a secure infrastructure, appropriate data governance, and a sustainable business model is challenging within one organization, this challenge is likely exacerbated by the necessity to solve problems across organizations with varying patient populations, provider attitudes and incentives, existing technical infrastructures, internal regulatory policies or beliefs, and short- and long-term objectives and profit motives.[22]. However, we found that the vast majority of the implemented solutions was from within single organizations or organized care delivery systems. Thus, these types of organizational contexts appear to provide the test bed for most patient portal developments, which may limit the relevance of current research to other organizational contexts

Recommendations for future research

Future research should seek to systematically improve our comprehension of what patient portal solutions actually work, for whom, and in what contexts. We offer three main recommendations for such research efforts.

1. Where available, we encourage researchers to base their designs on existing evidence, and report implementation and evaluation, so as to validate, advance and generalize existing evidence. Where there is no evidence, such as on how to secure financial sustainability, we encourage research that identifies and analyses problems, in addition to designing, implementing and evaluating solutions, so as to create a more well-rounded evidence base.
2. Patient portal development occurs through multiple iterations of the problem solving cycle. Hence we call for studies with an extended 'unit of analysis' in terms of a longer time horizon and several iterations of the process.
3. To be able to inform portal developments across contexts, the evidence base could benefit from research that accumulates knowledge from different types of patient portals, patient populations and across organizational contexts (and especially within fragmented care delivery contexts where portal development problems may be most severe).

Study limitations

By only including articles written in English, we have excluded many articles published in their authors' native languages. Further, we restricted our review to peer-reviewed studies, foregoing sources such as websites of specific patient portals or high-level policy and strategy documents issued by governments or large knowledge institutes. To advance the depth of understanding about development problems and solutions in various contexts, our review could have benefitted from inclusion of such grey literature from several countries.

The dominance of articles addressing user engagement may be explained by the fact that we excluded articles that focused on EHRs and Health Information Exchanges more broadly; since patient portals typically tie into existing health information technology infrastructures, insight into earlier design and development stages of these infrastructures are important to fully comprehend portals (see for example [23-30]). Hence, while it was outside of the scope of this review, we might have obtained a more even distribution of insights across problem categories if we had opened up the review to also include EHRs and Health Information Exchanges.

COMPETING INTERESTS

The authors report no competing interests.

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FIGURE LEGENDS

Figure 1: The Problem Solving Cycle. (We have permission to use this figure by Van Aken et al.)

Figure 2: Flow diagram