The State-of-the-Art of Patient Portals: Adapting to External Factors, Addressing Barriers, and Innovating

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Abstract

Background and Objective   Recent external factors—the 21st Century Cures Act and the coronavirus disease 2019 (COVID-19) pandemic—have stimulated major changes in the patient portal landscape. The objective of this state-of-the-art review is to describe recent developments in the patient portal literature and to identify recommendations and future directions for the design, implementation, and evaluation of portals.

Methods   To focus this review on salient contemporary issues, we elected to center it on four topics: (1) 21st Century Cures Act's impact on patient portals (e.g., Open Notes); (2) COVID-19's pandemic impact on portals; (3) proxy access to portals; and (4) disparities in portal adoption and use. We conducted targeted PubMed searches to identify recent empirical studies addressing these topics, used a two-part screening process to determine relevance, and conducted thematic analyses.

Results   Our search identified 174 unique papers, 74 were relevant empirical studies and included in this review. Among these papers, we identified 10 themes within our four a priori topics, including preparing for and understanding the consequences of increased patient access to their electronic health information (Cures Act); developing, deploying, and evaluating new virtual care processes (COVID-19); understanding current barriers to formal proxy use (proxy access); and addressing disparities in portal adoption and use (disparities).

Conclusion   Our results suggest that the recent trends toward understanding the implications of immediate access to most test results, exploring ways to close gaps in portal adoption and use among different sub-populations, and finding ways to leverage portals to improve health and health care are the next steps in the maturation of patient portals and are key areas that require more research. It is important that health care organizations share their innovative portal efforts, so that successful measures can be tested in other contexts, and progress can continue.

Keywords
► patient portals
► 21st Century Cures Act
► COVID-19
► proxy portal access
► digital health disparities

Background and Significance

Patient portals are a web- and smartphone-based technology that is typically linked to a health care organization's (HCO's) electronic health record (EHR) system to offer patients access to their medical records and, often, to support communication (e.g., secure messaging) and administrative needs (e.g., appointment management, bill pay).[1,2] As a result of the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, most HCOs now offer patient portals. Patient adoption of portals has been increasing since they became available.[3] However, two major recent events have significantly changed the landscape. First, the coronavirus disease 2019 (COVID-19) pandemic has catalyzed increased patient portal adoption and use—from viewing COVID-19 test results to the rapid deployment of telehealth through portals to enable care while adhering to social distancing measures. Second, key provisions of the 21st Century Cures Act (Cures Act) of 2016 went into effect in early 2021 and made more electronic health information (EHI) immediately available to patients through portals. These external factors have created the critical need to understand current state of the art in patient portal functionality and use, as well as likely future directions.

Existing literature reviews have established that portal use can have benefits such as improved patient adherence to provider recommendations and patient–provider communication[4–15] and that there are numerous barriers to patient adoption and use, such as limited access to technology or low digital literacy, that could prevent portals from achieving their intended outcomes.[4,14,16–23] Despite the significant existing knowledge, major gaps remain, including little being known about effective solutions to: (1) the well-known socio-demographic disparities in portal adoption and use[24] and (2) increasing and optimizing the utility of proxy portal access—when someone the patient has authorized (either informally through sharing login credentials or formally) accesses the portal on behalf of the patient.

Given the recent changes and gaps in current research, we conducted a state-of-the-art literature review focused on contemporary portal topics, issues, and future directions to provide suggestions for evidence-based use. We specifically focus on four topics: the impact of the Cures Act's rule on information blocking on patient portals; how the COVID-19 pandemic has affected patient portal design, governance, adoption, and use; proxy access to portals; and how to address disparities in portal engagement.

Objective

The objective of this state-of-the-art review article is to describe recent developments in portal research and to identify recommendations for patient portal design, implementation, and evaluation, as well as future trends and gaps in the literature.

Methods

We performed a state-of-the-art review[25] of the recent literature focusing on our four topics. We present our detailed search strategy in ►Table 1. These searches were developed iteratively through testing and review of the titles and abstracts of the results. All searches were restricted to 2020 to 2022 except the proxy access topic. The proxy access search was expanded to cover the last 5 years (2017–2022) because unlike the other topics it was an emerging area of

Table 1 Search strategy for identifying studies that align with our four topics: 21st Century Cures Act, COVID-19, disparities in portal adoption and use, and proxy access to portals

Topic	PubMed search strategy	Other identified	Search results
21st Century Cures Act	• Title and abstract • Search limited: 2020–2022 • Search string: ((("patient portal") OR ("personal health record")) AND (("opennotes") OR ("open notes") OR ("open result") OR ("open results") OR ("21st century cures act")))	2	• Total number of results: 26 • Total included: 18
COVID-19	• All fields • Search limited: 2020–2022 • Search string: ((("patient portal") OR ("personal health record")) AND ("covid"))	0	• Total number of results: 55 • Total included: 28
Disparities in adoption and use	• All fields • Search limited: 2020–2022 • Search string: ((("patient portal") OR ("personal health record")) AND (("healthcare disparities") OR ("health care disparities") OR ("health disparities") OR ("health equity")))	2	• Total number of results: 27 • Total included: 12
Proxy access	• All fields • Search limited: 2017–2022 • Search string: (((patient portal) OR (personal health record)) AND ("proxy"))	1	• Total number of results: 78 • Total included: 16

research prior to the COVID-19 pandemic and was not directly affected by the two recent phenomena.

