

Leveraging Patient-Reported Outcomes Using Data Visualization

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Abstract

Background Health care organizations increasingly use patient-reported outcomes (PROs) to capture patients' health status. Although federal policy mandates PRO collection, the challenge remains to better engage patients in PRO surveys, and ensure patients comprehend the surveys and their results.

Objective This article identifies the design requirements for an interface that assists patients with PRO survey completion and interpretation, and then builds and evaluates the interface.

Methods We employed a user-centered design process that consisted of three stages. First, we conducted qualitative interviews and surveys with 13 patients and 11 health care providers to understand their perceptions of the value and challenges associated with the use of PRO measures. Second, we used the results to identify design requirements for an interface that collects PROs, and designed the interface. Third, we conducted usability testing with 12 additional patients in a hospital setting.

Results In interviews, patients and providers reported that PRO surveys help patients to reflect on their symptoms, potentially identifying new opportunities for improved care. However, 6 out of 13 patients reported significant difficulty in understanding PRO survey questions, answer choices and results. Therefore, we identified aiding comprehension as a key design requirement, and incorporated visualizations into our interface design to aid comprehension. In usability testing, patients found the interface highly usable.

Conclusion Future interfaces designed to collect PROs may benefit from employing strategies such as visualization to aid comprehension and engage patients with surveys.

Keywords

- ▶ data visualization
- ▶ consumer health informatics
- ▶ human–computer interaction
- ▶ patient-reported outcomes
- ▶ patient engagement
- ▶ interfaces and usability

Background and Significance

Health care organizations increasingly collect patient-reported outcomes (PROs) to monitor patients' health status and determine perceived effectiveness of care.^{1–3} As defined by the U.S. Food and Drug Administration, a PRO is any report on a patient's health status that comes directly

from the patient, without additional interpretation from the clinician or anyone else. When collecting PROs, health care organizations use standardized survey questions to understand patient experiences and symptoms.¹ Organizations use various methods to convey PRO data to providers, and the results may inform each patient's care plan individually.

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The U.S. federal financial incentive policy *Meaningful Use* mandates that health care organizations collect and assess PROs.²⁻⁴ Studies have demonstrated that PROs improve patient outcomes such as quality of life and survival.⁵⁻⁹ The impact of PROs, coupled with policies encouraging their use, may explain their recent increase in popularity and use across multiple medical domains.¹ Recently, the National Institutes of Health (NIH) created the Patient-Reported Outcomes Measurement Information System (PROMIS) measures.¹⁰⁻¹³ PROMIS is a validated and standardized set of PRO measures applicable to a range of chronic conditions. The PROMIS scales map directly to so-called “legacy” instruments such as the Patient Health Questionnaire-9 depression questionnaire.

Promising initiatives to design electronic PRO (e-PRO) collection systems exist,¹⁴ including efforts to incorporate PROs into patient portals.^{1-3,14,15} The two largest U.S. electronic health record (EHR) vendors, Epic and Cerner, both recently incorporated PROs into their portals.¹⁴ Beyond portals, many institutions support independent e-PRO systems for cardiology, oncology, dermatology, orthopedics, and other specialized care.¹⁵⁻¹⁷ A recent review found that institutions often develop and use these systems locally.¹⁶

Despite the increasing popularity of PROs and e-PRO systems, several knowledge gaps and challenges remain. First, few studies have assessed user perceptions of PRO surveys and e-PRO systems. Investigating user perceptions should inform strategies to increase patients' engagement with surveys and systems. Second, low health literacy and low technology literacy may prevent patients from completing PRO surveys precisely and efficiently.¹⁸ Many e-PRO interfaces lack contextual information to help patients interpret survey questions and answer choices.¹⁶ Such limitations may inhibit patients from communicating PROs accurately and decrease clinicians' confidence in PROs.¹⁹ Third, current e-PRO interfaces do not provide the contextual information needed for patients to understand and act on their PRO survey results, if the patient receives their results at all.¹⁶ Because periodically repeated surveys can capture symptom progression over time, helping patients interpret their results may facilitate self-management. Receiving results may also increase the survey's value to patients and better engage patients in their own care. Previously studied strategies to display results for patients primarily used graphs.²⁰⁻²³ Additional strategies to aid patient's comprehension of their PRO data remain to be explored.

In this article, we present a user interface to increase heart failure patients' engagement with PROs using data visualization, called *mi.Symptoms*. We use the heart failure population to demonstrate our interface's utility for multiple reasons. Heart failure affects more than 26 million people worldwide²⁴ and 6.5 million people in the United States,²⁵ and is the leading cause of 30-day hospital readmissions in the United States.²⁵ Ineffective symptom management is the primary cause of repeated hospital readmissions in heart failure.²⁶ Clinicians typically spend the majority of each outpatient visit discussing symptoms, and time constraints may prevent the full elucidation of clinically relevant symptoms. As such, PROs hold the potential to transform clinical decision making and improve symptom management in heart failure.

