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A Tale of Two Perspectives: Harvesting System Views and User Views to Understand Patient Portal Engagement

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Abstract — **Patient engagement is recognized as a key factor in promoting care quality and experience. Although patient portals as a prevalent information infrastructure provide a viable means to achieve engaging patients, there is still a limited understanding of how to objectively and systematically evaluate engagement levels in the context of patient portals. We develop the *Patient Portal Engagement Framework* (PPEF) to objectively and systematically evaluate patient portal engagement and demonstrated its utilization and effectiveness in two scenarios: portal utilization and user feedback. Four engagement levels included in the PPEF are – *Inform Patients* that allows patients to access health information; *Involve Patients* that encourages patients to take initiatives; *Partner with Patients* that supports long-term collaboration between patients and providers; and *Support Ecology of Care* that extends the scope beyond hospitals into personal and social factors. We find more portal utilization and user feedback focus in lower levels of patient portal engagement (i.e., patients receiving information and taking active actions in managing care). Our thematic analysis of online user reviews reveals four core themes: conflicts between system and user views, evolving benefits and needs towards patient portals, debates about balancing emotional and informational needs, and reconsideration of power, accessibility, and privacy. We discuss how PPEF can help harvest and synthesize data from the system and user levels, as well as the design implications for patient portals. These results show that patient portals can be designed with practical guidance for engaging patients, complementing current efforts that focus on conceptualizing engagement or rely on psychometrics.**

Keywords — patient engagement, patient portal engagement framework, patient portal, user review, evaluation

I. INTRODUCTION

The current need for informed patient choices, shared-decision making, and patient-oriented care incentives by the Medicare and Medicaid Electronic Health Record Programs [1] has placed a critical emphasis on patient engagement. **Patient engagement** is an emerging and pivotal practice that promotes optimal care via a patient-centered model of mutual collaboration between patients, families, and providers [2]. This concept has been widely defined and applied across various research topics, ranging from patient safety [3] to research participation [4]. Patient engagement has also been recognized as one of the key factors in the delivery of quality care and patient safety through promoting 1) care experience, satisfaction, and mutual understanding, 2) shared decision making, 3) long-term patient-provider relationship, and 4) informed risk communication [5], [6].

However, scholarship has noted a concern that patient engagement is becoming tokenistic and that it needs to drive practical guidance [7]. Current patient engagement evaluation relies on psychometric properties [8] with potential biases such as leading question influences and acquiescence bias [9]. In addition, definitions of patient engagement have varied over time and across contexts [7], [10]. For example, patient engagement bears a different meaning in surgical shared-decision making than chronic care self-management. As a result, currently, most efforts reside in the conceptualization stage, e.g., the PACT definition (personalization, access, commitment, and therapeutic alliance) [11]. Therefore, it is critical to develop evaluation frameworks of patient engagement that can complement conventional surveys and contextualize the application, scope, and users.

An online **patient portal** is a health information technology (HIT) infrastructure that connects patients with providers through the asynchronous exchange of health information [12]. The patient portal has been demonstrated as one of the main means to promote patient engagement through its wide range of functionalities that provides patient digital access to health information (e.g., medical records, billing), care delivery services (e.g., scheduling, reminder), and patient-to-provider and provider-to-patient communication.

Despite a growing body of work that investigates how patient portals promote patient engagement, review studies have called attention to the lack of evidence [13] and the selective focus on certain features such as information access and communication instead of analyzing full portal systems [13], [14]. Furthermore, large-scale infrastructures offer limited room for redesign and end-user involvement, highlighting a need to amplify patient voices in the HIT development cycle for continuous improvements and local tailoring.

Our work aims to address the above challenges for an objective and contextualized engagement evaluation framework

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that examines patient portals in a user-centered holistic manner. The goal of this study, therefore, is to understand whether and how patient engagement is considered and realized in designing and utilizing patient portals. In particular, we ask:

RQ1. How to measure and understand patient engagement in patient portal design and utilization?

RQ2. How to incorporate user voices into system design and evaluation?

We adopted qualitative and quantitative methods including functionality evaluation, log mining, and thematic analysis of user feedback to analyze patient engagement data from both system level and user level perspectives. Such an approach enables us to gather a holistic and longitudinal evaluation of patient engagement on patient portal systems. We created the **Patient Portal Engagement Framework** to offer an objective reference in evaluating patient engagement and to integrate insights learned through three distinct data sources (functionality, usage, and feedback). Our contributions are three-fold: (1) present a framework examining patient engagement in patient portal design and in practice, (2) showcase an approach that allows both longitudinal trend examination and the harmonization of system and user views, and (3) identify design implications for future patient portals based on utilization and feedbacks.