Our study selection approach involved an expert-driven selection of patient portal articles along our four topics. We included original research with all types of study designs. We excluded papers that were not an empirical study (e.g., literature review, perspectives, editorials), experimental research on presenting portal data, studies focused on a technology that did not meet our patient portal definition (e.g., national portal), and studies in which the portal was used only as a means to an end (e.g., identifying study participants). In the first stage of selection, at least two authors reviewed titles and abstracts of all papers identified through our search strategy, with any disagreements resolved through discussion. In the second stage, one author reviewed full texts, applied the inclusion and exclusion criteria, and extracted predetermined information from included papers such as organizational setting, patient population, methods employed, relevant results, and limitations. We did not perform a formal quality assessment but did extract information on methodological weaknesses from each included study. We then performed a thematic analysis,[26] identifying themes within each topic to surface salient recommendations and emerging trends.

Results

We identified 174 unique papers. We excluded 88 based on title and abstract, with the most common reasons being not thematically relevant and not an empirical study. After reviewing the full text of the remaining 86 articles, we excluded an additional 12 for not being an empirical study, not meeting our definition of patient portal, or not aligning with any of the topics. Ultimately, 74 articles on our four topic areas were included. Of note, investigating and addressing disparities in uptake and use of patient portals were studied across categories; we report these results in the "Digital Health Disparities" subsection.

The 21st Century Cures Act

The Cures Act includes the information blocking rule, which stipulates that HCOs must make EHI available to patients immediately upon their request, except in rare cases when exceptions apply. For most health systems, the only feasible way to accommodate the information blocking rule is to place EHI preemptively in the patient portal, even prior to a patient request. While the Office of the National Coordinator for Health Information Technology (ONC) has clarified that this is not required from a policy standpoint,[27] real-world commercial patient portal software and clinical workflows prohibit other modes of capturing and responding in a timely fashion to patient requests for EHI. The reviewed literature lacks clear evidence about how HCOs are accommodating this rule, but ample anecdotal evidence suggests that Cures Act compliance is being achieved by making all visit notes (referred to as Open Notes) and laboratory and imaging test results (referred to as Open Results) immediately accessible to patients through portals. Prior to the Cures Act, some HCOs released visit notes and many released test results through

portals, but with delays based on the sensitivity and risk of misinterpretation.[28] We identified 18 papers that reported results relevant to this topic and three themes within this literature: (1) preparing for increased patient access to their EHI; (2) assessing consequences of increased patient access; and (3) leveraging Cures Act compliance to engage patients (results summarized in ►Table 2). Overall, the research published in the past 2 years has tended to focus more on notes release rather than test data release and has often been conducted in U.S. institutions that launched Open Notes or Open Results in advance of the April 2021 Cures Act deadline.

Preparing for Increased Patient Access

Some HCOs had been preparing for increased patient access to their EHI prior to implementing these changes, specifically understanding patients' and clinicians' preimplementation attitudes and preferences to immediate access to test results and making visit notes available for the first time[29,30] and developing and employing organizational change management strategies.[31–34] The preimplementation literature suggests that patients generally welcome these changes.[29,30] However, Bruno et al suggest that this may be nuanced—when asked about hypothetical scenarios and past diagnoses, patients tended to prefer immediate release of low-sensitivity results such as cholesterol, but contact from a clinician for more sensitive results.[30] In addition, Janssen et al found that clinicians were apprehensive about the idea of sharing visit notes with patients, with their greatest concerns being patient confusion and emotional distress.[29]

We identified a number of strategies targeting clinicians to support changes related to making notes more readily available to patients; there was little mention of proactive patient preparations.[31–34] Clinician-focused efforts included educating clinicians, often by distributing informational materials, and maintaining awareness of changing policies.[33] HCOs also developed a new confidential visit note type to handle sensitive information in specific care contexts (e.g., pediatric[34] and mental health[31]) that defaults to not being shared with patients or caregivers. Two HCOs have employed, or plan to, more active strategies focused on improving the readability of visit notes for patients, including through online education modules and/or functionality in the EHR (e.g., learning mode).[32,35] To date, limited literature suggests that clinicians appear resistant to changing their documentation practices, with the readability of notes sometimes remaining unchanged postimplementation.[29,35]

Consequences of Increased Patient Access

The literature on the positive or negative consequences of increased patient access fell into two groups: (1) evidence from early adopters of Open Notes that has only recently been published and (2) evidence of consequences when there is immediate access to EHI.

Open Notes

There is a significant body of evidence from Open Notes early adopters that has been published in the last 2 years and offers insights relevant to Cures Act compliance. Most of these

Table 2 21st Century Cures Act topic thematic analysis results summary table

Across themes, research has tended to:
1. Focus on Open Notes more than the immediate release of laboratory test results (i.e., Open Results)
2. Be conducted at U.S. institutions that launched the changes in advance of the April 2021 deadline

