

What Do Patients and Caregivers Want? A Systematic Review of User Suggestions to Improve Patient Portals

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Abstract

Significant investments have been made in patient portals in order to provide patients with greater access to their medical records, as well as to other services such as secure electronic communication with their healthcare provider(s). Unfortunately, overall, patient adoption and use of patient portals has been lower than expected. According to the user-centered design philosophy, including end-user voices in all stages of the design process is critical to a technology's success. Thus, as a part of a larger systematic review, we examined the patient portal literature and identified 42 studies that reported patient's or their caregiver's suggestions to improve patient portals. The results suggest that patients and caregivers want patient portals to (i) support human connection (e.g., virtual patient-provider interactions), (ii) give patients more control (e.g., over their medical record) and be designed for the variation in patient and caregiver experiences, and (iii) be innovative (e.g., provide contextualized medical advice).

Introduction

Patient portals – a patient-facing, web-based technology offered by healthcare organizations to provide patients with read-only access to their medical records and also often provide additional features to engage patients in their healthcare (e.g., secure messaging) – have been in development now for at least 20 years. In that time, there have been hundreds of patient portal-focused studies published. These studies have contributed to this technology becoming more mature and widely available. They have also established the potential of patient portals to have benefits such as improving patient-provider communication.¹ Unfortunately, in general, patient adoption and use rates have been lower than expected.²

User-centered design (UCD) is defined as “an iterative design process in which designers focus on the users and their needs in each phase of the design process.”³ This focus on the user is essential to developing technologies, as well as redesigning technologies, that are useful and that will actually be used. Indeed, the extant patient portal literature has found that the design of portals is a key factor in their adoption and use – when portals fail to meet patients’ or caregivers’ expectations or needs, such as inadequately supporting multiple healthcare interactions, it negatively affects use.^{4,5} In addition, patients *want* to be heard. For instance, Smith et al. reported, “An underlying finding was the need for patients to be listened to and taken into account when thinking about improving the tool [patient portal].”⁶ Thus, using the UCD philosophy may provide insights into how to improve the design of patient portals and, subsequently, into how to improve patient adoption and use of this technology. This is likely why following user-centered design principles is outlined as a key strategy to “advance the development and use of health IT [information technology] capabilities” in the draft 2020-2025 Federal Health IT Strategic Plan.⁷

In other words, there is a critical need to better understand what patients and their caregivers want from portals in order to capitalize on the investments that have been made in this technology and to achieve its potential. While Nazi et al. recently examined the Veterans Affairs’ (VA) UCD efforts over the last decade, to which they attribute their portal’s relatively high adoption and continued engagement, they do not consider patient voices outside of the VA context.⁸ We address this gap through a systematic review of the patient portal literature. Through our analysis, we aim to gain an understanding of how patients and their caregivers believe that portals should be improved in order to better meet their needs and to use this understanding to develop patient portal (re-)design recommendations.

Methods

This systematic review follows the PRISMA standard of reporting. It is a part of a larger systematic review of the patient portal literature exploring the barriers to and facilitators of patient adoption and use of portals. Briefly, for this larger systematic literature review, we used the queries in Table 1 to search three databases: Scopus, PubMed, and ACM Library. The last search was conducted in May 2019. In addition to these databases, we reviewed the reference lists of publications and co-authors also sent potentially relevant literature.

We included empirical studies of technologies meeting the definition of patient portals presented in the introduction, regardless of the term used (e.g., personal health record, PHR, versus patient portal), and addressing at least one of our two main research questions: (1) Are patients registering for and using patient portals? and (2) What are the barriers to and facilitators of patient registration and use? Articles were excluded if they met one or more of the following criteria (i) literature reviews; (ii) non-electronic or non-web-based PHRs (e.g., paper, USB); (iii) web-based PHR not connected to a particular healthcare organization; (iv) exclusively discuss functionalities, frameworks, architectures, policies, internet access, or patient attitudes towards a hypothetical/future portal; (v) lack direct evidence of an effect on patient enrollment or use (i.e., study does not include patients or their portal enrollment and use data); (vi) use simulated data (e.g., pilot tests); and (vii) non-English language articles. All types of study designs were eligible for inclusion (e.g., controlled trial, observational). In addition, while there are unique aspects of inpatient portals (e.g., discharge checklist), many of the factors that affect patient engagement with this technology are similar to outpatient portals (e.g., health status). Thus, studies of inpatient portals were also included in this review.