II. RELATED WORK

A. *Patient Engagement*

Researchers in Human-Computer Interactions (HCI) and health informatics have studied the needs and benefits of promoting and assisting patient engagement. Recently, this line of work has cast a reflective and critical perspective on the nature and social factors surrounding engagement. First, the scope of engagement goes beyond informational needs into experiential needs, such as transitioning from home to hospitals and preparing at-home care [15]. Second, the role of patients is changing from passive recipients to active contributors and collaborators [16], [17] and learners [18]. Third, the environmental context of patient engagement expands with the development of virtual health capabilities [19] and the maturity of healthcare research [20], [21]. However, most of the work evaluates patient engagement through conventional surveys and interviews [8] that can introduce potential bias [9] and limitations in scalability and timeliness.

In addition, attention has been called to investigate the outcome, power differentials, and political economy of engagement [20]–[22]. Gui and Chen challenge the missing discussion of the political economy of the healthcare industry where industrial profits are imbalanced with satisfactory service delivery and encourage researchers to question these outcomes [22]. Merlett et al. and Domecq et al. acknowledge that power differences exist between patients and clinicians or researchers [21] and that addressing the gap in practices requires costs and resources [20].

This study broadens this scholarship by extending the analysis scope from conventional surveys and interviews into objective and in situ log data and user reviews. At the same time, we follow the call of elucidating power relations and utilize self-initiated user-generated data to amplify patients' voices in evaluating large-scale healthcare infrastructure common with a top-down design approach.

B. *Patient Portal*

Patient portals are secure online platforms that allow patients to view and manage personal health information and communicate with their care teams [12]. Since the Health Information Technology for Economic and Clinical Health Act in 2009, patient portals have been widely implemented across the United States [23]. In 2014, eligible U.S. hospitals were required to provide patients with access to view, download, and transmit their health information [24]. Nearly all hospitals provided patients with access to view and download health information in 2017 [24]. Patient portals provide easy access to health information such as clinical visits, lab test results, medications, and clinical visit summaries [25]. Literature has demonstrated the role of patient portals in improving patients' self-management, disease knowledge, progress awareness, patient-clinician communication, and patient engagement [14], [25]–[27]. Patient portals that allow secure messaging between patients and their care team are shown to support both the continuity of care and preventative care in requesting appointments, medication management, timely reminders, and follow-ups [28]–[30].

Despite the benefits mentioned above, the actual utilization of patient portals is relatively low. Reports have shown that in 2017, 62% of hospitals have fewer than 25% of patients activated patient portal access [24]. In addition, more work is needed beyond system implementation and adoption, as previous research has noted the need for continuous evaluation of patient portals [31] and feedback gathered from users and nonusers [32]. We aim to build upon the literature by providing a comprehensive and longitudinal understanding of portal utilization and user experience.

III. METHOD

Patient portals as a large-scale commercial infrastructure have limited room for redesign and leave end-users little power in expressing their experience and perspectives. Thus, there is a need to study in situ interactions between portals and patients to facilitate a sustainable and iterative process for continuous evaluation and tailoring. To do so, we first revisited the Patient Engagement Framework [33] and adapted it to the design and use of patient portals. Then, we conducted an evaluation study with three parts: (1) reviewing the past: functionality review to measure patient engagement in the patient portal, (2) examining the present: log analysis to evaluate user behavior and measure longitudinal changes, and (3) looking into the future: user review analysis to capture user satisfaction and future design directions. Together the PPEF framework and approach help us harvest both the system views and user views to grasp an objective and holistic understanding of whether and how patient engagement is considered in the design and realized in practice. Fig.1 summarizes our approach.

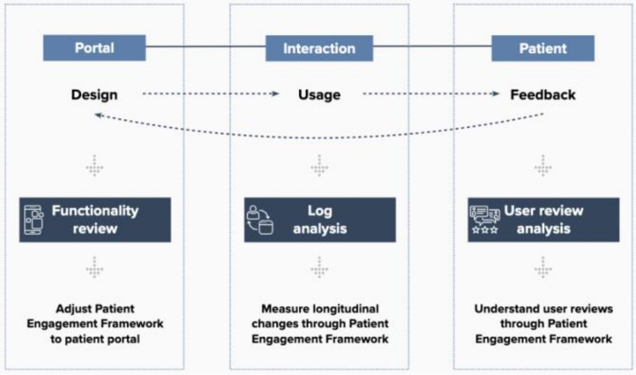


Fig. 1. A scheme to explain the strategy to develop and validate the Patient Portal Engagement Framework.

The study was conducted at Mayo Clinic, a large nonprofit medical center based in the U.S. that serves more than one million patients each year. This work was approved by the medical center's Institutional Review Board (19-002211).