Objective

In this article, we present results from an iterative, user-centered design process to develop *mi.Symptoms*, an e-PRO interface that uses visualizations to engage patients. First, we conducted semistructured interviews to assess patients' and providers' perceptions of the value and challenges associated with PROs. Using our interview data, we identified design requirements for *mi.Symptoms*. Then, we developed and evaluated the *mi.Symptoms* interface, including visualizations, to help patients interpret survey questions, answer choices, and results.

Methods

To develop the *mi.Symptoms* interface, we used an iterative, user-centered design approach with three stages. In *stage 1*, we conducted semistructured interviews with heart failure patients and their health care providers to understand their perceptions of the value and challenges associated with using PRO measures. Directly after the interview, participants completed the Health IT Usability Evaluation Scale (Health-ITUES)²⁷ to evaluate a *mi.Symptoms* mockup. In *stage 2*, we identified design requirements based on our interview results, and designed the *mi.Symptoms* interface. In *stage 3*, we conducted usability testing of the interface. The Columbia University Medical Center Institutional Review Board approved the study.

Participants and Recruitment

Patients: Using purposeful sampling on age and race, we identified study participants from a cardiac inpatient unit and an ambulatory cardiac clinic at an urban academic medical center. We recruited at both locations for stage 1 and at the inpatient unit only for stage 3. We included adult patients with a confirmed diagnosis of heart failure who could read 5th grade English. We excluded patients with severe cognitive impairment, major psychiatric illness or concomitant terminal illness. The research coordinator invited patients to participate in face-to-face encounters at the clinic or hospital. If the patient agreed to participate, the coordinator obtained written informed consent and collected data during the same encounter. Interviews were audio-recorded.

Providers: Using snowball sampling, we identified health care providers whose primary responsibility is managing inpatient or outpatient heart failure patients. The coordinator invited providers to participate through personal emails. Providers agreed to complete an audio-recorded interview and the Health-ITUES after providing written informed consent.

Qualitative Interviews and Health-ITUES (Stage 1)

Measurements and Materials: A content expert developed the semistructured interview guides based on personal experience and incorporated feedback from each study team member. The interview topics for both patients and providers included the application's general usefulness, its usefulness for patient-provider communication, helpful and unhelpful features, and suggested changes. To collect patient demographics, assess previous technology use, and determine health literacy, we used our previously described patient characteristics survey.²⁸

The patient characteristics survey relies on a three-item health literacy screening questionnaire to determine whether health literacy is inadequate.²⁹

To assess perceived usefulness and ease of use of mi.Symptoms, we adapted the Health-ITUES for our setting.²⁷ We created two adaptations, one for patients and one for providers. We added three items to elucidate mi.Symptoms' usefulness for patient-provider communication:

1. I think mi.Symptoms could improve how [I / my patients] report [my / their] physical symptoms to [my health care provider / me].
2. I think mi.Symptoms could improve how [I / my patients] report [my / their] psychological symptoms to [my health care provider / me].
3. I think mi.Symptoms could improve how [I / my patients] report social limitations that are a result of [my / their] symptoms to [my health care provider / me].

To familiarize the patient or provider participant with mi.Symptoms' purpose and content before the interview and Health-ITUES survey, we created an HTML/CSS mockup of mi.Symptoms (→Fig. 1). The mockup displayed sample PRO survey questions and a single sample results page. The mockup consisted primarily of text in a basic layout, and lacked visualizations. We included PROs from PROMIS^{10–13} and the Heart Failure Somatic Perception Scale (HFSPS).^{30–32} We included the HFSPS in addition to PROMIS because it assesses pertinent acute physical symptoms of heart failure.

Data Collection: The coordinator guided the patient or provider participant through the mockup, conducted the interview, and completed the Health-ITUES. In addition, the coordinator completed the patient survey with patient participants. Recruitment and analysis continued until thematic saturation was achieved, meaning that no new themes emerged after the last three interviews.

Data Analysis: We conducted a standard descriptive analysis of patient characteristics and Health-ITUES data in R version 3.3.3. A professional service transcribed the audio recordings of patient and provider interviews. We performed qualitative descriptive analysis of the transcripts in NVivo Version 11. First, two authors with training in qualitative methods independently read transcripts, and defined codes in a dictionary for the remaining analysis. In addition to codes that emerged from the data, the dictionary included a priori codes based on the research questions, interview guide, and literature. Then, the researchers independently coded the transcripts using the dictionary-defined codes. Kappa scores ranged from 0.76 to 0.96 for individual questions. The

researchers met to resolve conflicts through discussion and identify themes. To enhance confirmability, we used member checks and peer debriefing among the data collection team.^{33–35} In addition, we shared summaries of the coded data with two patients and two providers and asked for their confirmation or revisions to interpretation. The two patients and two providers confirmed the interview findings.