Table 1. Search queries submitted to databases.

Database	Query
Scopus	TITLE-ABS-KEY(("patient portal" OR "personal health record") AND ("evaluation" or "adoption" or "barrier") OR ("effective" OR "useful" OR "utility")) AND NOT ("online medical consultation" OR "evisit" OR "portal vein" OR "portal pressure" OR "portal venous stenosis" OR "transjugular intrahepatic portosystemic shunt" OR "doppler")*
PubMed	Search (((health records, personal[MeSH Terms]) OR "patient portal")) AND ((evaluation studies as topic[MeSH Terms]) OR (barrier OR barriers OR facilitator OR facilitators OR effective OR useful OR utility)))
ACM Digital Library	("patient portal" OR "tethered personal health record" OR "patient accessible electronic health record" OR "patient accessible health record")

*The exclusion terms in the final query are based on review of the results from preliminary queries.

Two authors [TLR and NA] first independently assessed the title and abstract of all identified articles for relevance. They then compared their judgments and resolved any disagreement through discussion. For articles not excluded based on title and abstract, one author [TLR] obtained and reviewed the full-texts, and excluded additional articles based on our criteria.

The data extracted from included articles were pre-determined. Data items included details of the technology (e.g., features and functionalities), methods (e.g., study design, how enrollment or use were defined/measured), results (e.g., barriers to and facilitators of patient engagement), conclusions, and risk of biases (e.g., selection bias). Importantly for this paper, we also systematically extracted any patient or caregiver suggestions for improvements to the portal.

We analyzed the subset of papers that reported these suggestions using an inductive qualitative approach to identify emerging categories and the constant comparative method of data analysis.⁹

Results

Using the search strategy outlined above, and after de-duplication, we identified 1,390 unique potentially relevant articles. We excluded 848 of these based on a review of the titles and abstracts, with the most common reasons being that they reported patient attitudes towards portals only or on the design and development process only as opposed to actual use. We then reviewed the full text of the remaining 542, and determined that 202 were relevant and were, thus, included in the larger review. Among these, we identified 42 publications (21%) that reported asking their participants for suggestions to improve the organization's patient portal. We focus on this subset of the literature in the remainder of this paper. Figure 1 presents an overview of the identification and screening processes.

Study Characteristics

Studies that reported patient or caregiver perceptions of how the patient portal could be improved (N=42) were published between 2003 and 2019, with over half (n=28, 66.7%) being published in the last 5 years. The most commonly reported study setting was a hospital/medical center (n=10, 23.8%), followed by two or more primary care practices (n=9, 21.4%) and health systems (n=6, 14.3%). A large majority of studies focused on adult patient populations (n=25, 83.3%). Among these, five specifically studied older adults (most commonly defined as 65 years and older), three veterans, one pregnant women, and one patient-couples. Only two of the studies that focused on adult patient populations explicitly included caregivers. In addition, half of the included studies did not concentrate on a particular condition. Among the remaining 21 articles, 15 focused on chronic conditions (71.4%), with diabetes mellitus being the most common (n=7, 33.3%). Finally, qualitative study designs were most frequently used (n=12, 28.6%), followed by cross-sectional (n=10, 23.8%) and mixed methods (n=7, 16.7%). Thirty of the 42 included studies

reported collecting data through surveys or questionnaires (71.4%) and 18 through interviews (42.9%), other methods were less commonly reported (e.g., focus groups).