A. Functionality Evaluation

The Patient Engagement Framework is a model created for health care organizations to use as a guidance and evaluation reference for patient involvement and engagement when designing, developing, and deploying HIT. It is developed by National eHealth Collaborative and adapted by the Health Information Management Systems Society [33]. This framework categorizes five levels of increasing patient engagement: Inform Me (information access), Engage Me (self-monitoring), Empower Me (self-inputs and communication), Partner With Me (remote assess), and Support My E-Community (online communities).

While previous work has explored the utilization of this framework in evaluating hospital adoption of patient-engagement-oriented technologies [34] and mobile applications supporting cancer survivorship [35], little work has explored how the Patient Engagement Framework [33] can be applied to understand patient portal and how its application can be extended beyond horizontal comparisons into longitudinal trends. Patient portals are a large-scale healthcare infrastructure that serves a significantly larger scope than other types of information technologies. At the same time, with the rapid growth of integrating patient portals into electronic health records (EHR) systems and pervasive access to the Internet and smart devices, the original five levels of the Patient Engagement Framework [33] are less feasible to differentiate.

Therefore, we utilized the Patient Engagement Framework [33] as a useful guide and adapted it to the design and evaluation of patient portals. We then followed the unified framework of EHR usability – Task, User, Representation, and Function (TURF) framework [36] to identify functions supporting user-meaningful operations and reviewed the patient portal in the research site. Per the Designer Model in TURF, we identified all user actionable operations, such as clicking a “view upcoming appointment”, typing and sending a message to a doctor, or following a process to request changes in medical records. Activity Model in TURF, on the other hand, refers to the set of functions that are used in users' real activities. We summarized all identified Designer Model functions into a list, filtered and synthesized them according to Activity Model, and classified the remaining functions into different levels of patient engagement according to the proposed framework. The new framework is described in the Result section.

B. User Log Mining

The portal log provides three types of information: user, action, and session. User data includes patients' group ID, clinical ID, gender, and date of birth. Action data is patient portal functionalities the users clicked. Session data refers to session begin timestamp and session end timestamp. Since 2018, the medical center has switched to a new patient portal powered by Epic Systems, one of the largest medical software companies that serve 54% of the U.S population [37]. To minimize the influence of the patient portal upgrade in 2018, we collected system logs in the February of 2019, 2020, and 2021. The numbers of unique users for these periods are respectively 194 419, 229 605, and 314 809. During this period, there were a total of 18,053,581 actions by 314,809 users.

C. User Review Analysis

The patient portal at the research site can be accessed by both mobile and website with the same set of functionalities. Therefore, we collect public user reviews specifically for this medical center's mobile version portal from 2019 to 2021, using official APIs of the Apple iTunes store and Google Play store. Among the collected 1,309 reviews, we found an unbalance of the number of reviews on two operating system versions: 202 reviews are for the iOS platform and 1,107 are for the Android platform. Considering the user demographic differences between iOS and Andriod in age, education, income, and technology familiarity [38], [39], we randomly sampled 202 Google Play reviews to make an even balance between two operating systems, and the final review dataset consists of 404 reviews (202 of iOS and 202 of Android).

The analysis included both classification labeling and affinity diagram and was conducted with three goals: (1) **Function**: what functionalities were discussed; (2) **Sentiment** – was the user satisfied in using that function; (3) **Theme** – what was the review about. The process was conducted by two researchers with adequate knowledge in patient portals and experience in thematic analysis [40].

The function and sentiment were classified following the PPEF framework, where functions were labeled as mentioned or not-mentioned whereas sentiments were coded as positive

(+1), negative (-1), or neutral (0). The process was conducted in an iterative manner. Two annotators first independently coded a random sample of 25 reviews, discussed any difference until reached an agreement, and then repeated another round of coding a sample of 25 reviews, discussing disagreements, and improving the labeling specification. After two rounds, the first author coded the remaining reviews. Themes were generated in a grounded-up and inductive manner. Two annotators first familiarized themselves with collected reviews and noted down their own initial low-level codes, such as "do not want emotionally challenging information without doctor explanation" and "youth's parent would like information access". With the combined set of initial codes, the annotators then collated codes into potential higher-level themes while continuously reviewing and adjusting themes. The final themes were defined and named based on low-level codes and specific examples within each theme cluster.