Design Requirements and Process (Stage 2)

We drew on our interview and Health-ITUES results to identify design requirements for mi.Symptoms. With the requirements in mind, we used storyboarding techniques to detail patients' interactions with the interface and determine the necessary components. We further refined mi.Symptoms through team discussions and informal review with providers, to produce a fully functioning interface consistent with our design requirements, running on an Apple iPad Pro. We used Bootstrap 3 as our front-end framework and jQuery 1.12.4 as our JavaScript library. We used jQuery 1.12.4 to support older versions of Internet Explorer, which is an important consideration in our population. We used ASP.NET as our back-end framework for compatibility with our hospital's EHR system.³⁶

Usability Study (Stage 3)

For the usability study, we recruited only new patients who did not participate in stage 1. The coordinator guided these patient participants through a previously described patient characteristics survey²⁸ and a three-part usability assessment protocol. The coordinator video-recorded the participant's screen using QuickTime Player and encouraged concurrent think-aloud. In the *first part*, the coordinator asked the participant to complete tasks using mi.Symptoms, such as answering survey questions and interpreting survey results. In the *second part*, we asked the participant to state preferences between the three strategies for visualizing PRO survey results. In the *third part*, we asked the participant to complete the eight-item Standardized User Experience Percentile Rank Questionnaire (SUPR-Q),³⁷ to assess the usability, credibility, loyalty, appearance, and overall quality of mi.Symptoms.

Data Analysis: We analyzed patient characteristics in R and SUPR-Q data in a proprietary Microsoft Excel calculator. Based on video data, a researcher assigned binary (pass/fail) performance indicators to each task for each participant, and computed summary performance statistics in Excel. The researcher transcribed relevant qualitative commentary into Microsoft Word and coded the commentary by hand. The research team met to discuss themes, and confirmed themes using peer debriefing among the data collection team.

Results

Study Population

In stage 1, we consented 13 heart failure patients and 11 health care providers to participate in interviews and complete the Health-ITUES. In stage 3, we consented 12 additional heart failure patients to participate in the usability study. On average, patient participants were 55 years old and over half reported inadequate health literacy (→Table 1).

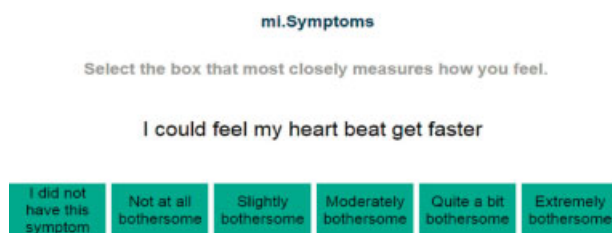


Fig. 1 Sample mockup of mi.Symptoms used in interviews.

Table 1 Characteristics of patient participants

Characteristics	Stage 1 (n = 13)	Stage 3 (n = 12)
Age in years: median (range)	53 (30–78)	57 (35–72)
Female sex: n (%)	8 (61.5)	2 (16.7)
Race: n (%)		
White	5 (38.5)	7 (58.3)
Black or African American	6 (46.2)	3 (25.0)
Asian or Pacific Islander	1 (7.7)	2 (16.7)
Other	1 (7.7)	0 (0.0)
Latino ethnicity: n (%)	3 (23.1)	2 (16.7)
Education: n (%)		
High school graduate	4 (30.8)	3 (25.0)
Some college/Trade school	3 (23.0)	5 (41.7)
Associate's degree	2 (15.4)	1 (8.3)
Bachelor's degree	4 (30.8)	1 (8.3)
Graduate degree	0 (0.0)	2 (16.7)
Inadequate health literacy: n (%)	6 (46.2)	10 (83.3)
Looks up health information online: n (%)	9 (69.2)	10 (83.3)

Providers participants included 3 cardiology attending physicians, 3 cardiology fellows, 2 cardiology residents, and 3 nurse practitioners.

Qualitative Interviews and Health-ITUES (Stage 1)

Interviews with Patients: ▶**Table 2** describes the main themes from patient interviews. Several patient partici-

pants (n = 5) described completing PRO surveys using mi.Symptoms as a reflective experience that prepared them to interact with their physicians. Participants felt that mi.Symptoms reminded them what to say in potentially intimidating or time-limited visits with their physician. Participants spoke about mi.Symptoms' usefulness as a reminder:

- "If you have a bunch of things that you can't really keep track of, they won't come up until you're asked the specific [mi.Symptoms] questions. If you're not asked the specific questions, you're not going to remember all the symptoms that you're having." [Pt. 11]
- "[mi.Symptoms] reminds the person what they want to talk about. It helps me say [to the physician]: 'in the 10 minutes we have together, let's make sure that we've addressed these things.'" [Pt. 1]
- "I think it would be really good have [mi.Symptoms] as a conversation starter, because a lot of times, the doctor will ask you many questions, and ... when the doctor asks them some people feel intimidated." [Pt. 4]

Several participants (n = 4) viewed mi.Symptoms as a potential tool to monitor their symptoms and identify the symptoms associated with their disease. Two participants requested the ability to use mi.Symptoms at home for "personal tracking." Three participants described not associating certain symptoms with heart disease until asked about them. Participants explained how mi.Symptoms helped them view their symptoms differently:

