Research and Applications

Patient and healthcare provider views on a patient-reported outcomes portal

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ABSTRACT

Background: Over the past decade, public interest in managing health-related information for personal understanding and self-improvement has rapidly expanded. This study explored aspects of how patient-provided health information could be obtained through an electronic portal and presented to inform and engage patients while also providing information for healthcare providers.

Methods: We invited participants using ResearchMatch from 2 cohorts: (1) self-reported healthy volunteers (no medical conditions) and (2) individuals with a self-reported diagnosis of anxiety and/or depression. Participants used a secure web application (dashboard) to complete the PROMIS[®] domain survey(s) and then complete a feedback survey. A community engagement studio with 5 healthcare providers assessed perspectives on the feasibility and features of a portal to collect and display patient provided health information. We used bivariate analyses and regression analyses to determine differences between cohorts.

Results: A total of 480 participants completed the study (239 healthy, 241 anxiety and/or depression). While participants from the tw2o cohorts had significantly different PROMIS scores ($p < .05$), both cohorts welcomed the concept of a patient-centric dashboard, saw value in sharing results with their healthcare provider, and wanted to view results over time. However, factors needing consideration before widespread use included personalization for the patient and their health issues, integration with existing information (eg electronic health records), and integration into clinician workflow.

Conclusions: Our findings demonstrated a strong desire among healthy people, patients with chronic diseases, and healthcare providers for a self-assessment portal that can collect patient-reported outcome metrics and deliver personalized feedback.

Key words: patient-reported outcomes, PROMIS, qualitative research, patient portal, patient engagement, patient generated health data

INTRODUCTION

Current “learning health system” initiatives heavily emphasize the potential for harvesting vast amounts of data generated by healthcare organizations and using data science methods to extract actionable information.¹ With recent advances in the ability to obtain information from electronic health records (EHRs),^{2–4} lowering costs of computing infrastructure,^{5–7} and a growing cadre of information scientists who can infer meaning from compiled datasets,^{8–10} a tipping point in the practice of medicine is currently underway. Point of care assessment and analysis of real-time data combined with knowledge gained from aggregate analysis of millions of patient records can and should inform precision medicine aimed at delivering the right diagnosis (or treatment) to the right patient at the right time.

A recent review illustrates the tremendous public interest in managing health-related information for personal understanding, self-management, and improvement.^{11–13} Patients are investing time and resources to generate their health data in mobile applications for personal use. Further, patient-facing portals and similar telemedicine strategies have become established approaches for collecting consumer-generated data across a range of chronic health conditions and feeding that information in an actionable way to healthcare providers.^{14–16} By coupling the desire of patients to generate data for understanding their health with the potential value of using personal health information to support learning health system initiatives and precision medicine programs, listening to the patient should be easier than ever before. However, challenges remain. Information overload for healthcare professionals is daunting and adding large amounts of unrestricted data to clinic workflows have significant burdens and risks. Examples include managing patient expectations for the use of self-generated data, privacy, security, quality concerns, and health system liability for missing critical information (eg dangerously high blood pressures).¹⁷ For patients, self-reported information requests from the healthcare system can seem unidirectional regarding benefit, and the process can be perceived as redundant and burdensome.

The current study was designed to explore how patient-provided health information might be captured and presented to inform and engage patients while delivering potentially useful and additive information for healthcare providers. For this project, we created a framework allowing individuals from the public (healthcare consumers) to complete validated Patient-Reported Outcomes Measurement Information System (PROMIS) instruments previously used in clinical settings^{18–20} and view their resulting score via a dashboard user interface that provides feedback regarding how collected and computed information could help them understand their health. We also utilized a “community engagement studio”²¹ to seek opinions from healthcare providers about perceived value and unanticipated burden associated with collecting and using patient provided information during clinical encounters. Our primary purpose in conducting this exploratory study was to examine opinions of 2 cohorts (individuals self-reporting as “healthy” and individuals self-reporting with anxiety and/or depression) and a representative healthcare provider group regarding desired features, benefits, and anticipated barriers to implementation of patient-reported information collection systems and review dashboards.