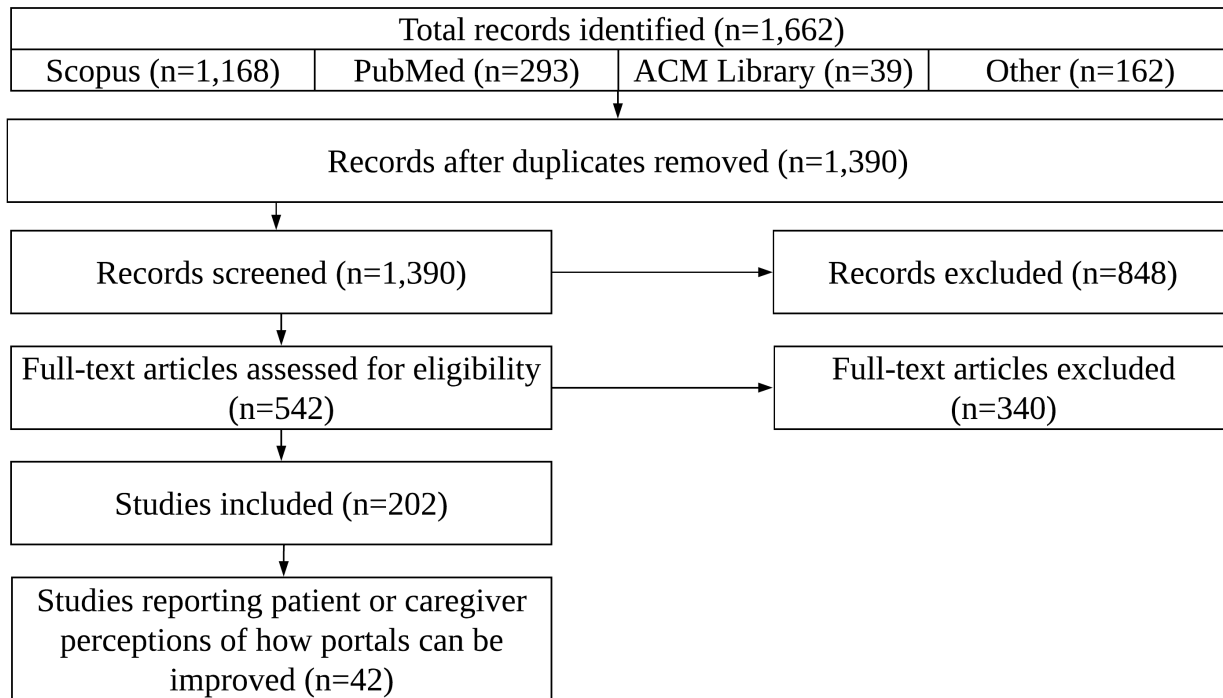


Figure 1. PRISMA flow diagram for the selection of literature reviewed.

Patient and Caregiver Suggestions for Improving Patient Portals

Five main categories of patient suggestions for improving patient portals and patient portal engagement emerged (N=42): Information (n=28, 66.7%), Features/Functionality (n=26, 61.9%), Usability (n=17, 40.5%), Training/Support (n=11, 26.2%), and Implementation (n=2, 4.8%). We present our findings related to each of the main categories in the sub-sections below; they are also summarized in Table 2.

Information

The most commonly reported recommendation was to improve the information provided in the portal (N=28). Specifically, patients want faster information (n=5, 17.9%), better or more explanations (n=13, 46.4%), more personal health information (n=15, 53.6%), more personalization (n=8, 28.6%), detailed information rather than simplified (n=3, 10.7%), more resources and education (n=5, 17.9%), and more transparency (n=4, 14.3%).

Patients desire faster information, including more timely email responses, release of test results, and updates following clinic visits.^{5,8,11,18,21} They also want better or more explanations of medications, laboratory results, and medical terminology.^{11,13,22–24,26–33} For example, Pillemer et al. reported that their participants wanted at least minimal provider interpretation with their laboratory results,²⁶ while O’Leary et al. found that their participants wanted additional information about medications such as both the brand and generic names.²² In addition, many studies reported that their participants wanted more personal health information,^{8,10–22,32} including doctor’s notes, care plans, test results from other healthcare organizations, radiology results, and cardiology reports. Dalal et al.’s participants also specifically noted the importance of keeping the personal health information in the portal up-to-date.¹⁶

Eight studies reported that patients want more personalization – in terms of the information presented to them or that is requested from them through the portal. For instance, through qualitative interviews, Gee et al. found that their participants wanted to customize the portal to see only the data and information relevant to their specific chronic condition.¹⁸ Similarly, de Jong et al. asked their participants to regularly submit questionnaires (e.g., pain level), but some of their participants did not find the questionnaire relevant to their condition, and recommended requesting

condition-specific information in the future.³² In addition, one study found that patients wanted contextualized medical advice¹⁷ and another reported that patients wanted the portal to predict their information needs.⁶

Although some studies found that their participants wanted the explanations or their personal health information in “patient-friendly” or “lay” language, e.g.,^{20,24} other studies reported that their participants wanted detailed information as opposed to simplified patient versions.^{30,31,34} Indeed, even within studies this sometimes varied. For instance, Kim and Fadem received polarized feedback from their older adult participants – some strongly preferring simplicity and others comprehensiveness.³⁰ This suggests that it may be preferable to provide patients with the raw clinical data with an easily accessible interpretation of that data and/or explanation of medical jargon rather than just a simplified patient version. Given the desire for personalization, another possible solution may be to allow patients to customize their view of their information.