Theme	Description	Key points
Preparing for Increased patient access	Focuses on the preparations that some health care organizations (HCOs) have done prior to providing patients with increased access to their electronic health information (EHI).	• Preimplementation patients are generally positive about increased access, especially to low-sensitivity EHI results such as cholesterol test results.[29,30] Clinicians tend to be more skeptical.[29] • Literature focuses on clinician-targeted implementation strategies, including education and communication around changing policies.[31–34] • Despite some efforts to improve the readability of visit notes for patients,[32,35] limited existing research suggests that the readability of notes postimplementation sometimes remains unchanged.[29,35]
Consequences of increased patient access	Positive and negative consequences of increased access to EHI, including studies after Open Notes and other Cures Act Compliance efforts have been implemented.	• There are few recently published studies of direct consequences of immediate access to EHI (e.g., incidence of patients viewing test results before clinicians[28]). • Postimplementation, patients remain positive about increased access[36–39] and clinicians remain concerned.[31] Existing literature overwhelmingly suggests that increased access to EHI supports patient engagement without harming the patient–provider relationship, *but* there is significant risk of bias in this body of literature.[33,35–38,40–43] • There is some evidence that Open Notes may be particularly beneficial to underserved populations, *but* there is also evidence of disparities in who accesses and uses their notes.[33,35,40,41]
Leveraging the Cures Act to engage patients	Research considering how to further engage patients by providing additional opportunities for collaboration and technical supports using or building upon the infrastructure being implemented to comply with the Cures Act.	• The few published studies focused on how to improve representation, understandability, and utility of EHI have been promising but have been experimental and limited by low uptake.[44–46] • Patients and caregivers have many suggestions for improving engagement through increased access to EHI such as increasing patient awareness (e.g., advertising availability and utility, notifications, and reminders) and increased clinician training (e.g., using nonjudgmental language in notes).[36,41,45,46]

papers do not specify the timing of the release of visit notes and are largely based on self-report (e.g., surveys) with a high risk of bias (e.g., response bias). However, this body of literature has assessed many outcomes: disparities in uptake[35]; understanding patient, informal caregiver, and clinician perceptions of access to notes[31,36–38]; effect on patient or caregiver engagement[35–41]; and effect on the patient–clinician relationship.[38,40] The postimplementation literature shows similar patient and clinician perceptions as the preimplementation literature. Specifically, studies have found that patients and caregivers who view their notes are generally positive about Open Notes, citing perceived benefits such as supporting care coordination and decreasing caregiver stress.[36–38] Clinicians, on the other hand, often focus on the problems, citing concerns such as patient wellbeing, damaging the patient–clinician relationship, and increasing clinician workload.[31]

Many HCOs have evaluated patient engagement with Open Notes, particularly patient comprehension and use of their data. The studies exploring the former generally show that patients do not report difficulties understanding their notes, but that reading notes may motivate some patients (e.g., those with two or more chronic conditions[37]) to put forth additional efforts such as information seeking.[35,37,38,40] Patients and their caregivers have also reported using Open Notes to better engage in their care in numerous ways such as preparing for appointments[36,37]; postappointment, for example, as a memory aid for care plans and medication regimens and making decisions[36–38,40]; sharing the data with others such as a family member (including across geographic locations)[36,37]; coordinating care with other doctors,[36] and in safety-related concerns such as identifying errors in care documentation.[40,41] While there is some evidence of particular benefit among underserved populations (e.g., patients with lower education levels tended to report higher engagement),[40] there is also evidence of disparities based on race and health status in who reported the errors.[41]

Finally, Open Notes seems to have had a positive impact on the patient– and/or caregiver–clinician relationship, especially among non-white patients.[38,40] However, Lam et al found that concern for harming their relationship with their clinician kept some patients from reporting perceived errors, suggesting that in order for the Cures Act to achieve some of its intended benefits, patients may need to be reassured that their relationship with their doctor will be preserved.[41]

Immediate Access to Electronic Health Information
There has been less focus in the recently published literature on the consequences when there is immediate access to EHI

and, importantly, even fewer studies of the direct consequences of that immediate access. One of the few exceptions is a study conducted by Steitz et al who reported a fourfold increase in the proportion of test results reviewed by patients first (i.e., before their clinician).[28] Another post-Cures Act compliance study found that patients overwhelmingly preferred immediate access to their test results, even when receiving abnormal results; however, although it was a minority of patients, those with abnormal results were more likely to report increased worry as a consequence of reviewing their results before being contacted by a health care provider.[39] Other outcomes that have been assessed when patients have had immediate access to their personal health information (PHI) include disparities in access,[33] patient or caregiver engagement,[33,42,43] and patient–clinician relationship.[43] The results from these studies are similar to those from early adopters of Open Notes, showing that patients and caregivers have used the immediate access to their EHI to engage in their care (e.g., identifying potential errors) and that it has not hurt their relationship with their clinician.[33,42,43]

Leveraging Cures Act Compliance to Engage Patients

The few published studies in this area have focused on ways to improve the representation, understandability, and utility of notes and results to support patient engagement that require no or little clinician effort.[44–46] For instance, Kemp et al found that patients who chose to view a patient-centered, interactive radiology report that included lay language and diagrams through a portal were more engaged with this report than those who chose to view their plain text report.[44] Despite the paucity of research since the deadline for Cures Act compliance, these studies offer promising directions for empowering patients in the context of increased transparency and "Open Everything" and some papers report that similar efforts are underway.[35]

Other studies have also documented patient and caregiver suggestions for improving engagement such as advertising the availability and utility of visit notes,[36] providing reminders when notes are available,[36] training clinicians to adjust their documentation practices (e.g., using nonjudgmental language),[36] offering communication guidance,[36,45,46] and providing clear mechanisms for reporting patient-identified errors.[41]

COVID-19 Pandemic

The COVID-19 pandemic has disrupted health care in many ways and has led to major shifts in service delivery and resources, with patient portals playing a central role particularly in the delivery of telehealth. We identified two primary themes in the 28 papers that published relevant results: (1) developing, deploying, and evaluating new care processes and (2) developing and deploying portal tools for COVID-19 (results summarized in ►Table 3).