METHODS

Population and Setting

We invited volunteers through ResearchMatch²² to participate in the study. Two cohorts were recruited: (1) self-reported healthy

volunteers (no medical conditions) and (2) individuals with a self-reported diagnosis of anxiety and/or depression. Participants were invited to participate via e-mail invitation and supplied with links to a secure web application (dashboard) described below. Participants were invited (randomly chosen from relevant ResearchMatch population cohorts) in small batches until approximately 480 total survey participants responded, including 239 healthy volunteers and 241 reporting a diagnosis of anxiety and/or depression. Participants were compensated with a \$10 gift card for their effort after completing required tasks.

Five healthcare providers were also recruited by email to participate in a community engagement studio²¹ to obtain perspectives of the dashboard and general opinions regarding the value and burden of processing patient provided information in the clinical setting. All providers actively practiced medicine in either primary care or chronic disease management. The studio lasted less than 2 hours, during which providers were provided with dinner and compensated with a \$50 gift card. The Vanderbilt University Institutional Review Board approved all aspects of the study.

PROMIS Surveys and Patient Report Dashboard

We designed a patient report study portal (Figure 1) with capacity to measure 6 PROMIS health domains (Sleep Disturbance v1.0,²³ Anxiety v1.0,²⁴ Depression v1.0,²⁴ Pain Behavior v1.0,²⁵ Physical Function v1.2,²⁶ and Social Isolation v2.0²⁷). Participants clicked on a “take survey” button, which took them to relevant PROMIS computer adaptive testing (CAT) questions for that domain.^{28,29} These PROMIS questions were administered through Research Electronic Data Capture (REDCap)³⁰ using standard PROMIS instruments obtained from the REDCap Shared Data Instrument Library.³¹ Once participants completed a given domain measure (eg sleep), the portal display for that measure immediately showed individual results. PROMIS calculations provide a raw T score based on a normal distribution. We converted this T score into a percentile and presented this as a semi-circular gauge (Figure 1). Participants could then click on the “see my score” button to get a more detailed view of their score including their percentile (eg “You scored in the 51st percentile on the Sleep survey. This detailed view of their score means that if 100 people in the United States took the same survey, we would expect about 51 of them to receive a score lower than yours.”).

For each of the 6 possible health domains, we included “more information” links allowing participants to learn more about specific health domains. For content, we chose health domain overviews from either the Office of Disease Prevention and Health Promotion within the Department of Health and Human Services, the Mayo Clinic, or the U.S. National Library of Medicine.^{32–37} These sources were selected because they were from recognized and reputable sources, copyright free, in the public domain, and targeted towards the general public rather than healthcare professionals.

The study portal provided clear instructions to participants regarding tasks to complete and how to receive participant compensation. Required elements for full participation included: 1) reading instructions; 2) participating in a sleep domain PROMIS questionnaire; 3) reviewing a personalized score based on sleep question responses; 4) completing an opinion and feedback survey about the process and personal preferences for completing, viewing (Figure 2, Figure 3) and sharing personal information about health measures; and 5) completing a short compensation questionnaire used for gift card distribution. Optional tasks available for participants included

Figure 1. Screenshots of the (A) introductory dashboard, (B) PROMIS survey screen, (C) survey results screen (detail), (D) more information screen.

Figure 2. Options for how health assessment results are displayed.

the ability to take additional (non-sleep) PROMIS questionnaires and review their personalized score in various health measure domains. Participants could also optionally view detailed “more information” content about any of the available health domains.

