



Patient and Family Perceptions of Real-Time Access to Electronic Health Information: A Social Media Survey

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Abstract

Objective This study seeks to understand pediatric rheumatology patients' and caregivers' utilization and perceptions of immediate access to their electronic health information (EHI) via patient portals.

Methods An anonymous, 23-question Qualtrics survey was distributed via social media to patients and families with pediatric rheumatic diseases. The survey link and Quick Response (QR) code were posted on disease-specific Facebook accounts. Descriptive statistics were used with a thematic content analysis performed on free-text responses.

Results The survey received 253 eligible responses. Nearly 48% of participants reported accessing their electronic patient portal >12 times in the last year, while only 0.4% (one respondent) reported accessing it zero times and 8% reported accessing it 1 to 2 times. Following a medical appointment, 45% reported regularly accessing their portal the same day as their appointment, 36% when they get an alert for new results, and 0.8% only in response to a healthcare provider message. About 98% use the patient portal to access laboratory results, 98% provider notes, 80% healthcare provider messages, 64% imaging results, 53% appointments, and 28% medications. Thematic content analysis found that respondents use the portal for coordination of care and to advocate for themselves or their child. The emotional impact of access to EHI without provider explanation was variable by respondent, with some reporting increased worry and some less worry. Many respondents (18%) found value in posting results to social media sites for help in interpretation.

Keywords

- ▶ clinical informatics
- ▶ electronic health record
- ▶ patient portal
- ▶ rheumatology
- ▶ patient participation

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Conclusion This study demonstrates pediatric rheumatology patients' and caregivers' strong portal engagement and expectation for immediate access to EHI through the patient portal. Although some did report that access to EHI without provider input can increase worry or anxiety, families perceive the patient portal as a tool for self-advocacy and engagement in care, leading to a stronger sense of their role as a member of the care team.

Background and Significance

As electronic health records (EHRs) have become widely adopted, patients' access to their own medical data through electronic patient portals has become common, with prior studies suggesting that patients with access to their electronic health information (EHI) may have improved medication adherence, better health outcomes, increased engagement in their care, and decreased utilization of emergency-level care.^{1,2} In one study, an activated patient portal account was found to be associated with higher rates of patient satisfaction, especially in relation to doctor–patient communication and care coordination.³ The COVID-19 pandemic served as a strong driving force behind rapid uptake of digital health solutions and more patients than ever now have access to their patient portals.⁴

In April 2021, the 21st Century Cures Act Final Rule went into effect, requiring healthcare institutions to provide all patients free and immediate access to their EHI, including unstructured data like medical notes.⁵ This prohibited information blocking and may have further increased the number of patients with access to their patient portals.^{6,7} Patient perception of this rule has largely been positive, although a small number of adult patients and caregivers reported increased worry as a result of viewing test results prior to discussion with a healthcare provider.^{2,8} The sensitivity of the data, such as a cancer diagnosis, has been shown to play a role in patients' willingness to receive results via the patient portal.^{9,10}

Pediatric patients and caregivers have also perceived benefits to immediate EHI access such as improved understanding of their/their child's medical care and increased trust in their/their child's doctor.^{11,12} However, few studies have been conducted in the pediatric population and therefore little is known about pediatric patient and parent/caregiver impressions of expanded EHI access. Portal and EHI access in the pediatric population present unique issues related to varying ages and developmental stages of patients, the dynamics between the patient and the parent/caregiver, and restrictions in EHI access for parents of many teenage patients.^{13,14} Furthermore, pediatric chronic disease presents its own challenges due to the high healthcare utilization with frequent medical visits, potential for hospital admissions, and long-term medications required for many of these patients. Interactions with the medical system, and thus potentially with the patient portal, may be higher and the impacts of the portal on health outcomes and quality of care more significant.¹⁵ With expertise in pediatric rheumatology, the authors sought to

explore patient and parent/caregiver utilization and perception of EHI access in a population of pediatric patients with multisystem chronic disease, so as to inform current provider and patient portal interactions and future patient portal engagement efforts.

Objectives

Through survey distribution using social media (Facebook), this study sought to:

1. Describe current use of and engagement with the electronic patient portal and EHI among pediatric rheumatology patients and caregivers.
2. Explore perceptions, impact on worry or anxiety, and preferences of immediate access to EHI among this population.
 - a. Examine the impact of disease duration on patient's perception of immediate access to EHI.

We hypothesized that patients and families with longer time since diagnosis would be less likely to be anxious about seeing their results before discussing with a provider.

Methods

Survey Development

The survey was developed in coordination with all research team members with feedback solicited from experts in the field of survey design. The survey was then pilot tested by three authors (CP, TR, and RP) with individual patients during clinic visits. Real-time, verbal feedback was provided by these patients as they completed the survey.

Study Setting

This is a cross-sectional study of pediatric patients with rheumatic disease and their parents/guardians/caregivers (hereafter referred to as "caregivers"). The survey was completed asynchronously by respondents online and no compensation was provided. For each survey response, either the patient (child) or the caregiver responded. This study was approved by the Duke Institutional Review Board (approval no.: Pro00113906).