Developing, Deploying, and Evaluating New Care Processes

New care processes and workflow changes involving many different stakeholders were needed to successfully transition to telehealth, including changes to scheduling, the additional preparations needed prior to virtual visits (e.g., patient portal enrollment, virtual processes for previsit questionnaires), conversion of in-person processes to the virtual context (e.g., "rooming"), and postvisit follow-up,[47–53] as well as increased remote disease monitoring and virtual patient education programs.[54] To achieve these changes, HCOs also needed to employ implementation strategies to encourage acceptance among the various stakeholders. We found that existing literature was more likely to describe health care professional-facing implementation strategies to encourage acceptance of virtual visits than patient-

Table 3 COVID-19 pandemic topic thematic analysis results summary table

Theme	Description	Key points
Developing, deploying, and evaluating new care processes, especially for telehealth delivery	Providing health care during the COVID-19 pandemic while complying with public safety measures required developing new virtual care processes, which have been documented in the literature.	• New virtual care processes were required for all stages of a visit—*previsit* such as patient portal enrollment, *during* such as "rooming," and *postvisit* follow-up—as well as remote disease monitoring and patient education.[47–54] • The literature describes a wide variety of clinician-facing, sociotechnical implementation strategies, including securing and organizing human resources (e.g., clinician champions); developing guidelines, standard scripts, and best practices; offering trainings and clearly communicating evolving processes and resources; and leveraging technological resources.[47–53,55] • The patient-facing initiatives reported in the literature are limited to technological training and support, with an emphasis on mitigating the risk of digital health disparities.[47–50,52,55–62]
Developing and deploying portal tools to respond to COVID-19	The portal was leveraged as key infrastructure for deploying tools to respond to COVID-19 such as triage.	• Limited literature suggests that portals may successfully be used for triaging, scheduling, and monitoring patients with suspected or confirmed COVID-19.[63–65] • Offering multimodal (e.g., portal and telephone) approaches was important to avoid disparities.[65]

facing strategies. Successful implementation or scaling-up of virtual care was a sociotechnical endeavor requiring multiple initiatives, including securing and organizing human resources (e.g., clinician champions, front-line staff working groups)[47–50,52,53,55]; developing an optimization methodology (e.g., using data-driven processes to map out workflows, identify areas for improvement, and design and evaluate interventions) and/or using an established implementation science framework[48,50]; clearly defining the roles and responsibilities for different members of the clinical team[49,51,53]; developing guidelines, standard scripts, and best practices[48–50,52,53,55]; offering regular trainings and educational materials[47–50,52,53]; developing a robust communication strategy for disseminating evolving processes and resources[47,48,52,55]; and leveraging technological resources to support humans where possible (e.g., automating processes).[49,51,53]

While the literature generally shows that patients are receptive to virtual health care services,[48,58,60,61] patients may also need support to adopt virtual care. The two main approaches in the existing literature focus largely on technical support: offering multiple opportunities for one-on-one patient portal and video visit support (e.g., technical support hotline)[47–49,52,55,56] and providing training and educational resources, sometimes in multiple languages, especially leveraging existing communication modalities (e.g., appointment reminders).[49,50,52,55,57] Only one publication reported efforts to address structural issues like the digital divide, such as providing tablets to patients lacking technological resources.[49] Finally, of note, few studies described including patients in the planning and decision-making stages of the transition to telehealth. While this was likely a function of the emergency context, as the COVID-19 pandemic ends, it will be critical to engage patients in the next stage of telehealth's evolution.

Research has evaluated the effectiveness of these organizational efforts based on metrics such as wait and exam times, proportion of patients completing forms previsit, patient satisfaction, portal enrollment, and portal use (e.g., secure message [SM] volume).[47,48,52,53,58,66–70] Early evidence shows high levels of satisfaction with virtual visits among patients, especially with the time savings (e.g., no travel, decreased wait times).[47,66] Additionally, many studies documented increased portal adoption and use during the pandemic, which is likely the result of a combination of the aforementioned HCO efforts and necessity of the pandemic.[48,52,53,58,66–70] However, studies also documented disparities in patient portal enrollment and virtual visits through the portal during the pandemic,[56,58,69,71–73] with one potential factor being that remote portal enrollment appears less effective than in-person workflows for underserved populations.[56,59]

Deploying Tools for COVID-19 Response
Three studies investigated how the portal, as important virtual care infrastructure, could be used in the COVID-19 response, particularly for triage and remote monitoring of those diagnosed with COVID-19.[63–65] For instance, Judson et al developed and deployed a COVID-19 self-triage and self-scheduling tool through their portal and early evidence showed significant use by patients, high sensitivity for patients with severe disease requiring emergency care, and reduced triage time for patients with less severe disease.[64] Offering multimodal opportunities may be critical to reducing the risk of disparities in uptake and use of COVID-19 response tools.[65]

Proxy Portal Access
Proxy portal access provides a formal mechanism that allows trusted care partners (hereafter referred to as caregivers) to access key EHI about a patient. For example, spouses and parents often serve as proxies for their spouses and children, respectively. Patient portals commonly support proxy access—in one study of the availability of shared access to patient portal accounts in 20 health care systems, all offered shared access for parents or legal guardians of children (most often defined as <12 or 13 years old), and almost all offered some shared access for adolescents and adults (although it tended to be more limited).[74] However, the literature suggests that while formal proxy portal account use in the pediatric context can vary (e.g., 45% of patients <18 years[33] vs. 90% of logins for 12-year-old patients[75]),[33,75,76] it has been almost universally low among different adult patient cohorts (e.g., less than 3% of patients with serious illness[77])[76–79] despite being recommended as a way to address eHealth literacy concerns.[80] It has been hypothesized that informal proxy use (share credentials to a patient's portal account) is relatively more common for adult patients. We discovered three themes in the 16 relevant papers: (1) who are portal proxies and how do they use the portal, (2) barriers to formal proxy use, and (3) identifying informal proxies and understanding the patients who share their account information (results summarized in ►Table 4).