Participant Feedback Survey

The participant feedback survey included questions mapped to 4 areas (Supplementary Appendix S1). The first area included questions surrounding the actual PROMIS questions within the dashboard, overall user impressions, and opinions regarding the

“more information” resource. The second area evaluated participant preferences for how health assessment results are displayed (Figure 2). The third area included questions related to participants’ interest in the ability to set goals (Figure 3) and their preferences for whether or not their provider should be involved in that process. The fourth and final area included questions related to participant preferences and perspectives on sharing information with their healthcare provider(s). For consistency, opinion questions were asked with either “yes/no” answer choices or a 6-point Likert scale (“strongly disagree” to “strongly agree” without a neutral option).

Figure 3. Options for the ability of setting goals for longitudinal data.

Community Engagement Studio of Healthcare Providers

Five healthcare providers were recruited to participate in a community engagement studio to assess their perspectives on the feasibility of a portal to collect and display patient provided health information. An engagement studio team leader worked with our study team before the actual engagement studio to formulate questions that would be posed to participants. Before the engagement studio began, participants had the opportunity to interact with the study portal, complete health domain surveys and see information as presented to study participants. The studio was facilitated by a trained, neutral moderator to ensure studio participants were comfortable sharing their ideas and that prepared discussion and questions were appropriately addressed.

After a brief presentation by the study team, the key questions were presented to studio participants, and the moderator facilitated the ensuing discussions (Figure 4). The results and insights generated from the studio were qualitative, with the design of the studio intended to elicit responses and comments from the group related to our research questions without hindering the ability of the discussion to lead to relevant topics or issues not considered initially. Notes were taken regarding participant responses during the studio and later used to prepare a summary for investigators.

Data Analysis

Survey participant demographics were summarized using descriptive statistics. All demographics were self-reported except for zip-code median household income. Median household income was derived by linking participant zip codes, from their contact information, to their corresponding zip code tabulation area (ZCTA). ZCTAs were then linked to the corresponding 2015 American Community Survey median household income values.³⁸ Continuous variables were summarized with medians and interquartile ranges, and categorical variables were summarized with counts and proportions. PROMIS CAT domains were scored using the HealthMeasures Assessment Center API,³⁹ which results in a score on a scale of 1–100. These scores were summarized with medians and interquartile ranges. Measurement differences between healthy and anxiety and/or depression cohorts were evaluated using Mann-Whitney U nonparametric methods.

Feedback questions were summarized by counts based on the option selected, and Likert scale questions were summarized by either disagreement (1–3 on the scale) or agreement (4–6 on the scale) with the question or statement. Logistic regression models were used to determine differences for feedback survey questions between demographic variables or cohort, either healthy or anxiety and/or depression, and agreement with the feedback question. Linear regression was used to determine associations between demographics and cohort, and the PROMIS score. Regression model variables were selected if they were significantly different between the 2 cohorts. Race was combined into White, Black or African American, and Other because of the low numbers of other races of participants. All analyses were performed with R version 3.3.2.⁴⁰

Qualitative assessment for participant feedback was accomplished by 1) recording and transcribing all information into a flat file (MS-Excel), 2) assigning independent reviewers (authors DC and RNJ) the task of reviewing each quote and categorizing these quotes into themes; and 3) post-assessment joint-review and harmonization of themes/meaning using consensus. Themes were created using a grounded theory approach in which the themes evolved from the quotes naturally.⁴¹ Qualitative data from the community engagement studio were recorded on paper by a neutral scribe as themes and agreed upon by the participants during the studio.

RESULTS

Survey Participants

A total of 5120 people were randomly selected from relevant ResearchMatch cohorts (self-reported healthy, self-reported anxiety and/or depression) and contacted via e-mail invitation. Invitations were sent in small batches until a total of 500 participants responded. Due to conflicting demographics within their ResearchMatch profile (eg multiple persons sharing an e-mail address), 20 records were removed, leaving a final sample size of 480. Of the people invited, 86% were White, 49% were Females, and 90% were not Hispanic or Latino. Among survey respondents, the majority of participants were White (83%), Females (59%), and not Hispanic or Latino (96%) (Table 1). Participants spanned a variety of ages and income strata. All participants completed requirements for compensation (sleep domain survey and study feedback questionnaire).

What are your first impressions of the dashboard?