- "It made me broaden my thinking, and it kind of brought together what [my doctors, nurses, and nutritionist] keep telling me. It gave a different perspective." [Pt. 7]

Table 2 Patient's perceptions of value and challenges associated with using PROs

Category	Theme	Example quote
Value	Encourages reflection on symptom experience	"If you have a bunch of things that you can't really keep track of, they won't come up until you're asked ... questions." [Pt. 11]
	Prepares patient for interaction with provider	"mi.Symptoms reminds the person what they want to talk about [with the physician]." [Pt. 1]
	Facilitates personal tracking and monitoring	"I'd like to use this system at home ... to keep track of my symptoms." [Pt. 4]
	Connects symptoms with disease	"Symptoms come up that, before you saw them, you didn't realized they were connected with [your disease]." [Pt. 4]
	Prompts positive emotions	"Answering these questions about my symptoms lifts me up, and I feel like I'm not alone." [Pt. 2]
Challenges	Trouble understanding PRO surveys	"The way the questions were worded was not straightforward. Could the questions just be more clear?" [Pt. 12]
	Lack of unstructured communication	"At the end, if you want make [a] comment you should be able to add one." [Pt. 8]
	Low technology literacy	"If I knew how to use it [the tablet] I could use [the PRO survey]." [Pt. 3]
	Concern that providers will not use PROs	"I'll do [the PRO survey] if you promise to read it. That's the problem, [the doctors] don't read." [Pt. 1]

Abbreviation: PRO, patient-reported outcome.

- “Sometimes symptoms come up that, before you saw them, you didn’t realized they were connected with [your disease]. Some people don’t associate that atrial flutter might cause your appetite to slow down.” [Pt. 4]

Several participants ($n = 6$) reported difficulty comprehending the PRO survey questions and answer choices. One participant reported that he “didn’t understand the words” and asked for audio. Another participant wanted more “understandable” questions that contained less medical jargon. Said a third:

- “The way the questions were worded was not straightforward. Could the questions just be more clear?” [Pt. 12]

Several participants ($n = 4$) felt that unstructured communication, such as electronic messaging, should supplement the PRO survey. Participants wanted to use messaging to ask their physician questions or add comments to their survey results. Multiple participants ($n = 3$) reported concerns about adapting to or learning to use the interface. One participant reported his poor eyesight made using the iPad difficult. Another participant described his reluctance:

- “I have a tablet at home, but I don’t use it right now... If I knew how to use it [the tablet] I could use [the survey].” [Pt. 3]

Multiple participants ($n = 3$) described the positive emotions associated with completing the PRO survey. These participants felt that the survey helped them normalize their symptoms by implying that others experienced the same symptoms. As one participant explained:

- “Answering these questions about my symptoms lifts me up, and I feel like I’m not alone.” [Pt. 2]

Multiple participants ($n = 3$) reported reasons mi.Symptoms may lack value. The reasons included worry that the physician will not read or use the PROs, a preference for communicating with the physician face-to-face, and a belief the PROs will not impact care. As one participant explained:

- “I’ll do [mi.Symptoms] if you promise to read it. That’s the problem, [the doctors] don’t read. You tell one doctor one thing and then the next set of doctors come and you have to start all over again.” [Pt. 1]

Interviews with Providers: Several providers ($n = 4$) discussed how mi.Symptoms might help patients recognize symptoms or associate symptoms with heart failure:

- “Some patients don’t recognize that abdominal bloating is fluid retention, or that nocturnal cough is orthopnea. They don’t link their diet to gaining weight. When people put those together they can better self-manage.” [Pr. 3]

Two providers reported that PROs might reduce their cognitive load. Providers thought survey results might supplement verbal information collected in one-on-one visits, and more easily identify the specific timing of symptoms,

progression of symptoms, or the most important symptoms. One provider explained:

- “Some patients, regardless of their literacy, are just not good at communicating what’s going on. They want to tell you a million different things. You have to be the interpreter and say: ‘From all these things you want to tell me, it really seems like everything has to do with fatigue.’ I think [mi.Symptoms] may help with this.” [Pr. 7]

Two providers felt mi.Symptoms might identify missed opportunities for medical intervention, by prompting patients to thoroughly report symptoms. One provider described how mi.Symptoms might enhance symptom review:

- “[Some heart failure patients] get this upper gastrointestinal gas buildup. A lot of them have complained to me: ‘Nobody ever asked me about that. Nobody ever does anything about it.’ That’s something I would definitely ask on [mi.Symptoms].” [Pr. 6]

Health-ITUES with Patients and Providers: Overall, both patients and providers perceived the mi.Symptoms mockup as useful and easy-to-use (→Table 3).