Who Are Portal Proxies and How Do They Use the Portal?
Patients often select family members (e.g., spouse, child), close friends, or even neighbors to have formal or informal proxy portal access,[36,56,81–83] but sometimes chose (or also chose) paid home caregivers or clinicians that document in a different EHR to help close the gap in care coordination caused by a lack of interoperability in clinical systems.[56,81,83] Meanwhile, Jackson et al found that 78% of proxies saw the patient daily, suggesting that proximity may be a consideration when choosing a portal proxy.[36]

Existing studies also provide insights into the roles that caregivers play in patients' health and wellbeing and how they use the portal to support these roles. Caregivers assist patients in both health care tasks, including providing instrumental support in getting patients to medical appointments, gaining digital access (e.g., assisting the patient to activate their portal account), reminding them to take medications, and communicating with clinicians,[56,81] and in everyday life tasks such as cooking.[81] Qualitative studies have found that proxy portal access supports some of caregivers' tasks, including communicating with clinicians and others (e.g., members of the patient's social support system), especially during times of transition[78,81,83]; managing appointments and medications[83]; checking laboratory test

Table 4 Patient portal proxy access topic thematic analysis results summary table

Theme	Description	Key points
Who are proxies and how do they use the portal?	Research characterizing proxy portal users and seeking to understand how they currently use, or may want to use, the portal.	• Patients usually choose lay-individuals close to them (in terms of physical proximity and/or social connection),[36,56,81–83] but sometimes choose health care professionals (home caregivers or clinicians with a different EHR) to address gaps in care coordination.[56,81,83] • Proxies use portal access to support their caregiving role such as communication (with clinicians and others), especially care coordination; managing appointments and medications; decoding information for the patient; and advocating for the patient.[78,81,83,84]
Barriers to formal proxy use	Understanding the barriers to formal proxy use, which is critical to decreasing informal proxy use and increasing formal proxy account creation.	• There are several sociotechnical barriers to establishing formal proxy accounts, including insufficient or ineffective communication around creating proxy accounts; technical challenges with setting up accounts (e.g., poor usability); and few obvious incentives for creating a formal account (e.g., granular control over the information to which formal proxies have access).[74,81,85–88]
Identifying informal proxies and understanding the patients who share their account information	Identifying informal proxies (those who log-in to a patient's account using the patient's credentials) and investigating whether certain patient populations are more likely to share their log-in credentials than others. This could be useful for targeting interventions to increase formal proxy account use.	• There are direct (i.e., asking study participants) and indirect (e.g., using linguistic indicators in secure messages) strategies for identifying informal proxies.[36,43,78,79,81,82] Indirect, natural language processing-based strategies could be useful for large-scale identification of "hidden proxies."[79] • Patients who are older, non-white, male, married, with lower education levels, and indicators of worse health have been found to be more likely to share their patient portal log-in credentials with a care partner (i.e., have an informal proxy). It could be efficient to target messaging about formal proxy accounts to these patient populations.[78,79,82]

Abbreviation: EHR, electronic health record.

results[83]; decoding information for the patient (e.g., explaining test results)[81]; advocating for the patient[84]; and providing access to key information during emergencies.[81,83] Importantly, limited existing research also suggests that many portal proxies try to respect patients' agency and privacy by only accessing the medical information necessary for a given task.[81,83]

Barriers to Proxy Portal Use

While HCO leadership (and proxies themselves[83]) may prefer that caregivers set up formal proxy accounts when they are available for security reasons, there appear to be a number of barriers to proxy use particularly through formal accounts, including some HCOs not offering proxy accounts (or not offering them for all patient groups such as adolescents),[74,85] institutional policies (in accordance with state laws) that limit parental access for adolescents,[87,88] insufficient or unclear communication around proxy accounts (e.g., HCO personnel endorsing password sharing),[85,86] challenges with setting up an account (e.g., poor usability),[86] and few obvious incentives to set up a formal account (compared to sharing login credentials).[74,85] For example, among HCOs that offer proxy access, the published literature suggests that 20% or

fewer offer patients control over the data their proxies are able to access.[74,85] This lack of granular control can be a major barrier to providing caregivers with proxy access outside of an emergency, particularly for stigmatized conditions.[81]

Identifying Informal Proxies and Understanding the Patients Who Share Their Account Information

We define informal portal proxies as those caregivers who access a patient portal account on behalf of a patient through the sharing of the patient's login credentials. Informal proxies circumvent organizational security precautions about access to PHI. Being able to identify when informal proxies exist is an important first step for targeting interventions to decrease this practice. There is not currently a published method for large-scale informal proxy identification. However, we identified three studies that approached this problem by directly asking participants through surveys or interviews[36,43,81] and three studies basing their estimates on language used in SMs, such as referring to patients in the third person.[78,79,82] In the former, estimates of informal proxies range from 2.1% (150/7,058 survey respondents[43]) to 40% (4/10 interview participants[81]). Among the latter, two

studies were based on manual review[78,82] and one study developed a computational mechanism that identified a similar percentage of patients with likely proxy-authored SMs as a manual review did (45.7% of 9,856 patients[79] vs. 54.1% of 1,254 patients[78]).