How feasible do think it would be to incorporate domain-specific participant reported data collection and review into your practice?

Would your patient population be able to easily use a dashboard similar to the one used in this study?

Would they be able to access a patient reported outcomes data portal?

What would motivate you to use a patient reported outcomes data portal in your practice?

What would motivate your patients to use a patient provided information dashboard?

What would prevent you or your patients from using a patient provided information dashboard?

What would you change or add to the dashboard used in this study?

Figure 4. Questions asked in the community engagement studio of healthcare providers.

Table 1. Demographics of the participants from the 2 cohorts of anxiety/depression and healthy

Demographics	Anxiety/Depression (<i>n</i> = 241)		Healthy (<i>n</i> = 239)		Total (<i>n</i> = 480)		p-value
Gender							.3
Male	106	44.0%	93	38.9%	199	41.5%	
Female	135	56.0%	146	61.1%	281	58.5%	
Race							<.01
American Indian or Alaska Native	1	0.4%	1	0.4%	2	0.4%	
Asian	4	1.7%	9	3.8%	13	2.7%	
Black or African American	10	4.1%	36	15.1%	46	9.6%	
Multi-Racial	7	2.9%	8	3.3%	15	3.1%	
Other	3	1.2%	3	1.3%	6	1.3%	
White	216	89.6%	182	76.2%	398	82.9%	
Age							<.01
18–24	20	8.3%	42	17.6%	62	12.9%	
25–34	84	34.9%	85	35.6%	169	35.2%	
35–44	46	19.1%	36	15.1%	82	17.1%	
45–54	36	14.9%	42	17.6%	78	16.3%	
55–64	39	16.2%	17	7.1%	56	11.7%	
65+	15	6.2%	16	6.7%	31	6.5%	
Ethnicity							.9
Hispanic or Latino	9	3.7%	10	4.2%	19	4.0%	
Not Hispanic or Latino	231	95.9%	228	95.4%	459	95.6%	
Zip-Code Median Income							.05
0–19 999\$	1	0.4%	4	1.7%	5	1.0%	
20 000–39 999\$	27	11.2%	37	15.5%	64	13.3%	
40 000–59 999\$	108	44.8%	82	34.3%	190	39.6%	
60 000–79 999\$	67	27.8%	65	27.2%	132	27.5%	
80 000–99 999\$	21	8.7%	21	8.8%	42	8.8%	
100 000–119 999\$	9	3.7%	15	6.3%	24	5.0%	
120 000–139 999\$	0	0.0%	5	2.1%	5	1.0%	
140 000–159 999\$	1	0.4%	2	0.8%	3	0.6%	

Participants with self-reported anxiety and/or depression scored distinctly different on health domain measures than did the self-reported healthy cohort, but both cohorts had similar agreement about most questions in the feedback survey.

While the Sleep Disturbance domain was the only required domain measure for survey participants, we also intentionally allowed participants to take additional domain measures if desired. Approximately 60% of our participant population

participated in at least one non-required health domain survey and scoring (with 40% completing all health domain surveys), validating that many participants will voluntarily participate after learning about health domain scores without additional payment.

Comparison of domain scoring across our 2 participant cohorts showed strong scoring differences between cohorts in expected directions (Table 2). Linear regression models showed significant

Table 2. PROMIS scores in the healthy cohort, the anxiety and/or depression cohort, and the total (combined) cohort