Design Requirements and Process (Stage 2)

Requirement 1: Design to aid comprehension. Although the NIH developed PROMIS with attention to low literacy, 6 of our 13 patient participants reported difficulty understanding questions or answer choices. Poor comprehension may inhibit the patient’s ability to reflect on their symptoms and report them accurately. By requirement, the interface should incorporate strategies to aid patient interpretation of questions and answer choices. In mi.Symptoms, we satisfied this requirement by providing previously tested infographics within questions and answer choices (→Fig. 2, panels 1–4).^{23,38–40} With validated surveys like PROMIS

Table 3 Health-ITUES scores for the mi.Symptoms mockup (scores range from 1 to 5, lowest to highest)

Construct	Patient score	Provider score
Perceived usefulness: mean (\pm SD)	4.2 (\pm 1.1)	4.1 (\pm 0.8)
Productiveness	4.1 (\pm 1.2)	4.0 (\pm 0.9)
General usefulness	4.4 (\pm 1.1)	3.8 (\pm 0.9)
General satisfaction	4.1 (\pm 1.0)	4.1 (\pm 0.7)
Performance speed	4.4 (\pm 0.8)	4.0 (\pm 0.9)
Communication	4.3 (\pm 1.1)	4.4 (\pm 0.7)
Perceived ease-of-use: mean (\pm SD)	4.4 (\pm 1.0)	4.0 (\pm 0.9)
Competency	4.4 (\pm 1.0)	4.1 (\pm 1.0)
Learnability	4.3 (\pm 1.1)	3.8 (\pm 0.8)
Ease-of-use	4.5 (\pm 1.1)	4.0 (\pm 0.9)

Abbreviations: Health-ITUES, Health IT Usability Evaluation Scale; SD, standard deviation.

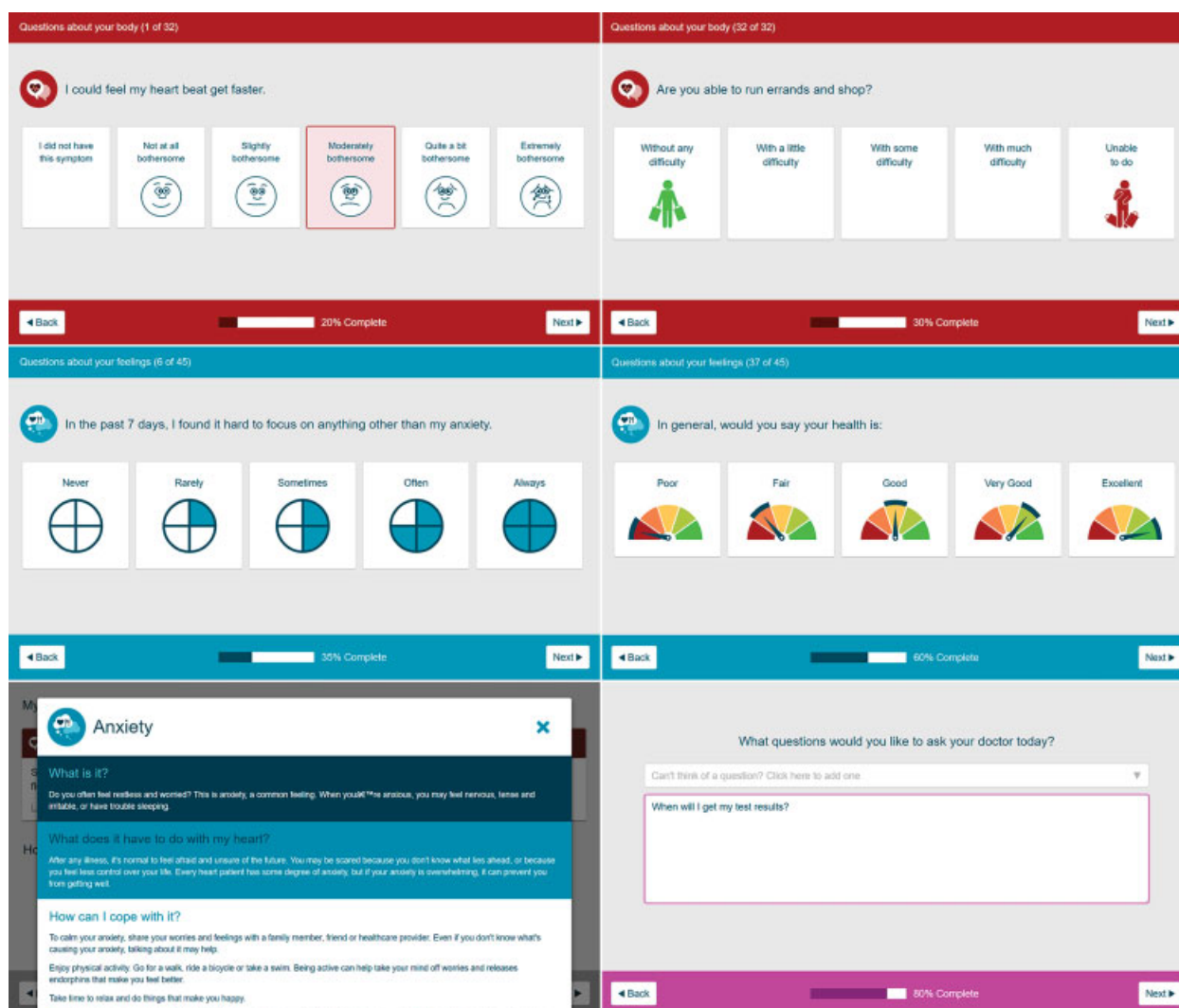


Fig. 2 Patient-reported outcome (PRO) questions with visualizations, educational information, and unstructured messaging in mi.Symptoms.