Five studies found that patients wanted more resources (e.g., facility information such as maps and quality of care information^{8,19}) and/or education (e.g., online education programs⁸) – either integrated into the portal or links to additional information and resources outside of the portal. Finally, patients want more transparency around portal use.^{21,25,29,33} For instance, King et al.’s mixed methods study of 18 caregivers of children with physical and developmental disabilities revealed that caregivers wanted more transparency around the “scope of confidentiality” and portal access after discharge from the pediatric rehabilitation hospital.²¹

Features/Functionality

Patients want additional features/functionality, as well as existing features/functionality to be improved (N=26). These generally fell into five main categories: Support for key activities (n=15, 57.7%), More control (n=23, 88.5%), Reminders and notifications (n=7, 26.9%), Other features/functionality added (n=5, 19.2%), Other features/functionality improved (n=7, 26.9%). First, patients want more support for communication with their provider(s), including virtual healthcare tools such as messaging and videoconferencing^{5,8,16,22,31,33,35} and features that inform their healthcare provider(s) of their status, such as provider notifications related to the patient’s medication adherence.^{16,28} In fact, one of Kim and Fadem’s main findings from their mixed methods study was that communication with providers was the main focus of their older adult participants, and that they viewed the portal as “one part of a larger communication system.”³⁰ In addition, patients and caregivers also want support for the administrative work associated with being a patient, including scheduling appointments, paying bills, and filling prescriptions.^{4,5,8,14,23,27,35} Finally, less commonly identified, but critical for patients and caregivers with more complex situations were support for caregiver and family care coordination (e.g., family calendar)^{5,29,31} and complex care (e.g., check for medication interactions).^{8,30}

Second, although patient portals are owned by healthcare organizations and tend to be primarily populated with clinical data generated by healthcare providers (e.g., doctor’s notes, laboratory results), patients want more control. For example, they would like to be able to contribute to their health record by adding or correcting data.^{4,11,14,18,23,27,35,36} They also want the ability to share their record with and among others, including caregivers,^{8,16,35} healthcare providers within and/or outside the healthcare organization,^{4,5,8,14,20,21,28,30,35,36} and trusted institutions.³⁵ Nazi et al. specifically investigated patient preferences for the type of access they want delegates to have, and found that most of their participants wanted their delegates to have read access with print and download capabilities.⁸ In addition to control over their health record, patients would also like more control over communication with their healthcare provider(s), including what is submitted to their physician (e.g., ability to create own topic as opposed to having to choose from a dropdown menu);^{36,37} when and how information is received^{29,30,38} and requested;³² and more options for and control over with whom they are communicating.^{18,21,24,25}

Third, seven studies reported patient or caregiver suggestions related to reminders and notifications. Specifically, four found that their study participants wanted reminders for events such as upcoming appointments, when it is time to refill a prescription(s), and when preventive care is due.^{8,23,28,35} In addition, four studies reported that patients or their caregivers suggested providing notifications when new content or features become available such as new test results.^{8,11,25,33}

Finally, there were also several less commonly reported features/functionality requested, including tools for self-tracking,^{32,35} decision making,⁸ peer-to-peer support,⁸ and inpatient stays (e.g., order food/room service),^{16,19} as well as requests to improve certain portal features/functionality such as for reviewability (e.g., ability to record videoconference visits),³² convenience (e.g., automatic upload of home readings from different types of devices),^{23,32} flexibility (e.g., adjust the frequency of reminders³²), and awareness (e.g., ability to track status of a question²⁴).

Table 2. Summary of patient and caregiver suggested improvements reported in the 42 included studies. *NOTE: Percentages do not add to 100%, because many studies reported more than one category.