PROMIS measure	Healthy	Anxiety or Depression	Total	p-value
Sleep Disturbance	<i>n</i> = 239 52.0 (46.3–57.1)	<i>n</i> = 241 56.1 (51.9–62.0)	<i>n</i> = 480 54.3 (47.9–59.5)	<.001
Anxiety	<i>n</i> = 147 56.0 (51.2–63.3)	<i>n</i> = 183 63.0 (57.6–68.1)	<i>n</i> = 330 59.8 (53.4–67.0)	<.001
Depression	<i>n</i> = 119 49.9 (44.2–58.5)	<i>n</i> = 159 60.5 (54.3–65.7)	<i>n</i> = 278 56.9 (49.4–62.6)	<.001
Emotional Support	<i>n</i> = 107 48.7 (43.4–56.2)	<i>n</i> = 139 48.7 (42.3–54.4)	<i>n</i> = 246 48.7 (42.3–54.5)	.139
Pain Behavior	<i>n</i> = 112 49.7 (35.3–56.6)	<i>n</i> = 135 56.3 (48.6–59.0)	<i>n</i> = 247 53.8 (35.3–58.6)	<.001
Physical Function	<i>n</i> = 117 55.8 (49.7–61.7)	<i>n</i> = 137 45.9 (39.8–53.1)	<i>n</i> = 254 51.1 (42.5–57.3)	<.001

Note: PROMIS scores range from 1–100, with a population mean of 50, and a standard deviation of 10. A higher score corresponds with more of the underlying construct; for example, a higher PROMIS score for depression indicates more depressive symptoms. Therefore, a low depression score accompanied by a high physical function score is desirable. The number of respondents that completed each PROMIS measure by each cohort is presented in each cell. The scores are summarized with medians and interquartile ranges. The p-value measures the difference between the health and anxiety and/or depression cohorts using Mann-Whitney.

Table 3. Linear regression models for PROMIS measures (a normally distributed continuous variable), cohort (healthy vs. anxiety and/or depression), and demographics (95% CI = 95% Confidence Interval)

PROMIS measure	Coefficient	95% CI	Pr(> z)
Sleep Disturbance (<i>n</i> = 480)			
Cohort: Anxiety or Depression	4.76	(3.31, 6.21)	<.001
Age	0.02	(−0.03, 0.07)	0.451
Race: Black or African American	1.83	(−0.62, 4.28)	0.144
Race: Other	0.82	(−1.88, 3.52)	0.553
Gender: Male	−0.42	(−1.86, 1.02)	0.566
Anxiety (<i>n</i> = 330)			
Cohort: Anxiety or Depression	6.27	(4.26, 8.28)	<.001
Age	−0.11	(−0.18, −0.04)	<.001
Race: Black or African American	−3.7	(−6.88, −0.52)	0.02
Race: Other	−3.22	(−6.9, 0.46)	0.09
Gender: Male	−1.72	(−3.69, 0.25)	0.09
Depression (<i>n</i> = 278)			
Cohort: Anxiety or Depression	7.78	(5.38, 10.18)	<.001
Age	−0.05	(−0.13, 0.03)	0.233
Race: Black or African American	−3.61	(−7.32, 0.1)	0.058
Race: Other	−1.32	(−5.63, 2.99)	0.548
Gender: Male	−1.24	(−3.57, 1.09)	0.3
Emotional Support (<i>n</i> = 246)			
Cohort: Anxiety or Depression	−1.87	(−4.38, 0.64)	0.146
Age	−0.04	(−0.12, 0.04)	0.301
Race: Black or African American	0.33	(−3.43, 4.09)	0.862
Race: Other	−2.9	(−7.95, 2.15)	0.261
Gender: Male	−2.99	(−5.38, −0.6)	0.015
Pain Behavior (<i>n</i> = 247)			
Cohort: Anxiety or Depression	5.35	(2.41, 8.29)	<.001
Age	0.13	(0.03, 0.23)	0.008
Race: Black or African American	4.77	(0.39, 9.15)	0.034
Race: Other	−2.25	(−8.37, 3.87)	0.473
Gender: Male	−0.36	(−3.2, 2.48)	0.807
Physical Function (<i>n</i> = 254)			
Cohort: Anxiety or Depression	−7.34	(−9.79, −4.89)	<.001
Age	−0.23	(−0.31, −0.15)	<.001
Race: Black or African American	−1.23	(−4.96, 2.5)	0.518
Race: Other	1.83	(−3.21, 6.87)	0.477
Gender: Male	1.72	(−0.64, 4.08)	0.155

differences between the cohort or demographics and PROMIS scores (Table 3).