Subject Characteristics

Respondent demographics were self-reported. Inclusion in the study required attestation to a diagnosis of a rheumatic

disease by a pediatric rheumatologist. Exclusion criteria included country of residence outside of the United States and lack of EHI access (no patient portal access). Survey responses outside of the United States were excluded with the understanding that access to EHI may be variable in other countries. Respondents who completed only the demographics sections of the survey were also excluded.

Data Collection

An anonymous, 23-question Qualtrics survey (Qualtrics, Provo, Utah, United States; [►Supplementary Appendix A](#)) was distributed via social media (private, disease-specific Facebook groups) to patients and families with pediatric rheumatic diseases. Surveys were distributed by parents of children with rheumatic disease who collaborate on research initiatives within the Childhood Arthritis and Rheumatology Research Alliance (CARRA). CARRA is an international research network for pediatric patients with rheumatic disease and facilitates collaborative research within the pediatric rheumatology community.¹⁶ Our parent collaborators identified contacts for juvenile idiopathic arthritis (JIA), juvenile dermatomyositis (JDM), systemic lupus erythematosus (SLE), chronic noninfectious osteomyelitis (CNO), autoinflammatory diseases, scleroderma, vasculitis, and Sjogren syndrome who shared the survey link and Quick Response (QR) code. Captcha verification in Qualtrics was used to confirm respondents were human and not bots. The survey was available for 10 days in November 2023.

Survey Content

Survey questions solicited respondent preferences around EHI access and receipt of results prior to a provider's review. Frequency and timing of patient portal login and usage of tools within the portal were explored. Respondents were asked to rate how often they use social media, the internet, or a friend/family member to help interpret results, post results to social media, read notes by their provider, request records be changed for accuracy, or use the patient portal to share EHI with another healthcare system. Finally, free-text questions queried respondent's likes and dislikes around EHI access, and respondent's suggestions for providers or the portal to minimize worry associated with this EHI access.

Analysis

Descriptive statistics and a Wilcoxon's rank sum test were utilized, including for those questions where a 5-point Likert scale was used (1 = strongly disagree to 5 = strongly agree). A p -value <0.05 was considered significant. Survey results were exported to R Studio for analysis.¹⁷ Respondents' preferences around release of test results in the patient portal and the impact on worry and anxiety of having access to the results without a healthcare provider's interpretation were analyzed by time since diagnosis (either within the last 5 years or more than 5 years ago) based on feedback from parent collaborators. For the three free-text response survey questions, thematic analysis was conducted as outlined by Braun and Clarke.¹⁸ Three of the study authors (CP, TR, and RP) reviewed the answers to the free response questions

using an inductive approach. In the first stage of coding, researchers individually assessed the free responses of each question separately for codes, which are the most basic features that describe the data in a meaningful way.¹⁸ The three researchers then reviewed the results for any fundamental differences in coding. Thematic saturation was defined as the number of responses after which no new codes were identified in the data. The entire research team agreed upon codes and then identified themes that emerged across responses to all free-text survey questions.

Results

The survey received 325 initial responses; 23 responses were never finished, 34 listed countries of residence outside the United States, 14 did not have, or were unsure if they had, EHI access, and 1 participant did not confirm a diagnosis by a pediatric rheumatologist. There were 253 eligible responses, the majority of which were English speaking (99%) with self-reported race of White (81%). About 5% of respondents were patients, and the remainder were caregivers ([►Table 1](#)). The

Table 1 Demographics and diagnoses of eligible respondents with completed surveys

Respondent demographics	N (%) N = 253
Respondent	
• Patient	12 (5)
• Parent/guardian/caregiver	241 (95)
Patient's age 12 years+	117 (46)
Primary language	
• English	252 (99.6)
• Spanish	1 (0.4)
Race	
• Asian	3 (1.2)
• Black, African American, African, or Afro-Caribbean	2 (0.8)
• Hispanic, Latino, or Spanish origin	6 (2)
• Native American, American Indian, or Alaskan Native	1 (0.4)
• White	204 (81)
• Two or more races	33 (13)
• Prefer not to answer	4 (1.6)
Diagnosis	
• Juvenile idiopathic arthritis (JIA), including those with hypermobility or amplified musculoskeletal pain	96 (38)
• Systemic connective tissue disease ^a	157 (62)
Years since diagnosis, median [IQR]	4 [2,8]

^aIncludes systemic lupus erythematosus, mixed connective tissue disease, Sjogren syndrome, inflammatory myositis, vasculitis, scleroderma, autoinflammatory syndromes (including periodic fever syndromes), and chronic noninfectious osteomyelitis.

median time to survey completion was 4.2 minutes (IQR: 3.2, 6 minutes).