Improvement Categories	No. (%)	Patients want:
Information	28 (66.7%)	<ul style="list-style-type: none"> Faster information (e.g., updates from clinic visits)^{5,8,11,18,21} Better or more explanations, especially of medications, laboratory results, and medical terminology^{11,13,22-24,26-33} More personal health and healthcare information^{8,10-22,32} that is kept up-to-date¹⁶ More personalization, including more personalized information (e.g., condition-specific) provided^{11,18,20,21,23} and requested,³² contextualized medical advice,¹⁷ and information needs anticipated⁶ Detailed information rather than simplified patient versions^{30,31,34} More resources (e.g., facility information) and education (e.g., online education programs)^{8,11,19-21} More transparency (e.g., will they be able to access after discharge, why days/times are blocked from online appointment scheduling)^{21,25,29,33}
Features/Functionality	26 (61.9%)	<ul style="list-style-type: none"> Support for: <ul style="list-style-type: none"> communication with their provider(s), specifically adding virtual healthcare tools (e.g., messaging, video conferencing)^{5,8,16,22,31,33,35} and informing their healthcare provider(s) (e.g., status of discharge checklist viewable to providers;¹⁶ notifications to provider specifically medication/adherence-related²⁸) administrative work (e.g., scheduling appointment, paying bills)^{4,5,8,14,23,27,35} caregiver and family care coordination (e.g., family calendar)^{5,29,31} complex care (e.g., check for medication interactions,^{8,30} ability to request multiple medication refills at once,²⁸ ability to prioritize medications³²) More control over: <ul style="list-style-type: none"> their health record, including the ability to correct or add data,^{4,11,14,18,23,27,35,36} the way data is displayed and the type of data collected,³¹⁻³³ where and when they can access it (e.g., ability to access outside hospital);²⁰ and the ability to share with and among others,⁸ specifically caregivers,^{8,16,35} healthcare providers (within and/or outside healthcare organization),^{4,5,8,14,20,21,28,30,35,36} and trusted institutions³⁵ communication, including what is submitted to physician (e.g., ability to create own topic);^{36,37} when and how information is received^{29,30,38} and requested;³² and more options for and control over with whom they are communicating^{18,21,24,25} Reminders (e.g., upcoming appointment, refill prescriptions, preventive care)^{8,23,28,35} and notifications when new content or features available,⁸ including new data such as laboratory results^{11,33} and secure messaging activity²⁵ Other features/functionalities added, including for self-tracking (e.g., diary),^{32,35} decision making (e.g., advance care planning),⁸ peer-to-peer support (e.g., online health forum),⁸ and inpatient stay (e.g., more entertainment/non-health content and the ability to order food online/room service)^{16,19} Other features/functionalities improved, including for reviewability (e.g., ability to record and store videoconference visits³²), convenience (e.g., automatic upload of home readings from different types of devices^{23,32}), flexibility (e.g., printer-friendly formats,^{20,36} ability to set different reminders for weekdays and weekends,³⁸ to have reminders work in different time zones,³⁸ and to adjust the frequency of reminders³²), and awareness (e.g., preview of messages³² and the ability to track status of a question²⁴ and delivery of filled prescriptions⁸)
Usability	17 (40.5%)	<ul style="list-style-type: none"> More user-friendly format, easier to use and navigate (e.g., important tabs/features visible, keep simple, include standard email features)^{6,8,11,18,25,30,32,37,39-41} Better display of information,⁴⁰ especially laboratory results (e.g., provider annotations, highlight abnormal, graph)^{15,16,30} and large amounts of information^{16,24,25,30} More platform options (e.g., smart phone application)^{5,8,32,37} Burden to log-in to be minimized (e.g., automatic log-in from email)^{11,17,29} Improved accessibility (e.g., visual impairment, multiple co-morbidities)^{11,25,29} Other usability improvements,¹⁵ including reduced constraints (e.g., days/times blocked from online appointment scheduling),²⁹ and notifications before automatic actions (e.g., before a session times-out)⁸
Training/Support	11 (26.2%)	<ul style="list-style-type: none"> Education, training, or support^{17,18,21,27,42} (person, not web-based video or guide,^{6,43} and someone outside of the busy clinical team²⁹) More or clearer instructions,^{29,40,41} including examples of appropriate questions and comments (secure messaging)²⁴
Implementation	2 (4.8%)	<ul style="list-style-type: none"> Organization-wide acceptance, with portal use embedded in routine practice, and uniform patient experience (e.g., implementation of features, response times)^{21,29} Marketing that captures patient stories²⁹ and that promotes proxy users²⁹ Computer literacy screening²⁹