The anxiety and/or depression cohort exhibited a few significant differences in their perception of the patient report dashboard when compared to the healthy cohort. As compared with the healthy cohort, the anxiety and/or depression cohort was less likely to report that they liked learning their personal health score (odds ratio (OR): 0.42, 95% confidence interval (CI): (0.21, 0.85)), was more interested in seeing their results over time (OR: 1.79, 95% CI: (1.08, 2.95)), was more likely to want goals to be set by themselves or their doctor, but not both (OR: 1.81, 95% CI: (1.07, 3.07)), and thought their doctor would be surprised to learn about their results from the sleep survey (OR: 1.65, 95% CI: (1.01, 2.68)). No other feedback questions were significantly different between the two cohorts.

Information from PROMIS Questions and Results in the Dashboard Were Positively Received

At least 90% of individuals thought the questions and results were easy to understand (Table 4). Participants with anxiety and/or depression were less enthusiastic about learning their scores than healthy participants (88% and 95%, respectively). When given simple examples of text-based result sharing, graphic representation of results and a combination of both approaches, a majority of survey participants (56%) recommended displaying both text and simple graphics to convey meaning.

Thematic analysis of qualitative information from the feedback survey reinforced that most participants felt a customized health assessment portal would improve awareness of themselves and their health issues ultimately leading to shared decision-making with their healthcare provider (Supplementary Appendix S2). Participants felt a persistent self-assessment portal could be useful in sharing results and health awareness with others on their healthcare team (eg providers, caregivers, and family). Some participants had concerns about the accuracy of results and potential problems associated with comparing themselves and other individuals to a “national average.” Some people indicated that seeing their scores made them feel worse and that they would prefer not to see these results because the scores would cause these participants to worry.

Table 4. Dashboard feedback survey questions and results

Survey questions and breakdown	Healthy (n = 239)		Anxiety/Depression (n = 241)	
I liked learning my personal health scores.	226	94.6%	213	88.4%
Questions were easy to understand.	235	98.3%	229	95.0%
Results were easy to understand.	221	92.5%	218	90.5%
Out of the total, 178 participants selected and reviewed the “more information” resource	(n = 87)		(n = 91)	
The “more information” was useful.	82	94.3%	79	86.8%
The more information was understandable.	84	96.6%	89	97.8%
I would have liked more information from multiple sources.	68	78.2%	65	71.4%
Given the choices shown below, how would you prefer to view your results after taking a health assessment survey?	(n = 239)		(n = 241)	
a. Text only	12	5.0%	14	5.8%
b. Simple graphic	29	12.1%	26	10.8%
c. Simple graphic and text	138	57.7%	129	53.5%
d. Compare your score to other populations	60	25.1%	72	29.9%
Out of the total, 399 participants were interested in using a secure web-based patient portal system that would enable them to save and review health assessment survey results over time.	(n = 191)		(n = 208)	
How would you prefer to view results after taking a health assessment survey?				
a. Simple time graph	26	13.6%	45	21.6%
b. Time graph with goal setting	165	86.4%	163	78.4%
328 participants selected time graph with goal setting	(n = 165)		(n = 163)	
Who would you like to set the goals on the graph?				
a. Your doctor	6	3.6%	13	8.0%
b. You	28	17.0%	37	22.7%
c. Both you and your doctor	131	79.4%	113	69.3%
I would like to share these sorts of results with my doctor.	(n = 239)		(n = 241)	
(Yes)	175	73.2%	188	78.0%
I would like my doctor to discuss these sorts of results with me.				
(Yes)	184	77.0%	188	78.0%
Do you think your doctor would be surprised to learn any of the results you’ve gathered from taking the . . . surveys?				
(Yes)	33	13.8%	54	22.4%

Note: Note the first 6 questions were six-point Likert scales for agreement, without the option of a neutral response. The numbers and percentages listed for those questions represent all positive mentions (strongly agree, agree, slightly agree).