Portal Usage

Nearly 48% of respondents reported accessing their patient portal more than 12 times in the last year, with only 8% reporting access 1 to 2 times in the past year. One respondent (0.4%) had not accessed the patient portal within the last year. Following an appointment with a provider, 45% said they regularly access the portal the same day, 36% access only when they get an alert regarding new results, 10% access the portal the day after the appointment, and 0.8% access the portal only when a healthcare provider reaches out. With regards to how they use the patient portal, most respondents (90%) recognized multiple uses of the patient portal, with 98% using the portal for laboratory results, 80% for healthcare provider messages, 64% for imaging results, 53% for appointments, and 28% for medications. About 5% of respondents indicated they use the portal for “other” reasons, including reviewing physician charges, letters, and patient instructions (→Table 2).

Respondents were then surveyed regarding their uses of the patient portal and EHI on a 4-point Likert scale (always, sometimes, rarely, never; →Fig. 1). Most respondents (80%) reported getting help in interpreting laboratory results from social media, the internet, or a family member/friend, though 82% had never posted screenshots of test results to social media sites. Overwhelmingly, respondents reported reading provider notes in the portal, with 80% indicating they “always” do and 18% indicating they sometimes read the notes. With this high rate of portal usage, nearly one-quarter of respondents (23%) have requested their records be changed for accuracy after viewing them in the patient

Table 2 Portal access and data usage

Portal access and data usage results	N (%)
Number of times portal was accessed last year	
• 0	1 (0.4)
• 1–2	19 (8)
• 3–6	51 (20)
• 7–12	38 (15)
• More than 12	121 (48)
• Null values ^a	23 (9)
Timing of access to portal after physician visit	
• Same day	113 (45)
• Next day	26 (10)
• Only with an alert for new results	90 (36)
• Only when a healthcare provider reaches out	2 (0.8)
• Null values ^a	22 (9)
Portal uses (multi-select)	
• Laboratory results	249 (98)
• Physician notes	248 (98)
• Healthcare provider messages	202 (80)
• Imaging results	161 (64)
• Appointments	133 (53)
• Medications	71 (28)
• Null values ^a	0 (0)

^aFor any missing data, the number and percentage are included under “null values.”

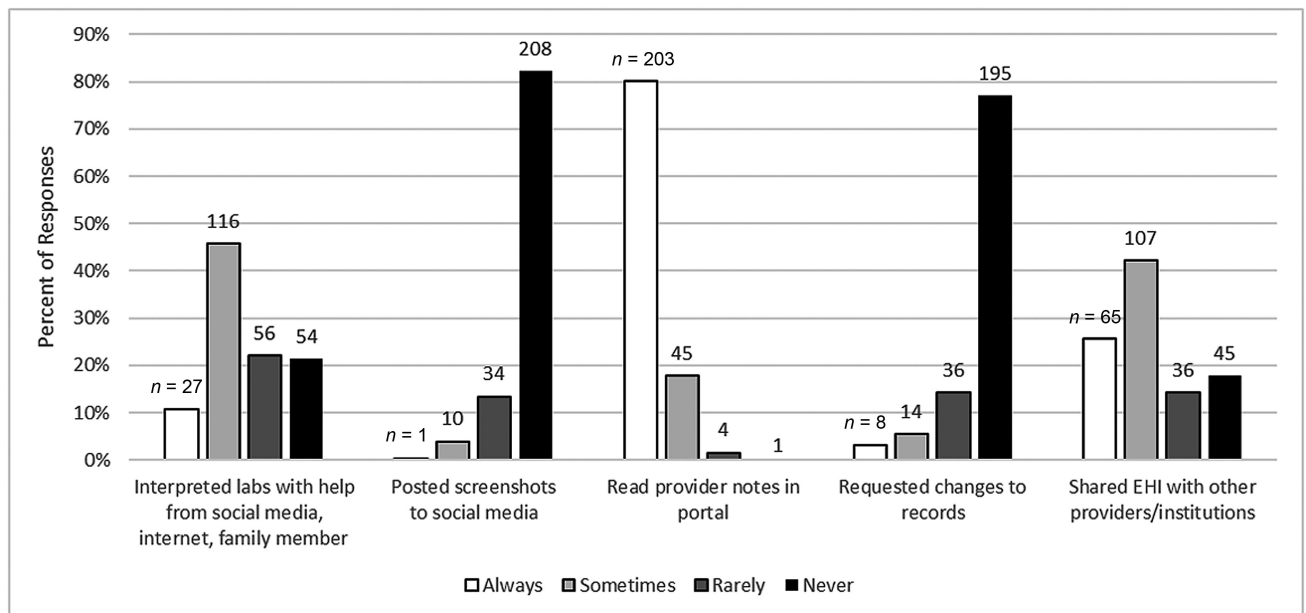


Fig. 1 Percentage rates of response on a 4-point Likert scale (always, sometimes, rarely, never) regarding respondent’s use of the patient portal and electronic health information (EHI).

portal. Finally, respondents reported using the patient portal to share their EHI with other providers or healthcare institutions, with only 18% of respondents reporting they had “never” used their patient portal for this purpose.