Usability

The most common suggestion related to usability was to make the portal more user-friendly and, in particular, easier to use and navigate.^{6,8,11,18,25,30,32,37,39-41} The studies that reported more detail found that patients wanted the portal's organization to be clear and intuitive and navigation to be simple, especially for completing common tasks, while not obscuring any of the portal's functionality (e.g., important tabs/features should be visible).^{6,8,25,30,41} Patients also commonly requested better display of information in general, and particularly of laboratory results (e.g., highlight abnormal values) and large amounts of information.^{15,16,24,25,30,40} For example, one mixed methods study of older adults found that many of their participants wanted to be able to filter out medications that they took for only a short time (and are no longer taking), so that they could view a list of only the medications that are relevant (i.e., the ones they are currently taking).³⁰

Patients or their caregivers also requested more platform options, especially a smart phone application.^{5,8,32,37} In addition, the burden to log-in should be minimized, such as enabling automatic log-in from an email message,^{11,17,29} and accessibility should be improved (e.g., larger font). Patients want portal designers to be especially cognizant of the many users with challenges, including visual impairments and multiple co-morbidities.^{11,25,29} Finally, other less commonly mentioned usability improvements include reduced constraints (e.g., days/times blocked from online appointment scheduling)²⁹ and notification before automatic actions (e.g., log-out).⁸

Training/Support

Eight studies reported that patients or their caregivers want more portal education, training, or support.^{6,17,18,21,27,29,42,43} Two studies found that their participants want human connection as they learn about the portal and how to use it, as well as when they encounter issues.^{6,43} These users do not feel that a web-based video or guide is sufficient. Price-Haywood et al. found that patients believe that someone outside of the busy clinical team may be best able to provide an introduction to the portal, especially for those with low computer self-efficacy.²⁹ In addition, patients want more or clearer instructions for using the portal and its features.^{29,40,41} For instance, Wilcox et al. found that their participants wanted examples of appropriate questions and comments to send through secure messaging.²⁴

Implementation

Two studies reported patient suggestions related to implementation. Of note, one of these studies reports suggestions from a patient advisory board, which includes patients that are portal users and non-users, based on the results from a survey of 247 older adult patients.²⁹ The advisory board recommended marketing that captures patient stories to show the benefits of using the portal and that promotes proxy users to help address concerns about patient self-efficacy in using the portal.²⁹ They also recommend screening for computer literacy to identify individuals who may need additional assistance.²⁹ Finally, patients want a consistent experience, including the features available and response times, across providers.^{21,29} This suggests that organization-wide acceptance is critical.

Discussion

A relatively small proportion of the patient portal literature reported patient or caregiver suggestions to improve patient portals. Among those that did, the most common requests were to improve the information provided through the portal (e.g., more timely information, better or more explanations of medications and laboratory results) and its features/functionality (e.g., support for communication with providers). While there are several logistic and policy implications of these findings, such as related to the timing of the release of laboratory results through portals (i.e., in general, sooner is better), we are going to focus our discussion around three key overarching recommendations based on our findings (1) support human connection; (2) give patients and caregivers more control and design for variation; and (3) keep innovating.

Support Human Connection

First, whether it is features that connect them to their healthcare provider(s), caregivers, or peer patients or how they are introduced to the portal and receive technical support, patients and caregivers want human connection. This may be especially true for certain populations that have been less likely to adopt and use patient portals (e.g., older adults).^{e.g.,30} In terms of connecting patients and providers, many portals offer secure messaging, and videoconferencing tools are also becoming more common.⁴⁴ However, in addition to usability issues with portals that can make it difficult for patients to find and use these features,^{e.g.,25} healthcare provider acceptance of these tools varies significantly, which also affects patient acceptance.^{e.g.,25,27,45,46} Thus, it is important to continue to improve these features, including by making them intuitive to use (e.g., making the secure messaging feature similar to commonly used email clients²⁵) and by making all virtual interactions reviewable so that cognitively and emotionally burdened

patients and caregivers are able to revisit the interaction at their convenience.³² Furthermore, taking steps to promote provider acceptance is critical. For instance, research suggests that pre-implementation efforts such as reassuring providers that the organization is ready for the change was associated with healthcare provider support for a portal.⁴⁷ It also includes addressing the common provider concerns about disruptions in workflow, increased workload, and reimbursement for virtual interactions.^{e.g.,48,49}