The “more information” button had mixed usage and reviews

While all participants completed the sleep domain and finished the feedback survey, only 37% of all participants stated they reviewed the “more information” button. Over 95% of those that viewed “more information” reported the information was understandable. Slightly fewer participants with anxiety and/or depression who viewed “more information” found it useful (87% vs. 94%) and would have liked more information from multiple sources. Qualitative responses demonstrated issues with the quality of information in the “more information” resource. Participants stated that the information resource had too little or too much information, and that the information could be better tailored to their specific issues. Qualitative responses for those that did not review the “more information” button included concerns about psychological effects of learning more information, information accuracy, lack of time, technical issues, or the fact that information was not coming directly from their healthcare provider.

Participants Wanted to Track Health Results Over Time and Set Result-based Goals

Most participants were interested in using a dashboard to track their health assessments over time (83%). A majority of those interested in longitudinal assessments favored a time graph with the ability to

set and review goals (82%). Participants with anxiety and/or depression had a slight tendency to want results without goal setting as compared to the healthy cohort (22% vs. 14%, respectively). For those who wanted to have goal setting on graphs over time, a majority wanted to have both themselves and their doctor set time-based goals (74%). Qualitative feedback from participants expressing no desire to save/review survey assessments over time included perceived lack of utility, skepticism of accuracy, concerns about security and privacy, concerns about the time commitment, and apprehension for what results might convey about their health.

Participants Want to Share Information with Providers and Feel Information Could be Additive

A majority of participants expressed a desire to share and discuss self-generated health domain results with their doctor (76%) and approximately 1 in 5 participants (18%) thought their doctor would be surprised by the results. In qualitative responses, participants noted the portal could provide supplemental information that is not already available to providers for shared decision making. Some concerns were also recorded, including (1) privacy concerns about information breach, (2) perceived provider preference to only use the data privately and not discuss with them as patients, (3) lack of perceived provider trust in the data, (4) lack of interest or receptiveness from the provider for the information, (5) missing information

about the full history of the patient, and (6) provider labelling or profiling of patients based on the results.

Participants Suggested Various Features for a Health-assessment Portal

Suggested ideas for portal improvement included a social media component, weight tracker, journaling option, ability to set goals, and the capability to document relevant events (eg grief event before depression collection). Some wanted the dashboard to be more accessible like a mobile app. Integrating information was important (eg show participant-generated health domain information in the context of other patient-level data collected in the EHRs and patient portals). Participants wanted fine-grain control for results sharing with all health providers (eg results not limited to a single healthcare system). Participants also desired data portability, so that data can be exported and used outside the portal. Finally, participants wanted a data sharing option for family members and various caregivers.

Provider Community Engagement Studio

The community engagement studio included five healthcare providers (3 MDs, 2 NPs) that practice in primary care or the management of chronic diseases. Two MDs practiced primary care, 1 MD practiced pediatric endocrinology, 1 NP practiced gastroenterology, and 1 NP practiced in pulmonary care. Participants were from multiple organizations including academic medical centers and federally qualified health centers (FQHC).

Providers were receptive to the portal concept and its potential ability to improve patient care and engagement but stressed the need to customize domains and integrate the portal into clinic workflows to optimize the chance for successful implementation (Supplementary Appendix S3). Providers identified 4 themes that were essential to address to implement this type of portal into their practice successfully. First, the domains must be customizable to best meet the needs of the patient and provider, in particular, working within the clinician workflow to avoid overburdening the provider. Second, the tool must allow for the remote collection of data from patients as well as in clinic options to ensure underserved populations have access. Third, the data collected should be integrated into EHR notes to maximize usage and efficiency. Finally, depending upon the time and resources required to utilize this type of data, the potential to bill for these types of services must be further explored.