Perceptions of Increased Electronic Health Information Access

We then explored respondents’ preferences around release of test results in the patient portal and the impact on worry and anxiety levels of having access to the results without a healthcare provider’s interpretation (►Table 3). When comparing responses by time since diagnosis (either within the last 5 years or more than 5 years ago), both subsets of respondents reported they “strongly agree” with having electronic access as soon as test results are available (median = 5, IQR: (5,5), p -value 0.28). Overall, respondents diagnosed within the last 5 years were significantly more likely to disagree with waiting for results to be released until provider review (p -value 0.03). Finally, a majority of respondents in both subsets (53 and 58%) reported they “strongly disagree” or “somewhat disagree” that their ability to understand the test results within the portal has caused them worry. Although a larger percentage of respondents diagnosed within the last 5 years reported they “somewhat agree” or “strongly agree” that the patient portal has caused them to feel worried (33% compared with 24%), there was no significant difference overall (p -value 0.22).

Priorities Around Electronic Health Information Access

Free-text responses were initially assessed for codes to describe the data. In response to the question “If you have felt worried about seeing your/your child’s results before a physician can discuss them with you, is there anything a healthcare provider or patient portal has done (or that you would like them to do) to help address any of this worry?,” quick provider response was a recurrent code. Many participants also appreciated additional provider explanation and patient education, or provider reassurance if appropriate. Some participants noted that it would be helpful to set expectations and provide anticipatory guidance ahead of time, potentially by providing a rheumatic disease-specific

health information guide describing common abnormal findings. Caregivers noted difficulty accessing EHI via their various portal platforms and a need to improve interoperability of the patient portal when accessing care across health systems. Overall, participants appreciated the use of portal messaging for patient and provider communication and expressed that the ability to trust their provider to contact them with significant results was important. Finally, some respondents suggested delaying results release until a provider can offer explanation, though this is in contrast to other responses, such as “*the results aren’t going to change so I might as well see them as soon as possible.*” Thematic saturation was met after 112 out of 144 responses.

When asked, “What do you like about having access to your/your child’s electronic health information,” frequent responses included immediate access to EHI and the ability to use portal messaging, view radiology images, or access appointment reminders. Respondents expressed that access promoted improved comprehension of their diagnosis, care coordination with external providers, and adherence to the treatment plan, noting “[It] allows me to feel like I am a part of his team” and “It is often difficult to understand medical explanations in situations of high stress. It can be reassuring to check records and look back for accuracy.” The concept of a safety net for ensuring results were addressed was also a theme, with one respondent saying, “Doctor’s [sic] could be busy with patients all day and not see results for hours, but when the parents have access, they can see the results and act accordingly to potentially save the child’s life.” Patient empowerment and self/caregiver advocacy were also recurrent themes, with responses including “There is no gatekeeping around the results,” or “I feel strongly I have the tools to advocate and support them.” Finally, many respondents emphasized that as patients they have a right to their own health information, with one respondent reporting, “It’s data about ME; it is only fitting that I should know it.” Thematic saturation was met after 51 out of 225 responses.

In contrast, “What do you dislike about having access to your/your child’s electronic health information” highlighted increased worry as a common concern. Responses included “I have to stop myself from looking because even though I don’t understand the results, I will start imagining worst-case

Table 3 Survey responses analyzed by number of years since diagnosis

Question	Years since diagnosis ≤ 5 $N = 153$	Years since diagnosis > 5 $N = 83$	p -value
I like having electronic access to my/my child’s results as soon as they are available, before discussing with my/my child’s healthcare provider.	5 (5,5)	5 (5,5)	0.28
I would prefer that my/my child’s results only get released after my/my child’s healthcare provider has discussed them with me.	1 (1,2)	1 (1,3)	0.03
I have felt worried about how to understand my/my child’s test results when accessing them electronically.	2 (1,4)	2 (1,3)	0.22

Notes: Median (IQR). $N = 236$. 17 records excluded for null values.

Agreement level measured on a 5-point Likert scale where strongly disagree = 1 and strongly agree = 5.

scenarios.” Some respondents specifically noted that receiving life-threatening or sensitive results (such as a new cancer diagnosis) would be especially challenging and may impact their desire to receive results before provider review. Other respondents noted concerns with incomplete records, either due to proxy settings or institutional rules. Finally, a lack of understanding of the results without provider context, particularly those results flagged as “abnormal,” was a recurrent challenge. Many respondents expressed frustration with results marked as abnormal, but which are not clinically significant, for example, “*Sometimes I don't know what all of the levels mean, or something shows outside of the normal range, but the doctor says everything is normal.*” Thematic saturation was met after 43 out of 182 responses.

Through analysis of the codes derived from the free-text responses, themes were identified as shown in [Table 4](#). For some themes, responses were discordant. For example, for “Sharing on social media,” some respondents found this helpful for interpretation, and other respondents felt frustrated by patients posting results to social media inappropriately.