Unfortunately, there can be tensions inherent to balancing patient and healthcare provider needs. For example, one of the ways that many healthcare organizations have addressed physician concerns about secure messaging is to have another member of the healthcare team (e.g., medical assistant, nurse) first review and triage the messages, reducing the number of messages to which the physician must respond. However, this can be contrary to patients' desire to have more control over with whom they communicate through secure messaging. In this case, one potential solution that also aligns with the results of this review is simply increasing the transparency around how a particular provider handles secure messages (i.e., do they personally review and respond to all messages?). Exploring patient perceptions of such compromises is a key avenue for future research.

Beyond connecting patients and healthcare providers, patient portals also have the potential to provide social supports (e.g., informational, emotional)⁵⁰ to patients and their caregivers, among families, and among peer patients. Supporting existing relationships and providing a space to build new ones around shared health experiences and needs, especially for those with complex situations (e.g., families with multiple children with health conditions), are important ways that patient portals could be improved to better meet patients' needs.

Give Patients More Control and Design for Variation

Second, patients and caregivers want more control over their health record and, as mentioned above, communications with healthcare providers. Part of this control includes being able to contribute to their medical record both in terms of adding data (e.g., patient-generated health data such as self-tracking data) and making changes (e.g., if a mistake is identified). While there may be barriers to giving patients more control (e.g., liability issues with allowing patients to amend their record without any restrictions), in some cases it may be possible. For instance, research suggests that co-authoring clinician's notes could be feasible, acceptable, and beneficial.^{51,52} Opportunities for more patient contribution to and ownership over their medical record should continue to be explored.

Even among patients that share similar characteristics (e.g., in the same age group), there can be significant variation in what patients want (e.g., simplified versus comprehensive).^{e.g.,30} Now consider the vastly different contexts of the spectrum of patients and caregivers – from patients who only interact with the healthcare system when they have an acute illness (e.g., influenza) to patients that generally only need annual preventive care visits to patients with a chronic condition to patients with multiple chronic conditions to parents of multiple children with chronic conditions (and everything in between). A portal that meets patients' and caregivers' needs must be designed for this variation and must be flexible, enabling customization based on the user's needs, preferences, and values. This could also give users some of the control they desire.

Keep Innovating

Finally, our findings suggest that patients and caregivers recognize the unmet potential of patient portals and want them to do and be more. For example, patients want access to medical records from multiple providers regardless of institutional boundaries.^{e.g.,11} In addition, they also want to receive contextualized medical advice¹⁷ and decision support⁸ through the portal. Rather than just meeting minimum requirements, continued innovation, both in terms of the technology and policy, is needed in order for portals to truly achieve their potential.

Limitations

This systematic literature review has several limitations. One of the most important is that research suggests that key voices are largely missing from the patient portal literature (e.g., low income patients) and, thus, we likely have an insufficient understanding of what these patients and their caregivers want. More research focusing on these populations and how to improve their adoption and use of patient portal technology is needed.⁵³ In addition, while users recommended these improvements to patient portals, and there is some evidence to suggest that implementing user suggestions is correlated with improve adoption and use,⁸ few studies have evaluated the effects of making these improvements. Future research should investigate which improvements are most effective in different contexts. Finally, while two reviewers participated in the screening phase of the review (where the majority of papers were excluded), only one reviewer assessed the full texts, which could have introduced bias. Despite these limitations, this systematic review provides important insights into what patients and their caregivers value in portals, which is

important for a user-centered design approach. A natural next step would be to assess whether major electronic health record vendors' portals meet the patient and caregiver needs described in this paper.

Conclusion

Understanding what users and potential users want from patient portals, and improving portal design accordingly, could be an effective way to increase adoption and use. Existing research suggests that patients and their caregivers want more human connection and control over their health record and their communications with their provider(s) through the portal, as well as more innovation. However, more research is needed to ensure that all patient voices are heard and to evaluate the effects of improving portals based on patient and caregiver suggestions.

Acknowledgements

The project described was supported by the National Center for Research Resources and the National Center for Advancing Translational Sciences, NIH, USA, through Grant UL1 TR001414. The content is solely the responsibility of the authors and does not represent the official views of the NIH.

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