and HFSPS, changing the question text is impossible, but visualizations may aid comprehension. Additional strategies include providing definitions of potentially unclear jargon using links or pop-ups. Notably, interpretation aids may impact the validity, reliability, and overall performance of PRO measures, and future work must explore this. In the context of individual patient care, however, such interpretation aids may help patients better report outcomes and improve patient-provider communication.

Requirement 2: Design to aid interpretation. Both patients and providers wished to track symptoms over time to aid management and identify missed opportunities for intervention. By requirement, the interface should convey PRO survey results to patients. In mi.Symptoms, we satisfied this requirement by visualizing survey results for patients, using three strategies (→ Fig. 3):

1. **Small cards:** A set of cards, each containing a short sentence describing a severe symptom, which when clicked on provides textual educational information.

2. **Graph:** A bar graph that lists the patient's symptoms from most to least severe and displays each symptom's severity score.
3. **Large cards:** A set of cards, each displaying a symptom name, its two-sentence description, a visual representation of its severity, and a link to textual educational information.

By requirement, the interface should also track PROs longitudinally. Although the current version of mi.Symptoms does not display PRO data over time, future versions should.

Requirement 3: Design to support education. Participants described how PROs helped patients connect their symptoms with their disease. By requirement, the interface should incorporate strategies to help patients strengthen this connection. In mi.Symptoms, we satisfied this requirement by adding American Heart Association education materials and in-application links that define medical terms (→ Fig. 2, panel 5). Educational information conveyed alongside survey

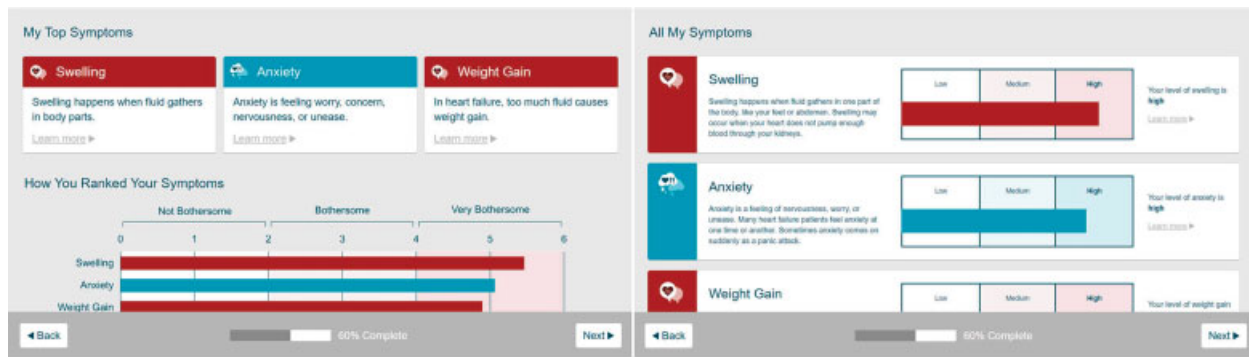


Fig. 3 Sample strategies for visualizing patient-reported outcome (PRO) survey results. (Left: small cards and graph; Right: large cards).

results may help patients make connections more explicitly and improve their health literacy.

Requirement 4: Design to promote communication. In interviews, patients described wanting unstructured messaging features to ask their physician questions and communicate further regarding their symptoms. By requirement, the interface should include options for unstructured messaging. In *mi.Symptoms*, we satisfied this requirement by including an unstructured messaging feature (→ **Fig. 2**, panel 6).

Use Case Scenario: When a heart failure patient arrives at the clinic, the receptionist enters the patient's medical records number (MRN) into *mi.Symptoms*, installed on an iPad (→ **Fig. 4**). The MRN triggers *mi.Symptoms* to display the patient's identifying information, which the receptionist verifies. Then, the patient completes the PRO questions and views the summary visualization of their results while in the waiting room. When the patient presses a "submit" button, the application prompts the patient to return the iPad.

Usability Study (Stage 3)

Participants preferred the buttons and cards to the graph when visualizing survey results. Half of the participants failed to interpret the graph correctly, and even participants who could read it often required multiple attempts. Participants perceived that the buttons and cards provided more information than the graph. However, two users preferred the graph because it summarized the results in one location.

Participants appreciated design elements they perceived as "fun," such as icons in colorful bubbles. Participants preferred lighter colors, which they reported enhanced the survey's positive emotional effect. All participants understood tapping or clicking, but two participants did not understand scrolling. These participants could navigate through the application using "next" and "back" buttons and complete the survey without assistance, but never viewed educational content available via scrolling.