Discussion

This is the first study evaluating patient and caregiver utilization and perception of EHI in pediatric rheumatology patients, exploring their perception across the entire multispecialty care experience. We found that respondents use their health data for care coordination, self-advocacy, and to co-direct their care with providers. Respondents in this survey reported strong portal engagement with nearly half of respondents accessing their portal >12 times per year and 90% using the portal for multiple reasons, including viewing physician notes and laboratory results. Respondents also reported overwhelmingly positive feedback regarding immediate access to their EHI.

Implications for Technology Design

Prior studies have emphasized the need for direct user feedback to identify barriers to portal adoption and overcome technical challenges.¹⁹ In this study, over one-third of respondents reported that they access the portal after a visit only when they receive an alert for new results, and approximately 1% only when they receive a new provider message. Enabling patient communication preferences for specific portal action items may improve timely portal engagement. For example, patients with a smartphone may prefer to receive portal communications via text message, with non-smartphone users preferring to receive communications via email. Furthermore, only half of respondents reported using the portal to access appointment information, which is surprising in a patient population with multisystem disease involvement and the need for multispecialty appointments. This may be secondary to text and email reminder systems that have been shown to reduce non-attendance to medical appointments²⁰ and may reduce the need for patients to consult the portal. This should be explored in more detail as non-attendance and late cancellation rates remain an expen-

sive issue in healthcare²¹ and patient portal utilization may be a potential solution.²²

In this engaged population, almost one in five patients reported having posted screenshots of laboratory results to social media to elicit help interpreting the results. This practice may pose significant privacy and security risks and may be an area of focus for future portal education initiatives. There may also be an opportunity to design the portal user interface to display a warning if a patient takes a screenshot or include a disclaimer regarding the risks of posting PHI to social media.

Only 18% of respondents reported “never” using the patient portal to share EHI with another provider or institution. Many of these respondents are likely patients seeing multiple providers within the same organization who should have access to internal records. In situations where health information exchange (HIE) or other data sharing systems are lacking, the patient portal may be an alternative pathway for the efficient sharing of EHI among providers and institutions. To streamline data sharing, patients should be informed of tools to facilitate information transfer within the patient portal, and otherwise encouraged to bring patient portal login information to clinical visits if the portal does not have this functionality. Though this may improve patient care in the short term, it may also be putting an extra burden on patients that could be limited by improving data sharing through HIEs.

Implications for Clinical Care

Although this survey found that most patients wanted their results electronically, even prior to a provider's review, the results also demonstrate the variability in how patients may perceive the increased access to EHI. This is consistent with prior studies in which clinicians expressed reservations around sharing of all EHI, particularly that it may add to patient's worry or confusion.^{23,24} Furthermore, prior studies have emphasized the disconnect between clinician and patient expectations, with one survey noting that 75% of patients expected to be contacted within 24 hours for abnormal results, whereas only 9% of clinicians felt this was appropriate.²⁵ Clinicians' awareness that patients may have different comfort levels with their electronic patient portal may inform how they help patients manage this digital access. For example, for patients who reported more anxiety around immediate release of results, setting expectations regarding a timeline for provider response may be helpful, such as “These labs typically take three business days to come back. If nothing is urgent, anticipate a message around that time.” Additionally, providing patients with a disease- or medication-specific health information guide, as recommended by respondents, may provide a standardized way to offer education and anticipatory guidance for patients, particularly following a new diagnosis. Current EHR technology could be used to allow this information to be automatically added to a patient's visit instructions or included as health education in the portal. These recommendations complement additional “rules of engagement” identified in

Table 4 Themes identified in content analysis of free-text responses of the survey