IV. RESULT

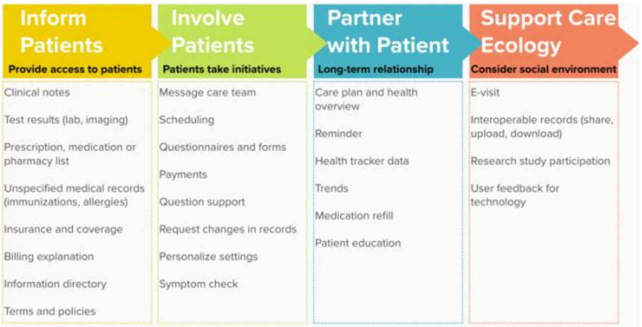
A. *Patient Portal Engagement Framework*

We adapted the general Patient Engagement Framework [33] into the design and evaluation of patient engagement in patient portals as the **Patient Portal Engagement Framework (PPEF)**. Compared with the Patient Engagement Framework [33] that differentiate levels of engagement based on characteristics of data (i.e., classification based on whether the data is patient-generated and for what purposes, and whether that data is remotely accessible), PPEF on the other hand defines the classification from patient perspectives by examining whether patients are actively, continuously, and fully involved. More specifically, PPEF has four levels of engagement – inform, involve, partner, and ecology – that indicate to what degree do certain functions support patient technological engagement:

1) **Inform Patients (Inform):** This level views patient portals mainly as a platform with information access and regards patients as passive information recipients.
2) **Involve Patients (Involve):** This level views participation as a two-way interaction and emphasizes patients taking initiatives in the care process.
3) **Partner with Patients (Partner):** This level adds time as a factor and considers healthcare as a long-term collaboration rather than one-time encounters.
4) **Support Ecology of Care (Ecology):** This level extends the scope beyond hospitals and considers the micro and macro social factors, such as remote healthcare, cross-system collaboration, clinical research, and technology use.

Fig. 2 summarizes the four engagement levels in the Patient Portal Engagement Framework (PPEF) as well as the functionalities of patient portals under each level. From the patient portal used by the research site, we found twenty-six functions that are reflected both in the system design and unique user activities. **Inform** level includes functions of clinical notes, test results (lab, imaging), prescription, medication or pharmacy list, unspecified medical records (immunizations, allergies), insurance and coverage, billing explanation, information directory, and terms and policies. **Involve** level has functions of messaging care team, scheduling, questionnaires and forms, payments, question support, request changes in records, personalize settings, and symptom check. **Partner** level supports care plan and health overview, reminder, health tracker data, trends, medication refill, and patient education. **Ecology** level assists with e-visit, interoperable records (share, upload, download), research study participation, and user feedback for technology.

We note that specific functionalities under each level are subject to the organization being studied. Since each health institution's portal supports a unique set of functionalities, this framework is more helpful for longitudinal evaluation than direct horizontal comparisons.



Inform Patients Provide access to patients	Involve Patients Patients take initiatives	Partner with Patient Long-term relationship	Support Care Ecology Consider social environment
Clinical notes	Message care team	Care plan and health overview	E-visit
Test results (lab, imaging)	Scheduling	Reminder	Interoperable records (share, upload, download)
Prescription, medication or pharmacy list	Questionnaires and forms	Health tracker data	Research study participation
Unspecified medical records (immunizations, allergies)	Payments	Trends	User feedback for technology
Insurance and coverage	Question support	Medication refill	
Billing explanation	Request changes in records	Patient education	
Information directory	Personalize settings		
Terms and policies	Symptom check		

Fig. 2. Patient Portal Engagement Framework (PPEF). Specific functionalities under each level are subject to the organization being studied.

B. *The System View – Utilization*

Table I summarizes the demographic statistics of portal users. Looking at different age groups, we can see that the elderly group with an age greater than 65 constitutes about 42% of all users in the period. We note a significant user increase from 2020 to 2021 (37%) than the previous year (18%). This could be due to the worldwide pandemic COVID-19 caused by the severe acute respiratory syndrome coronavirus, which happened in late 2019 and confirmed the first U.S. case in January 2020. As previous research has noted technologies' potential in assisting remote care and reducing in-person visits and transmission risks during COVID-19 [41].

TABLE I. DEMOGRAPHIC STATISTICS OF PATIENT PORTAL USERS

Year	Num of Users	Age			
		13-18	*18-45*	*45-65*	*>65*
2019	194,419	0.22%	22.77%	35.26%	41.74%
2020	229,603	0.47%	23.02%	35.93%	40.58%
2021	314,809	1.16%	23.43%	33.94%	41.48%

The trend view of the aggregated patient engagement level is presented in Fig 3. Percentages are calculated by the number of unique users utilizing certain functions in that year divided by the total number of users in that year. The figure indicated a mild upward trend in the Involve and Ecology levels. On the other hand, the Inform level has had a mild decrease since 2020. A strong-moderate dropping of engagement level in the Partner category is observed.