Research suggests that informal proxy-authored SMs are more likely for patients who are older[79]; non-white[79]; male[82]; married[82]; have lower education levels[79]; and have indicators of worse health (e.g., more comorbidities, more advanced disease) or conditions that affect cognition (e.g., Alzheimer's disease).[78,79,82] Similarly, Semere et al also found that patients with a high proportion of predicted proxy-authored SMs were more likely to be older, non-white, and have indicators of communication barriers (e.g., lower health literacy) and worse health (e.g., more comorbidities).[79]

Digital Health Disparities

Twenty-five included articles covered disparities related to patient portal adoption and use, with two themes emerging: (1) identifying disparities and barriers to adoption and use and (2) addressing disparities (summarized in ►Table 5).

Identifying Disparities and Barriers to Adoption and Use

Research demonstrates consistent disparities in portal adoption and use through studies of the general population (i.e., Health Information National Trends Survey [HINTS]),[89–91] within specific HCOs,[56,58,69,71–73] and among specific subpopulations (e.g., palliative care patients).[77,92,93] These studies have found that disparities remain in who is offered portals, who accesses them, and who uses certain features, particularly Open Notes and video visits. The recently published literature shows that portal engagement is less likely among patients who are older[35,56,73,77] or younger in the context of telehealth during the COVID-19 pandemic,[56,58] men[35,56,72,90] or women in the case of serious illness,[77]

nonmarried,[35] and non-White,[33,35,73,77,89,92,93] as well as those with limited English-language proficiency,[33,58,71,72,90,92,93] indicators of lower socioeconomic status,[33,35,72,73,90,92,93] better health,[35,58,77,93] lower technological engagement,[55,58,71–73] and less access to health care (e.g., without a regular doctor).[73,90] Two analyses of HINTS datasets found conflicting results from existing HCO-based studies: among those who access portals, there do not appear to be disparities in feature use. This difference in findings may reflect methodological differences between studies (e.g., self-report vs. audit logs, the specific features investigated).[89,90]

Research has also identified barriers among underserved populations and especially surrounding certain, often stigmatized, health conditions, including perceived lack of need to access EHI,[91] privacy concerns,[91,94,95] usability issues (e.g., too many links overwhelming patients),[94] and perceived negative effect on patient–care team communication (e.g., extra step to contact care team).[84]

Addressing Disparities

Numerous telehealth studies suggest the importance of offering multimodal opportunities for remote patient engagement, including telephone calls and text messages, to mitigate the risk of disparities.[58–62] For example, Davis et al reported on their telephone outreach efforts to augment their patient portal process for remote symptom monitoring among cancer patients, finding that they were able to increase the number of completed screens, identify additional needs, and capture a higher percentage of black and older adult (61–80 years) patients through telephone outreach.[59]

Outside of the telehealth context, few studies published within our timeframe evaluated strategies for addressing disparities in portal engagement, with two exceptions.[89,96]

Table 5 Digital health disparity topic thematic analysis results summary table

Theme	Description	Key points
Identifying disparities and barriers among specific populations or people with specific conditions	Recent studies have continued to monitor for disparities in patient portal adoption and use.	• Current data suggest that portal adoption and use is still less likely among several groups, including men and black and Hispanic patients, as well as those with limited English-language proficiency, lower levels of education, and less access to health care.[56,58,69,71–73,89–91] Similar disparities are seen in special care contexts such as palliative care.[77,92,93] • There is some evidence that, among those who access, there may be few differences in feature use,[89,90] but this may depend on the study methodologies, features evaluated portals, and care contexts. • There is also some evidence that perceived need, privacy and security concerns, usability issues, and perceived negative effect on patient–care team communication are driving some of the disparities in portal engagement.[84,91,94,95]
Addressing disparities	Developing, deploying, and evaluating strategies for addressing disparities in portal adoption and use.	• Clinicians play an important role in encouraging or discouraging portal engagement.[89] • Addressing the digital divide[96] and offering multimodal mechanisms[58–62] to engage in one's care can mitigate the risk of digital health disparities.

Through their analysis of a nationally representative survey, Richwine et al found evidence that clinicians play an important role in black and Hispanic patient engagement with portals.[89] Griffin et al found an association between providing tablets to veterans with access barriers and an increase in portal adoption and use, although the biggest increase was among those who were already active users of the portal and lowest among nonusers, suggesting that other interventions are still needed to improve the initial engagement with portals.[96] Other studies provide recommendations based on their results such as: EHR vendors should (1) remove technological barriers to enrollment (e.g., email address requirements)[97] and (2) include safety net patients in their user experience testing to identify issues earlier in the design process,[97] and (3) HCOs should improve their portal marketing (e.g., clearly articulate the portals' everyday utility, targeted messaging).[97,98]

Discussion

The findings of this state-of-the-art review point to ongoing and emerging sociotechnical challenges with portals, especially the rapid evolution of portal policies, processes, and features in response to the external environment and significant implementation efforts by many HCOs. These efforts seem to have effectively increased patient engagement with portals during the pandemic, providing patients access to video visits and key resources (e.g., remote screening and monitoring programs). However, the literature also shows that portals do not seem to be the most effective way to interact with all patient populations and that flexible, multimodal delivery of care is crucial to avoid creating barriers to health care access. While there have been noteworthy efforts to make patient portals more user-friendly and empowering

for patients, the extent to which these efforts extend beyond single HCOs (and especially academic institutions) is largely unclear. Ultimately, it is critical to learn from and build upon the experiences of innovative HCOs.