Objective: Describe current use of and engagement with the electronic patient portal and EHI.
<p>Theme: Care coordination Definition: Use of the portal and available data to facilitate care among multiple providers or institutions. Illustrative quote: "Our hospital has no complex care coordination and things routinely are thought to be 'some other specialists concern'—I am able to make sure [medications] and [treatments] are coordinated...and can cue one specialist to look at another's [treatment]/[medication]/[diagnosis] info."</p>
<p>Theme: Portal messaging for communication Definition: Patient portal messaging functionality improves communication. Illustrative quote: "If I have a concern about any of her labs (especially early on in the diagnostic process), I send a message through the portal to her rheumatologist. He always responds in a timely manner with either a reason not to worry or a suggestion for follow-up."</p>
<p>Theme: Care management tool Definition: The patient portal enables patients to recall, and act on, the treatment plan. Illustrative Quote: "The ability to track trends over time in lab results; the ability to read after visit summaries on demand to make sure I've followed up on 'next steps' and to see any details I may have forgotten from the visit."</p>
<p>Theme: Patients/caregivers using data to co-direct care Definition: Patients and caregivers use portal data to ensure all results are addressed by the physician. Illustrative Quote: "I've had issues in the past where the doctor did not get the results in a timely manner, and they were critical to my daughter's health."</p>
<p>Theme: Sharing on social media^a Definition: Patients or caregivers post EHI on social media for help with interpretation. Illustrative Quote: "I am also in several groups where parents are always posting and asking for opinions and I am not a fan of that as so many things can be the cause and those answering are not doctors or nurses." "Being a parent of a child with a rare disease, we've often researched exhaustively all of the available medical literature over a period of many years, so records are helpful to compare and contrast to other patients in papers and in social media support groups."</p>
Objective: Explore perceptions, impact on worry and anxiety, and preferences of access to EHI.
<p>Theme: Concern for patients viewing results before the provider Definition: Patients may view results well before a provider can offer interpretation. Illustrative Quote: "When unexpected abnormal results result on a Friday afternoon, because then it'll be many days before they're addressed."</p>
<p>Theme: Incomplete/partial access to data Definition: EHI within the patient portal is limited or even restricted based on the age of the pediatric patient. Illustrative Quote: "I feel like sometimes the things I have access to change. I get nervous that something I have at one time had access to, I will no longer have access to in the future."</p>
<p>Theme: Patient difficulty understanding health data Definition: Patients find it challenging to understand the clinical significance of results. Illustrative Quote: "Sometimes, it is hard to know if a flagged result is of concern or not."</p>
<p>Theme: Provider communication mitigates patient concerns Definition: Streamlined communication with providers is important to allay patient concerns. Illustrative Quote: "My provider quickly responds to messages so my concerns are quickly addressed."</p>
<p>Theme: Immediate access to information Definition: Respondents appreciate on-demand access to EHI, rather than waiting for a provider to share results. Illustrative Quote: "Providers are busy so it's nice to have results asap, not just when they have time."</p>
<p>Theme: Emotional impact^a Definition: Access to EHI without provider input can be both reassuring and anxiety provoking, depending on the patient and the clinical situation. Illustrative Quote: "It helps ease some of the 'waiting' anxiety. Also, allows me to feel like I am a part of his team." "Sometimes I don't know what [I'm] looking at, and Google sends me into a panic."</p>
<p>Theme: Patient autonomy Definition: EHI access in the patient portal allows patients to view and interpret results independently. Illustrative Quote: "We have been dealing with scleroderma for many years, so I know which tests to look at in her bloodwork and I don't need to wait for her doctor to tell me results."</p>
<p>Theme: Poor functionality and interoperability Definition: Respondents feel the utility of the patient portal is limited by poor functionality and limited interoperability between other institutions or systems. Illustrative Quote: "Send out labs sometimes don't get posted to chart and I call until I get access."</p>

Note: ^aReported as both a positive and negative theme.

a recent publication that highlighted patient and provider training strategies to improve communication via the patient portal.²⁶

It is notable that patients diagnosed more than 5 years ago were less adamant that results be released immediately, compared with respondents diagnosed more recently. This may reflect increased patient and caregiver comfort with disease management over time, with less emphasis placed on laboratory work and more emphasis on symptoms and clinical presentation. Perhaps since these patients were diagnosed prior to the 21st Century Cures Act Final Rule, they may be used to having limited access to their EHI. This distinction may have important implications for how clinicians help patients manage their digital access.

This study also demonstrates the importance of the electronic patient portal in allowing patients and families to self-advocate and engage at a higher level in their medical care. This has important implications for shared decision-making and patient outcomes, particularly in pediatric rheumatology where patients are often faced with multiple reasonable treatment options, and factors like mode of administration, dosing interval, and cost must be individualized for each patient and family.²⁷ A recent study of two primary care clinics demonstrated that the odds of completing diagnostic tests or referrals was 40% higher in patients who read their visit notes in the patient portal and 20% higher in patients who had a patient portal account, compared with patients without an active portal registration.²⁸ Beyond engagement with their care plan, respondents to this survey expressed that the patient portal enables them to co-direct care with their provider (as per one respondent, “*Parents often work in partnership with rheums*”), which is important for patient-centered care and improves healthcare outcomes.²⁹ Although results regarding engagement in the patient portal and improvement of outcomes have been mixed,¹⁵ high-quality studies have shown improved glycemic and lipid control in adults who engage with their patient portal,³⁰ suggesting that in a patient population such as ours with complex chronic diseases requiring long-term treatment and monitoring, high portal use could have a positive impact on clinical outcomes and health.

Implications for Health Equity

Despite the promise of improved health outcomes, it is notable that prior studies have shown patient portals may exacerbate pre-existing healthcare inequities; patients with low income, of minority race, with limited education, with Medicaid insurance, with poor health literacy, and of older age are less likely to utilize patient portals.^{7,10,31} This uneven distribution of EHI access through the portal leads to widening of the digital divide, which refers to both access and utilization of technology in healthcare.³¹ Additionally, a lack of access to technology in these populations may bias recruitment for technology interventions in research, limiting the generalizability of results and excluding those populations with the worst health outcomes.³² Ultimately, those patients who engage with their patient portal and reap the

benefits of high portal use may see an even wider gap in healthcare outcomes as compared with those patients who do not engage effectively with technology to manage their health. Institutional and provider efforts to continue to encourage patient portal access are critical, with patient and caregiver education and support being effective methods.²⁶

Study Limitations

This study is limited by the fact that it targeted an already engaged, English-speaking, predominantly White population with digital literacy and engagement in disease-specific social media sites, likely overestimating patient and caregivers' comfort with EHI. Surveying patients in person during a clinic visit may have included a broader population but would be influenced by the specific portal software of the locations recruiting respondents. Additionally, the survey was anonymous and relied on respondents' verification that they were previously diagnosed with a rheumatic disease by a pediatric rheumatologist; thus, the validity of our surveyed population cannot be verified. The survey may have been completed several times by members of the same family, but each respondent shared his or her own experience. Finally, numerous questions in the survey were not required, leading to gaps in survey results, particularly regarding the number of years since diagnosis.