SUPR-Q Results: Overall, *mi.Symptoms* scored highly on all four dimensions of the eight-item SUPR-Q compared with well-known applications (→ **Table 4**).

Table 4 SUPR-Q scores for *mi.Symptoms* (scores range from 0 to 1, lowest to highest)

Domain	Score
Overall: mean (\pm SD)	0.94 (\pm 0.10)
Usability	0.93 (\pm 0.10)
Credibility	0.92 (\pm 0.10)
Loyalty	0.92 (\pm 0.13)
Appearance	0.97 (\pm 0.08)

Abbreviations: SD, standard deviation; SUPR-Q, Standardized User Experience Percentile Rank Questionnaire.

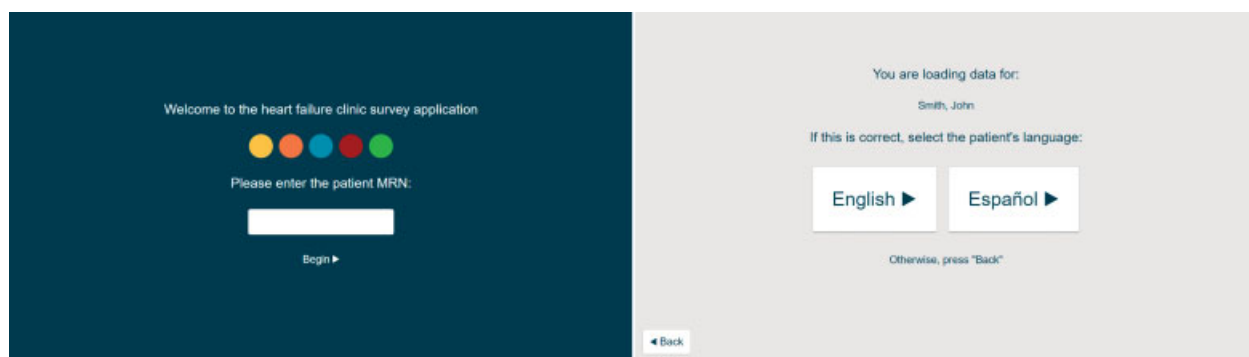


Fig. 4 *mi.Symptoms* interface for the clinic receptionist.

Discussion

Engaging patients with PROs is challenging, and technology is an important tool to help patients report and interpret PROs. In this study, we aimed to understand both patients' and providers' perceptions of the value and challenge associated with PROs. We also aimed to improve upon current e-PRO systems, using visualizations to enhance the patient experience. We developed a user interface, *mi.Symptoms*, that met a series of design requirements, and conducted usability testing with it. We reported on the design process, and discussed our generalizable insights about designing e-PRO systems. Our interview findings suggested that patients perceive the value of PROs. PROs encouraged patients to reflect on their symptom experience and recognize the symptoms associated with their disease. Two participants, unprompted, asked for *mi.Symptoms* access at home to aid self-tracking of symptoms. Providers reported that PROs could potentially support their patients' self-management. As per the situation-specific theory of heart failure self-care,^{41–43} reporting PROs may increase patients' symptom perception by helping them recognize the range of symptoms associated with their disease. Viewing visualized PRO data and educational information may increase symptom perception by helping patients attribute meaning to their symptom experience.

Patients reported difficulty understanding PRO survey questions, answer choices, and results. Their confusion emphasizes the need to contextualize PROs to aid comprehension, using visualizations or explanations. Future work should explore the impact of different visualizations on comprehension, and how visualizations impact the validity, reliability, and overall performance of PRO measures. Visualized PRO measures may perform differently, ideally better, but may lack comparability with nonvisualized versions. For individualized patient care, comparability is less of a concern than ensuring accurate patient-provider communication. However, comparability over time is necessary for many administrative and research tasks. The tension between using comprehension aids to assist low literacy patients and ensuring comparability of PRO measures is one that requires exploration.

Our usability study found that patients preferred visualizations with brief text descriptions. This is consistent with previous research that brief text descriptions combined with visualizations perform better than either alone.^{23,38,40} Additionally, most patients in our study failed to comprehend graphs. This is consistent with previous research that inadequate graph literacy is prevalent, around 40% of the U.S. population.⁴⁴ Notably, graph literacy and numeracy vary widely even in populations with high health literacy,⁴⁵ and low graph literacy is correlated with low patient portal use.^{46,47} Previous studies have primarily displayed PRO data for patients with graphs.^{20–23} Given our results and the prevalence of inadequate graph literacy, exploration of additional visualization strategies beyond graphs is warranted. When displaying PRO data over time, avoiding graphs is potentially difficult. In this case, strategies to help patients understand graphs or brief text descriptions of the graph's interpretation may be necessary. Future work should eval-

uate comprehension of graphs and additional visualization strategies in large samples.