Toward this end, we drew on our findings on HCO experiences and successes, as well as other relevant literature, to develop several recommendations for HCOs, EHR vendors, and researchers to continue improving the design and implementation of patient portals. **Box 1** contains the full list of recommendations by the stakeholder group. We discuss a selection of these recommendations, specifically the need for multistakeholder commitment to addressing disparities in portal adoption and use and to supporting patient and caregivers when they view EHI, as well as more research to understand how newer mechanisms for accessing and leveraging EHI will affect patient portal adoption and use.

HCOs, EHR vendors, and researchers all have a role to play in the continued work to (1) address disparities in portal adoption and use and (2) better support all patients and caregivers as they view EHI with little support from clinicians. First, patient portals are integral to many HCOs' infrastructure and can be leveraged in many ways both during a crisis and in everyday contexts. For example, while outside of the scope of this review, we identified several studies that have leveraged portals as critical infrastructure for purposes outside of direct patient care, often research (e.g., delivering surveys).[99–106] Investing in the continued improvement of portals has the potential for benefits to patient care and beyond. However, it also means that addressing the well-established disparities in uptake and use[56,58,69,71–73,107–111] is critical for equitable access to these benefits. HCOs should develop, evaluate, and disseminate the results of innovative portal efforts to equitably engage patients; suggestions from the literature include screening

Box 1 Recommendations for health care organizations, electronic health record vendors, and researchers to continue improving the design and implementation of patient portals based on the findings from this state-of-the-art review

Health care organizations
• Continue to invest in the infrastructure necessary to virtual services, including offering flexible, multimodal options that can meet the preferences and needs of diverse patient populations. • Better support patients, especially through transitions in access to EHI and engagement in their health care. • Understand and address clinician concerns and resistance to changing visit note documentation practices to better communicate with patients. • Develop, evaluate, and disseminate the results of innovative portal efforts to equitably engage patients. Electronic health record vendors • Make it easier to create a proxy account and offer patients more control over what formal proxies can access. • Engage diverse patients in the design and testing of portals and features. Researchers

Future research directions include the need for more evidence to understand
• How to better support patients as they view their EHI, especially test results, outside of interactions with health care professionals (e.g., understanding the potential role of artificial intelligence tools such as chatbots). • Direct consequences of immediate access to EHI, and especially test results, for patients across health care contexts (e.g., safety net). • How newer mechanisms for viewing and leveraging one's clinical data will affect patient portal engagement. • How to address persistent disparities in the uptake, use, and effectiveness of portals. • How proxy accounts could be improved to better support caregiver needs and how to increase proxy account creation. • How to build on the progress in portal engagement made during COVID-19 for sustainability outside of the public health crisis.

Abbreviation: EHI, electronic health information.

for eHealth literacy,[80,112] ensuring that portal accounts are automatically created for all patients upon registration,[113] leveraging care settings with high proportions of vulnerable patients and significant wait down-times (e.g., emergency department),[114] using innovative methods to improve the understandability of EHI in portals,[115] providing targeted training and support,[80,112] and promoting formal proxy users.[80,116] Additionally, and as Casillas et al[97] and others[49] have recommended, EHR vendors should include diverse patient populations (e.g., non-English speaking patients) in the early phases of portal design, re-design, and feature development to ensure that they meet the needs of these users. Researchers should focus on how to sustainably address structural barriers to portal engagement. With the exception of initiatives that provide tablets to patients,[96,117,118] existing solutions have largely focused on patient education or have bypassed portals altogether, instead using other modes of communication such as telephone. While telephone communication may be acceptable in some cases, video visits have advantages such as allowing for some visual assessments.[119] There continues to be a need to identify organizational and societal strategies that enable equitable access to patient portals.

Second, as others have noted,[120] overall, clinicians should feel reassured about early evidence on increased patient access to EHI; however, that does not mean that patients do not need more support and preparation. The few existing efforts to prepare patients for increased access to their EHI have tended to focus on patient education. While this is an important tool, it is not the only one that could be employed. More socio-technical solutions that leverage the existing technological infrastructure and limit additional burden on clinicians should be developed and evaluated.[121,122] For example, portal-integrated artificial intelligence tools such as chatbots and GPT (Generative Pretrained Transformer) could be explored for addressing common patient questions or providing lay-person summaries. Given the high proportion of patient portal users accessing their test results[108,110,123–143] and the existing research showing that many patients have questions about their results and sometimes seek information outside of the formal health care system (e.g., online health communities),[121,144–147] researchers should especially focus on developing effective tools for helping patients understand their test results at the point of viewing. HCOs should focus on preparing patients prior to key transitions in access to EHI. The two transitions highlighted in our review were increased access to EHI among all patients and autonomous viewing of medical records during adolescence. Finally, similar to the findings from another recent review,[148] EHR vendors should develop mechanisms to prevent inappropriate account creation and access (i.e., caregivers of adolescents),[149] make it easier to create a formal proxy account, and offer patients more control over what formal proxies can access, as the existing research suggests that caregivers support patients in decoding their EHI (among many other tasks).

Another key future research direction is understanding how newer mechanisms for viewing and leveraging one's clinical data will affect patient portal engagement. Specifi-cally, another key aspect of the Cures Act was the provision that certified EHRs must provide standards-based application programming interface (API) access to EHI. This creates the potential for patients to access and leverage their data using new mechanisms such as non-HCO affiliated mobile applications (apps). This could affect portal engagement in the future if the more modular approach offered by an interconnected mobile health app ecosystem provides significant relative advantage for patients. However, given that this is currently a one-way transfer of information (EHI pushed to apps), the slow uptake of existing apps,[150] and relatively limited number of apps with the capability to download data via a standards-based API in the open app marketplace,[151] it is far from certain whether this will be a viable alternative to patient portals.