Although the majority (95%) of respondents were parents and caregivers, this is not surprising in a pediatric population where fewer patients may be personally engaged in disease-related social media accounts. However, the small proportion of patient responses limited our ability to compare patient responses to caregiver responses. As adolescent patients may have a different perspective compared with surveyed caregivers, particularly regarding their comfort with and utilization of technology, future studies should incorporate a variety of age groups. This could be accomplished by surveying patients in person, to better elicit the perspective of pediatric patients.

Future Work

Future work should explore the positive and negative impacts of social media on healthcare, specifically related to the strategies patients utilize to solicit feedback or ask questions regarding their own personal healthcare, in addition to the accuracy and reliability of the resources patients use to educate themselves on a health topic. Additionally, the relationship between patient portal engagement and clinical outcomes such as medication and treatment plan adherence, disease activity markers, and disease morbidity should also be examined.

Conclusion

Respondents in this social media survey of the pediatric rheumatology population reported strong portal engagement and an expectation of immediate access to EHI through the patient portal. Although some did report that access to EHI without provider input can increase worry or anxiety,

families perceive the patient portal as a tool for self-advocacy and engagement in care, leading to a stronger sense of their role as a member of the care team.

Clinical Relevance Statement

Respondents from a pediatric subspecialty patient population reported strong engagement with their patient portal and an appreciation for immediate access to their electronic health information. Respondents routinely read provider notes in the portal and use the portal to facilitate medical care and advocate for themselves or their family members.

Multiple-Choice Questions

1. Which of the following functionalities did the most respondents report accessing in the patient portal?
 - a. Laboratory results
 - b. Appointments
 - c. Medications
 - d. Provider messages

Correct Answer: The correct answer is option a. In regard to how they use the patient portal, most respondents (90%) recognized multiple uses of the patient portal, with 98% of respondents using the portal for laboratory results, 80% for healthcare provider messages, 64% for imaging results, 53% for appointments, and 28% for medications.

2. Which of the following actions is suggested as a potential privacy and security risk with patient portals?
 - a. Accessing a patient portal account through the health system's smartphone application.
 - b. Posting screenshots of laboratory results from the portal to social media sites.
 - c. Using the patient portal to share electronic health information with other providers for patient care.
 - d. Saving a patient portal username and password in a password manager.

Correct Answer: The correct answer is option b. There is potential for a breach of protected health information when posting screenshots to social media sites.

Protection of Human and Animal Subjects

The study was performed in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects and was reviewed by the Duke Institutional Review Board (approval no.: Pro00113906).

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Conflict of Interest

A.J.T. and C.S.P. are elected members of the Epic Rheumatology Steering Board.

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References

- 1 Tapuria A, Porat T, Kalra D, Dsouza G, Xiaohui S, Curcin V. Impact of patient access to their electronic health record: systematic review. *Inform Health Soc Care* 2021;46(02):192–204
- 2 Reynolds TL, Cobb JG, Steitz BD, Ancker JS, Rosenbloom ST. The state-of-the-art of patient portals: adapting to external factors, addressing barriers, and innovating. *Appl Clin Inform* 2023;14(04):654–669
- 3 Fareed N, MacEwan SR, Vink S, Jonnalagadda P, McAlearney AS. Relationships between patient portal activation and patient satisfaction scores among CG-CAHPS and HCAHPS respondents. *Am J Manag Care* 2022;28(01):25–31
- 4 Hägglund M, McMillan B, Whittaker R, Blease C. Patient empowerment through online access to health records. *BMJ* 2022;378:e071531
- 5 ONC's Cures Act Final Rule | HealthIT.gov. Accessed September 5, 2024 at: <https://www.healthit.gov/topic/oncs-cures-act-final-rule>
- 6 Turer RW, Martin KR, Courtney DM, et al. Real-time patient portal use among emergency department patients: an open results study. *Appl Clin Inform* 2022;13(05):1123–1130
- 7 Turer RW, McDonald SA, Lehmann CU, et al. Real-time electronic patient portal use among emergency department patients. *JAMA Netw Open* 2024;7(05):e249831
- 8 Steitz BD, Turer RW, Lin CT, et al. Perspectives of patients about immediate access to test results through an online patient portal. *JAMA Netw Open* 2023;6(03):e233572
- 9 Bruno B, Steele S, Carbone J, Schneider K, Posk L, Rose SL. Informed or anxious: patient preferences for release of test results of increasing sensitivity on electronic patient portals. *Health Technol (Berl)* 2022;12(01):59–67
- 10 Turer RW, DesRoches CM, Salmi L, Helmer T, Rosenbloom ST. Patient perceptions of receiving COVID-19 test results via an online patient portal: an open results survey. *Appl Clin Inform* 2021;12(04):954–959
- 11 Sarabu C, Lee T, Hogan A, Pageler N. The value of OpenNotes for pediatric patients, their families and impact on the patient-physician relationship. *Appl Clin Inform* 2021;12(01):76–81
- 12 McCallie KR, Balasundaram M, Sarabu C. Family perception of OpenNotes in the neonatal intensive care unit. *Appl Clin Inform* 2024;15(01):170–177
- 13 Jackman KP, Ohene-Kyei ET, Barfield A, et al. Patient portal privacy: perspectives of adolescents and emerging adults living with HIV and the parental/guardian role in supporting their care. *Appl Clin Inform* 2023;14(04):752–762
- 14 You JGT, Potter JE, Mishuris RG. Electronic health record adolescent confidentiality in a safety net setting. *Appl Clin Inform* 2023;14(05):878–882
- 15 Kruse CS, Argueta DA, Lopez L, Nair A. Patient and provider attitudes toward the use of patient portals for the management of chronic disease: a systematic review. *J Med Internet Res* 2015;17(02):e40
- 16 Beukelman T, Kimura Y, Ilowite NT, et al; CARRA Registry Investigators. The new Childhood Arthritis and Rheumatology Research Alliance (CARRA) registry: design, rationale, and characteristics of patients enrolled in the first 12 months. *Pediatr Rheumatol Online J* 2017;15(01):30