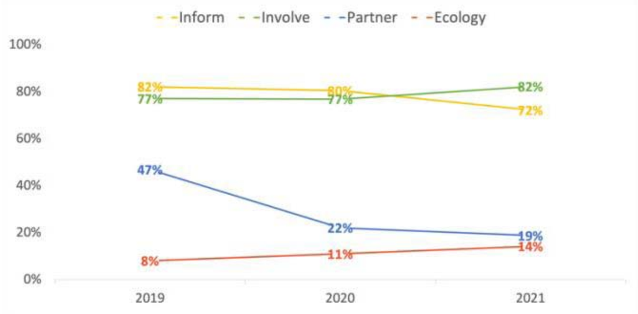


Fig. 3. Longitudinal changes of four levels of patient engagement. (Percentages calculated by unique users utilizing functions under PPEF engagement level in that year divided by the total number of users.)

The longitudinal summarization of patient engagement level stratified by age groups is presented in Table II. As suggested by the PPEF framework, we observe an average moderate-high engagement level in Inform (avg 78.16%) and Involve (avg 78.61%) categories, moderate engagement level in the Partner with Patients level (avg 29.14%), and low engagement level in Support Ecology of Care (avg 10.98%). On average, the adult and elderly groups present a slightly higher engagement level in Inform level. The elderly group has the highest engagement level in Involve level. This is in accordance with previous work [42] opposing the stereotype of associating older adults with negative attitudes towards technologies. On the other hand, the teenage group presents a higher level of engagement in Partner and Ecology levels compared with the three other age groups. This finding is in accordance with previous work [43], [44] discovering how teenage patients often work with their parents in care management.

TABLE II. SUMMARY OF PATIENT ENGAGEMENT LEVEL BY AGE GROUPS

(Percentages calculated by unique users utilizing functions under PPEF engagement level in that year divided by the total number of users.)

a. Teen (13-18)			
Engagement Level	***2019***	***2020***	***2021***
Inform	72.99%	72.00%	71.58%
Involve	82.94%	77.26%	75.23%
Partner	50.95%	24.40%	16.93%
Ecology	13.03%	14.70%	24.35%

b. Adult (18-45)			
Engagement Level	***2019***	***2020***	***2021***
Inform	80.79%	76.80%	70.09%
Involve	70.25%	66.53%	72.02%
Partner	45.37%	21.70%	17.28%
Ecology	9.25%	12.71%	16.58%

c. Middle Age (45-65)			
Engagement Level	***2019***	***2020***	***2021***
Inform	82.92%	80.26%	73.44%
Involve	76.58%	76.33%	81.13%
Partner	49.07%	22.28%	19.08%
Ecology	7.90%	10.76%	13.81%

d. Elderly (>65)			
Engagement Level	***2019***	***2020***	***2021***
Inform	82.03%	82.50%	73.16%
Involve	80.96%	82.87%	88.98%
Partner	45.52%	21.89%	19.16%
Ecology	7.30%	9.86%	12.64%

C. The User View – Feedback

The average rating of the 1,309 reviews is 3.44 (in the sale of 0-5 with 5 representing the highest). The average ratings for iOS and Android apps are 3.00 and 3.52 respectively.

1) Function: The most discussed clinical information under the Inform level is lab/imaging test result (40), followed by unspecified medical records (29) and clinical notes (12). We observe that portal message function (35), scheduling (25), and question support (11) are the top three mentioned categories under the Involve level. At the Partner level, users are most concerned about reminder and notification (12) and patient education (10). Lastly, interoperable records (5) are mentioned most frequently at the Ecology level. The results suggest that patients have strong needs for medical records access and control, providers' collection and communication, and informational support.

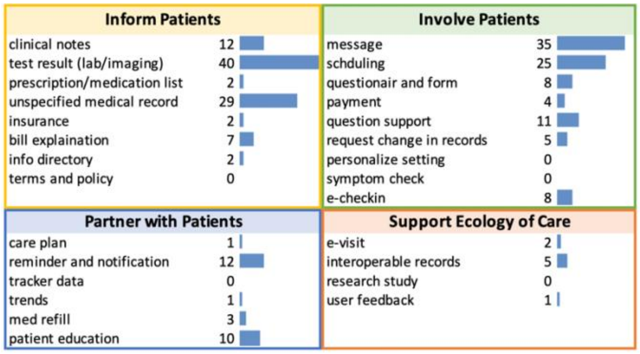
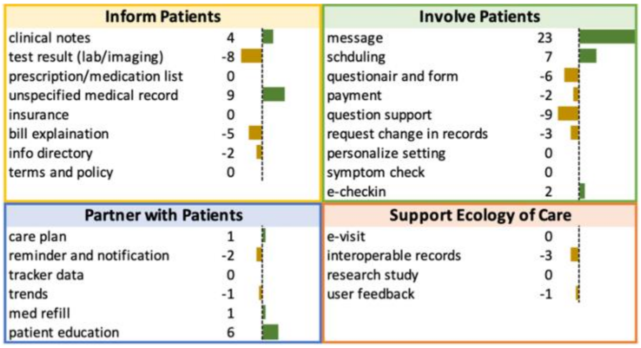