Limitations

This state-of-the-art review has several limitations. First, while we used a systematic approach for this review, it was not intended to be a systematic review and, thus, we cannot claim comprehensive coverage of the literature. Second, given the plethora of existing reviews, we chose to maximize our efforts and focused on a narrow timeframe and set of topics. It is important to note that many of the unaddressed problems highlighted in previous literature reviews are likely to still be problems despite being out of the scope of this review. For instance, many prior studies have cited usability issues with portals,[124,152–163] but it was not a major finding in our review. This does not mean that problems such as inconsistency across platforms are not still issues, especially considering that a recent survey of U.S. adults found that 44% of those with a portal account were managing two or more accounts.[164] Third, although multiple researchers performed the initial screening, collaboratively refined the inclusion and exclusion criteria, and built consensus around decisions, a single researcher was primarily responsible for the full-text screening (based on the first-round discussions), data extraction from included papers, and thematic analysis. However, it should be noted that most papers were excluded in the first stage of screening (88%, 88/100). Fourth, we chose to include articles where the research was conducted far in advance of the 2020 to 2022 publication date criterion (sometimes several years), which was particularly common in the 21st Century Cures Act research, because we felt that the results were still relevant to the topic. Finally, the authors acknowledge that there are other models of patient-accessible EHI, such as national portals which are common outside of the United States, that have been widely studied, and may include some results that are also relevant to portals, but given that there may be somewhat different levels of access to data (i.e., summary record vs. raw EHI), drawbacks, and benefits, these technologies are outside of the scope of this review.

Conclusion

While the COVID-19 pandemic and the Cures Act have catalyzed progress in providing more of what patients want in portals (e.g., video visits, faster access to test results),

and consequently increased uptake and use in many places, it remains to be seen whether this progress is sustainable postpandemic. The recent trends toward understanding the implications of increased access to EHI and how to best support patients as medical records become more transparent without corresponding increased support from health care professionals, closing gaps in portal adoption and use among different sub-populations, and finding innovative ways to leverage portals to improve health and health care are important steps in the maturation of patient portals and are areas that will likely continue to be explored. It is crucial that HCOs share their innovative portal efforts, so that successful measures can be tested in other contexts, and progress can continue.

Clinical Relevance Statement

Patient portals are a critical part of the health care infrastructure. While several literature reviews focusing on patient portals have been previously published, recent external factors (i.e., the Cures Act and COVID-19 pandemic) as well as open questions and gaps from previous reviews call for a targeted investigation of the recent literature. This state-of-the-art review offers HCO examples of how to prepare for, thoughtfully implement, and evaluate major changes in care revolving around the patient portal infrastructure. Key findings include the importance of building and maintaining a strong sociotechnical infrastructure for virtual care (including the people, policies, workflows, and technologies) that can be adapted based on changing HCO needs and providing multimodal opportunities for patients to access care remotely. Based on these results, we offer several recommendations to HCOs such as better supporting patients through changes in clinical information management (e.g., from parent-managed information to adolescent-managed) and work to understand and address clinician resistance to visit note documentation changes to improve the utility of these data for patients.

Multiple-Choice Questions

1. What strategies have health care organizations deployed to prepare for major externally driven changes to care such as increased patient access to their EHI and telehealth?
   a. Having a test period prior to full implementation.
   b. Offering regular trainings and educational materials.
   c. Developing guidelines, standard scripts, and best practices.
   d. Leveraging technological resources to support humans where possible (e.g., automating processes).
   e. All the above.

   Correct Answer: The correct answer is option e. Murugan et al reported their experience with having a test period prior to the 21st Century Cures Act going into effect (referred to as "learning mode") to offer clinicians the opportunity to prepare for this change and get feedback on their visit note practices. Several papers credited the remaining answer options (b–d) for the successful launching or scaling up of virtual care at the beginning of the COVID-19 pandemic. With that said, most of the evidence for these practices is anecdotal and lacks an implementation science approach to evaluating their effectiveness.

2. Which of the following is a key barrier that could affect formal proxy account registration?
   a. Adult patients are not interested in having care partners.
   b. Lack of granular patient control over what proxies can access.
   c. It is impossible to identify informal proxy use.

   Correct Answer: The best answer is option b. The literature has proposed this as a barrier, and it is possible that, without some obvious benefit such as enabling more control over the data and services for which proxies have access, patients do not see a reason to formally grant a care partner access. However, more research is needed to test the effectiveness of this feature. Adult patients are indeed interested in having care partners and the literature suggests that many are willing to grant care partners at least some access to their data. Finally, although it is challenging to identify informal proxy use of portals, there are promising mechanisms such as algorithms for identifying messages with linguistic indicators such as referencing themselves in the third person. More importantly, though, this has not been identified as a key barrier to formal proxy account registration in the literature.

Authors' Contributions
S.T.R. and J.S.A. conceived and designed this state-of-the-art review. T.L.R., B.D.S., J.S.A., and S.T.R. developed the search strategy and participated in the first round of screening. T.L.R. conducted the second round of screening with input as needed from the other co-authors. T.L.R. led the thematic analysis with input from the other co-authors. T.L.R. drafted the manuscript. All co-authors contributed to the final manuscript.

Protection of Human and Animal Subjects
No human or animal subjects were involved in the project.

Conflict of Interest
None declared.

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