- 17 R Core Team. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. 2022. Accessed at: <https://www.R-project.org/>
- 18 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(02):77–101
- 19 Wachenheim D, Hurwitz I, Dukhanin V, Wolff JL, DesRoches CM. Shared access to adults' patient portals: a secret shopper exercise. *Appl Clin Inform* 2024;15(04):817–823
- 20 Koshy E, Car J, Majeed A. Effectiveness of mobile-phone short message service (SMS) reminders for ophthalmology outpatient appointments: observational study. *BMC Ophthalmol* 2008;8(01):9
- 21 Marbough D, Khaleel I, Al Shanqiti K, et al. Evaluating the impact of patient no-shows on service quality. *Risk Manag Healthc Policy* 2020;13:509–517
- 22 Chiereghin A, Pizzi L, Squillace L, Bazzani C, Roti L, Mezzetti F. The positive effect of an online appointment portal on a breast cancer screening program. *Appl Clin Inform* 2023;14(04):609–619
- 23 Hamze MK, Joshi SS, Li Y, Repp AB, Jacobs A, McEntee R. The 21st Century Cures Act: inpatient clinician perceptions of changes to information sharing at an academic medical center. *Cureus* 2023;15(06):e40184
- 24 Leonard SM, Zackula R, Wilcher J. Attitudes and experiences of clinicians after mandated implementation of open notes by the 21st Century Cures Act: survey study. *J Med Internet Res* 2023;25:e42021. Doi: 10.2196/42021
- 25 Leonard LD, Himelhoch B, Huynh V, et al. Patient and clinician perceptions of the immediate release of electronic health information. *Am J Surg* 2022;224(1 Pt A):27–34
- 26 Hefner JL, Sieck CJ, Walker DM. Patient and physician perspectives on training to improve communication through secure messaging: clarifying the rules of engagement. *Health Care Manage Rev* 2022;47(01):3–11
- 27 Brinkman WB, Lipstein EA, Taylor J, et al. Design and implementation of a decision aid for juvenile idiopathic arthritis medication choices. *Pediatr Rheumatol Online J* 2017;15(01):48
- 28 Bell SK, Amat MJ, Anderson TS, et al. Do patients who read visit notes on the patient portal have a higher rate of “loop closure” on diagnostic tests and referrals in primary care? A retrospective cohort study. *J Am Med Inform Assoc* 2024;31(03):622–630
- 29 The SHARE Approach—Achieving Patient-Centered Care with Shared Decisionmaking. A Brief for Administrators and Practice Leaders. Accessed September 5, 2024 at: <https://www.ahrq.gov/health-literacy/professional-training/shared-decision/tool/resource-9.html>
- 30 Brands MR, Gouw SC, Beestrum M, Cronin RM, Fijnvandraat K, Badawy SM. Patient-centered digital health records and their effects on health outcomes: systematic review. *J Med Internet Res* 2022;24(12):e43086
- 31 Otokiti A, Williams KS, Warsame L. Impact of digital divide on the adoption of online patient portals for self-motivated patients. *Healthc Inform Res* 2020;26(03):220–228
- 32 Toscos T, Drouin M, Pater J, Flanagan M, Pfaflman R, Mirro MJ. Selection biases in technology-based intervention research: patients' technology use relates to both demographic and health-related inequities. *J Am Med Inform Assoc* 2019;26(8-9):835–839