Fig. 4. Frequency of mentioned functions in user reviews to PPEF framework (N = 404)

2) Sentiment: The sentiment evaluation of user reviews from 2019 to 2021 is summarized in Fig 5. The aggregated sentiment score (e.g., med refill contains 2 positive and 1 negative review) is ranked in descending order and organized by four levels of the PPEF framework. Overall we find strong positive sentiment in Inform, Involve, and Partner levels, strong negative sentiment in Inform and Involve, and moderate negative sentiment in Partner and Ecology. Users are most in favor of the functionalities that are related to messages, unspecified medical records, scheduling, patient education, and clinical notes. On the other hand, functionalities that received the most negative comments are question support, test result (lab/imaging), questionnaire and form, bill explanation, interoperable records, and request change in records.



Inform Patients	
clinical notes	4
test result (lab/imaging)	-8
prescription/medication list	0
unspecified medical record	9
insurance	0
bill explaination	-5
info directory	-2
terms and policy	0

Involve Patients	
message	23
schduling	7
questionair and form	-6
payment	-2
question support	-9
request change in records	-3
personalize setting	0
symptom check	0
e-checkin	2

Partner with Patients	
care plan	1
reminder and notification	-2
tracker data	0
trends	-1
med refill	1
patient education	6

Support Ecology of Care	
e-visit	0
interoperable records	-3
research study	0
user feedback	-1

Fig. 5. User review overall sentiment to PPEF framework (Green bar demotes positive sentiment; yellow bar represents negative sentiment)

Taking frequency and sentiment together, we found that at the Inform level, users' most mentioned functions are clinical notes, unspecific medical records, and test results, while satisfaction towards test results is lower. An improvement is witnessed in the Involve level. Users have a generally positive attitude towards the two most mentioned functions of messaging and scheduling; but are less satisfied with questionnaire and form, question support, payment, and record change request. At the Partner level, care reminders and patient education are brought up the most. Attitudes towards patient education are mostly positive while reminders can be better with more setting flexibility. In terms of the Ecology level, interpretable records as the most discussed function receive mostly negative evaluations.

3) Themes: Common themes we discovered are conflicts between system views and user views, evolving benefits and needs of patient portals, debates in balancing informational and emotional needs, and reconsideration of power, accessibility, and privacy. Below we explain each theme in detail with some paraphrased examples.

a) Conflicts between system views and user views

We noticed some conflicts between system needs and user preferences. The most common conflict happens when users desire convenience, while standardization and security are the priorities for the system. For example, first-time portal users need patient IDs to register accounts, which can be troublesome for new patients who haven't physically been to the hospital to be assigned an ID. Similarly, some users find log-in credentials and authentication checks that ensure security inconvenient.

This conflict also happens when multiple stakeholders (such as caretakers) are closely involved in the care process. In pediatric care, once patients reach adolescence or the age of consent, they are given full control of their patient portals, while this determination of independence can vary from person to person, as one user wrote: *"The hospital should not be given the right to withhold medical information of 13-year-olds from their parents. They are minors, not adults. This is not a right rule morally and ethically."*

b) Evolving benefits and needs towards patient portals

In line with existing literature, we noted that the use of patient portals has gone beyond accessing health information. Many reviews acknowledged the benefit as making them *"feel in control and confident."* Accordingly, the need for a portal changes as users start to care about continuous monitoring and communication with the care team, ease of access and use, and interoperability with other applications or devices. This change is evident with the prevalence and ubiquitousness of wearable and tracking devices. For example, one review said that *"my health issue makes cell-phone unaccessible and I prefer access through my smartwatch."*

Interestingly, the informational needs also evolve from specific treatment into proactive care as users appreciate general health and wellbeing information. One user noted the benefit of *"tips and recipes for a healthy life, and access to health professionals at fingertips."*

c) Debates in balancing emotional and informational needs

When it comes to informing and educating patients, the focus is often given to informational needs; however, emotional needs should also be acknowledged. Such a balance of information and emotional needs is reflected in user reviews but lacks a consensus of how the balance should be drawn, reflecting an opportunity for future study. For example, one user wants more direct and comprehensive information for medical issues and thinks the current design *"pull[es] too many punches,"* while acknowledging the need of empathy, *"many people can be unformattable with direct or emotional challenging information."*

The need of balancing informational and emotional needs casts questions of "what contributes to informed patients", e.g., how much information makes a patient informed? If, how, and when should the information be presented to them? As one review challenges that "*certain test results should not be given to patients before discussing with healthcare providers*." On the other hand, we also witnessed many dissatisfactions on not providing access to all available data and information.