Information engagement is a two-way process involving exchanges between patients and providers. In our interviews, participants occasionally expressed concern about providers not utilizing PRO data. Such concerns might stem from health system skepticism⁴⁸ or recent, high profile cases of ransomware attacks against EHR systems, and press coverage of cybersecurity vulnerabilities in general.^{49,50} Future tools should consider indicating when PRO data are seen by and used by medical staff, or educating patients on uses of PRO data, to encourage patients to continue providing PROs.

Patient-provider communication through portals may be described as unstructured or structured. In unstructured communication, such as secure electronic messaging, the patient selects the topic of communication. In structured communication, such as PROs, the interface prompts patients with topics or questions to communicate about. Our interview results suggest that patients want unstructured communication channels to supplement structured ones. In previous studies, providers have expressed concerns that unstructured messaging may overwhelm them with patient contact.⁵¹ Future work should address the potential burden of unstructured messaging on providers.

Our findings echo previous research on e-PRO systems in several ways. First, as our interviews suggested, e-PRO systems offer an opportunity to educate patients and improve health literacy. Previous systems have incorporated disease management tips, education modules, and data interpretation guidelines.¹⁶ Future work should explore additional opportunities for patient education directly within the e-PRO interface. Second, our provider interviews echoed previous research on the value of PROs. Like others, our providers thought PROs could save time, enhance symptom review, and identify missed opportunities for medical intervention.^{15,17} Finally, as our interviews suggested, heart failure patients anticipate using PROs for personal tracking and management, similar to surgical and oncology patients.¹⁷ Future work should explore how disease type impacts patients' perceived value of PROs.

We chose to use an external, or "wraparound," e-PRO system, rather than building a system within the EHR itself. External systems offer several strengths over internal systems, including the easy customization necessary to create our visualizations. However, external systems also demonstrate several weaknesses. First, although our system does not require any username or password, the clinic receptionist must link it directly to the EHR using the patient's MRN. Second, our external system uses a unique protocol to communicate with our EHR, which is not easily generalizable to other EHR systems.

We choose to implement *mi.Symptoms* in the waiting room for five key reasons. First, although our institution offers an online patient portal, monthly use for patients with access lies below 2%, consistent with the low adoption of portals across the United States.⁵² Second, physicians can immediately act on information collected in the waiting

room, decreasing legal liability. For example, if the patient screens positive for depression in the waiting room, the physician can immediately place them on an antidepressant trial. Third, because every patient reports PROs from the waiting room, the provider can integrate PROs into their standard clinic workflow, which may increase PRO utilization. As such, we do not need to prompt providers with notifications to view PROs, and this may prevent alert fatigue. Fourth, the clinic receptionist can assist patients with the application in the waiting room, potentially increasing reliability and therefore clinician trust in the patient-reported information. Fifth, restricting the frequency of PRO collection to clinic visits reduces the burden of reporting on patients. Although collecting PROs in the waiting room has many strengths, one weakness is the inability to monitor symptoms between visits.

Limitations

Our patient participants represent a wide range of demographics. However, a broader sample representing multiple chronic conditions, including but not limited to heart failure, might expand our understanding of user perceptions and needs. Including patients in other countries or institutions should also expand our understanding. Future work should offer patients a broader variety of visualizations and strategies for interpreting results, and evaluate their comprehension and preferences on a larger scale. Older adults experience more chronic illness than younger populations, and future work could target this age group. Future work could also target high-risk populations such as cognitively impaired and terminally ill populations, which we excluded from our study. The sample size for our usability study is small, and future work should explore mi.Symptoms' usability in a larger sample. In this study, we explored three strategies for visualizing a single survey's results, but we did not explore strategies for visualizing multiple survey results over time. Future work should evaluate strategies for longitudinal visualization of results for both patients and providers.

Conclusion

Engaging patients in PRO collection may improve symptom reporting and illness understanding. In this article, we described results from an iterative, user-centered design process to develop an electronic user interface to collect PROs. Patients reported difficulty understanding PRO survey questions and results, prompting the integration of visualizations into the interface. Future interfaces design to collect PROs may benefit from the lessons learned from our design process and from employing similar strategies to engage patients with PROs.

Clinical Relevance Statement

This study advances the knowledge of design requirements for an interface that collects patient-reported outcomes (PROs). Our results contain generalizable knowledge to inform the development of PRO collection systems and to

improve symptom monitoring in chronic illness for practitioners and consumers.

Multiple Choice Question

What do patients perceive as the value of using patient-reported outcomes?

- a. Encourages reflection on symptom experience
- b. Facilitates personal tracking and monitoring
- c. Connects symptoms with disease
- d. All of the above

Correct Answer: The correct answer is option d, all of the above. In our study, patients reported all three as valuable effects of using patient-reported outcomes (PROs). Patients used PROs as a reflective experience that prepared them to interact with their physician. Patients reported interest in using PROs for personal tracking of symptoms longitudinally. Finally, PROs helped patients associate symptoms with disease, such as connecting gastrointestinal symptoms with heart disease.

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 Columbia University Medical Center Institutional Review Board.

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Conflict of Interest

None.

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