*d) **Reconsideration of power, accessibility, and privacy***

Through the thematic analysis of user feedback, we also note a need in reflecting and reconsidering power relations, accessibility, and privacy in future design.

First, the power issue is often rooted in the indeterminate distribution of agency and power among stakeholders (such as patients, clinicians, caregivers, and care team including nurses and technicians), while technologies hold the capability of revealing and reinforcing power relations hidden behind. It has been demonstrated in the previously mentioned conflict between pediatric patients' autonomy and guardians' proxy access.

More importantly, the power dynamics are ingrained in the traditional norm of professionals dominating the care process. As one review mentioned, *"functions [as exchanging information with other institutions] are not allowed until doctors demand that change."* With the rising awareness of collaborative care and the promotion of patient empowerment, patients are willing to take a proactive role in care management. We saw increasing demand for the capability of adding and retrieving data and viewing care history and plans.

Second, to avoid leaving out users and non-users in technology adoption, accessibility considerations should be given to not only the interface design but also technology literacy and generation habits. In interface design, we need to consider the marginalized populations, such as the elderly and the visually impaired. Many reviews criticized the non-adjustable font size, unreadable color contrast, and inability to work with voice control.

At the same time, we call the attention that accessibility also needs to consider technology literacy and generation habits. Accessibility is not only about accessing information, but also the form and absorption of that information. For example, many reviews complained about the incapability to print information: *"not enough information to print from this app."* Technology education is also needed in assisting users with limited technology literacy, as reviews said *"this can be my problem as I am 75 years old, but I cannot understand the electronic billing"* and *"senior users did not grow up in the Internet era."*

Lastly, privacy concerns demand abilities to customize with "affirmative consent" in deciding whom and what to be informed. Recent work by Im et al. suggested affirmative consent as a theoretical foundation to build socio-technical systems [45]. Affirmative consent, often known as "yes mean yes", refers to the idea that before interacting with others, one must "ask for, and earn, enthusiastic approval" [45]. Patients should own the full agency in determining whom and what to be informed, as suggested by users *"I want to specify my message recipients instead of messaging the whole care team"* and *"I don't want caregiver to view my appointments."*

V. DISCUSSION

We presented the Patient Portal Engagement Framework (PPEF) and applied it to consolidate system and user perspectives. In this section, we summarize and discuss how this approach helps line up two viewpoints and amplify user voices in large-scale infrastructure.

A. Patient Portal Engagement Framework

The proposed framework systematically summarizes four distinct levels of patient engagement measurements in the context of online patient portal use, including 'Inform Patienrts' (patients as passive information recipients), 'Involve Patient' (patients take initiatives), 'Partner with Patient' (long-term collaboration), and 'Support Ecology of Care' (consider social factors). This paper highlights the use of the PPEF in the patient portal however future researchers can use the four levels of engagement to evaluate and design other HITs.

These engagement levels present a progressive and hierarchical relationship of the degree and type of engagement ranging from basic information access to ecological considerations. Our designed framework differs from the previous work by providing both a conceptual representation and data-driven measurements based on the design of patient portal functionality, which serves as a translational instrument and can be applied to the real-world patient portal environment. Potential use cases of the framework include system design, quality improvement, workflow optimization, etc. Particularly, it can serve as a knowledge standard for user-generated content management and use, which aligns with the goal of Learning Healthcare Systems (LHS) [46]. Specifically, this framework can be used to guide patient portals' design and development to enable high throughput utilization and synthesizing patient-generated data for promoting shared decision-making within the learning healthcare environment and improving patient-centered care. We also note that each health institution's portal supports a unique set of functionalities. As such, this framework is more helpful for longitudinal evaluation than direct horizontal comparisons.

B. Lining Up Two Perspectives

In this study, we utilized multiple data sources to harvest both system views and user views. We find that users' feedback foci are in accordance with system usage – more discussions and utilization in the lower engagement levels (Inform Patients and Involve Patients).

At the same time, we note that conflicts between two perspectives can happen. We find that oftentimes, conflicts between users and systems lie behind the need disparity – users desire convenience, whereas, for the system, standardization and security are the priority. Conflicts also happen when multiple stakeholders (such as caretakers and parents of pediatric patients) are closely involved in the care process, and their involvements can cast disagreements in the agency in managing care.

C. Amplify User Voices in a Large-scale Infrastructure

The patient portal as a large-scale infrastructure leaves very limited room for redesign and end-user involvement. Patient voices need to be amplified throughout the development cycle of design, deployment, and evaluation for continuous improvements and local tailoring.

We summarize findings into design implications for patient portal systems. First, in line with previous research [16], we find that users' needs towards patient portals are constantly evolving. The focus of design should not be limited to easy access and better information presentation, but also how to help patients "feel in control and confident" during the care process. Second, technology is built upon existing power relations and is capable of further reinforcement. Second, as noted in previous work [43], [44], design should consider the relationships among patients, clinicians, caregivers, the care team to help patients maintain agency in care management and decision-making process. This is reflected by the trend of patients taking more proactive roles and demanding information shared with other institutions. Third, information presentation should consider the balance between emotional support and informational needs, which can be different from person to person. Personalized answers can be found in answering questions of "how much information makes this patient informed" and "if, how, and when should the information be presented". Fourth, accessibility considerations can go beyond interface design into personal and social factors, such as technology literacy (e.g., instructions of online actions or new features) and habits (e.g., prefer to have paper copies of records besides online access). Lastly, privacy settings can adopt a customizable style with "affirmative consent" [45] in allowing users to decide whom to inform and what to inform them about (or not).

D. COVID-19 as an External Factor

We observe a surge in user increase rate from 18% (2019 to 2020) to 37% (2020 to 2021). This could be explained by the worldwide pandemic COVID-19 as an external factor. COVID-19 has impacted the U.S. since 2020, while U.S. Centers for Disease Control and Prevention (CDC) has recommended healthcare facilities limit office visits to reduce virus transmission risks [1]. Thus, millions of non-urgent and non-COVID-19 medical encounters were postponed or canceled by patients and health systems to reduce the risk of COVID-19 infection during in-person visits and prevent the virus from spread [47]–[49]. For continued healthcare access, many clinic visits have transitioned to online platforms including patient portals for healthcare access including COVID-19 diagnosis and treatment and non-COVID-19 health issues [50], [51]. COVID-19 is transforming telehealth for the rising means of healthcare delivery [50]. This hypothesis is in accordance with previous research that shows in-person visits during COVID-19 can be reduced through remote care and technologies [41].

E. Limitation and Future Work

Our study has limitations and points out some interesting future work directions. First, as this work focuses on organizational-level longitudinal changes and reflections, we focus on one specific healthcare system and the results have risks of limited generalizability. We remind readers that findings are based on a large U.S. medical center with a great percentage of elderly patients and functions mentioned in this study may not be supported by other healthcare systems. Similarly, user reviews are collected from mobile application stores but many healthcare institutions may not support mobile portals yet. Second, we acknowledge the limitations of log analysis as it can leave out non-users, user differences, motivations, and successes/failures of their tasks. Future work can continue to explore the impacts of demographics and socio-economic factors, what factors or barriers contribute to non-users, and the nuanced differences in actions and perspectives among the whole user population. Another possible future direction is to study the goal of users as well as the successful and non-successful use scenarios.

CONCLUSION

This paper proposes the Patient Portal Engagement Framework (PPEF) to objectively and systematically evaluate patient engagement levels in patient portals. PPEF includes four engagement levels: *Inform Patients* that regard patients as passive information recipients; *Involve Patients* that encourage patients to take initiatives; *Partner with Patients* that treat healthcare as a long-time collaboration with patients; and *Support Ecology of Care* that extend the scope beyond hospitals into personal and social factors. We demonstrate its utilization and effectiveness in two scenarios – portal utilization and user feedback. Harmonizing both system views (reflected through log mining) and user views (reflected through online reviews), we find both more portal utilization and user focus in lower levels of patient portal engagement (i.e., receiving information and taking actions in managing care).

Our thematic analysis of online user review reveals four core themes: conflicts between system and user views, evolving benefits and needs of portal systems, debates in balancing emotional and informational needs, and reconsideration of power, accessibility, and privacy. Design implications for future patient portals are: (1) Design focus should not be limited to access and information presentation, but help patients "feel in control and confident". (2) Design should consider the relationships among patients, clinicians, caregivers, the care team to help patients maintain agency in the care process. (3)

Health information presentation should balance needs of emotional and informational support which varies at the individual level. (4) Accessibility considerations beyond interface design should consider personal and social factors, such as technology literacy and habits. (5) Privacy settings can adopt a customizable style with "affirmative consent" in allowing users to decide whom and what to be informed. While this paper highlights the use of the PPEF in the patient portal, we invite future researchers to apply the four engagement levels and design implications for other HITs.

CONFLICTS OF INTERESTS

All the authors have no conflicts of interest to declare.

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