Overall benefits identified for providers included the obvious ability to improve patient outcomes, the potential for shortened appointment times if patients can prescreen, and this type of tool's support for more engaging and patient-centered discussions between providers and their patients. Benefits identified for patients included the potential to shorten appointment times, the ability to set functional goals defined by the patient that can be tracked, and provision of a more empowering experience in patients' management of their health. Providers did express concern regarding the inability of patients to engage with the portal outside of the clinical setting due to either age or underserved status.

DISCUSSION

This study is one of the first to pilot a platform to collect patient-reported outcomes using validated instruments and obtain both patient and provider input across 2 different populations of patients (healthy versus anxiety and/or depression) to understand the abilities and pitfalls of using a portal to capture patient-reported outcomes

in clinical care. Our findings demonstrate the desirability of a portal that delivers questions from standardized patient-reported outcomes measures and delivers feedback about their scores among healthy people, those with anxiety and/or depression, and the healthcare providers that care for them. Our findings further demonstrate the need for the ability to customize the domains and data gathered to the specific needs of the patient and their provider, and that that process of customization must include a process whereby patient and provider communicate their needs and expectations clearly, as well as limitations.

Several themes were consistent between patient feedback surveys and the provider engagement studio regarding their experiences with the portal. Participants described the ability of the dashboard to improve patient/provider communication and decision making. Patient-generated health data has the potential to allow patients to engage in their health, to enable healthcare providers to have more insight into their patients, and to allow patients and providers to have more meaningful communication.⁴² However, to be most effective, both patients and providers described several needs in the portal. The need for personalization of the dashboard domains was discussed, consistent with prior literature.⁴³ Patients and providers also described a need for the ability to set goals, as targets for improving health. Another desire for the portal was integrating dashboard data with other data sources like EHRs and mobile applications. Additional concerns included time burden and technological literacy for both patients and providers and setting unrealistic expectations. Overburdening clinicians with too much time or data that would limit the use of the portal is similar to issues described in other literature.⁴⁴ Patients wanted additional portal abilities like adding measures and features of their interest, documenting relevant events (eg grief event before depression collection), as well as data sharing to providers out of network, family members, and the care team, along with easy data export features. Ultimately, both groups thought the concept of a portal to collect, display, and share patient data between patients and providers would be a valuable tool to engage patients, while providing beneficial information for healthcare providers. Both groups also felt that it was essential to personalize this information and tailor the portal to the needs of the patient for it to be successfully incorporated into clinical care.

PROMIS domains were useful in demonstrating the concept of patient-reported outcome surveys and results. We chose PROMIS domains because they serve as validated patient-reported outcomes used in clinical settings^{45,46} with increasing applications in EHRs⁴⁶ and research database systems like REDCap.³¹ Sleep was the one required PROMIS domain as we felt it would apply to both healthy and anxiety and/or depression cohorts. We were pleased to note that participants in both cohorts (63%) filled out other domains that were not required to obtain their gift cards and complete the study, indicating a genuine interest in the information experience. Participants also expressed a desire for more information than was presented. In general, we found that participants felt the health information generated would add value to traditional point-of-care assessments and that longitudinal collection and presentation benefits could be bi-directional between patients and providers. Other groups have worked on developing patient-reported outcomes dashboards.^{43,46–50} Many of these manuscripts focus on static reports,^{47–49} and others were done solely in chronic conditions like cancers,^{43,46} or gastrointestinal diseases.^{50,51} Our findings were concordant with Hartzler's findings demonstrating that participants had a strong interest in viewing their results and sharing with their providers, that they wanted longitudinal trends, and that

personalization was very important.⁴³ Our work demonstrates as well that minimal significant differences exist between healthy people and those with a chronic condition in their desire for and preferences in a patient report portal.

A few important participant concerns need to be addressed to improve the portal. Concerns about the quality and usefulness of “more information” will require trusted and useful information resources for patients. These resources could include personalized information based on patient preferences for level and type of information. For example, general information that is given in the government websites in this study may be useful for those who need basic knowledge; however, those who might be well versed in the topic may require more detailed information. Input from the lay public and patients may help improve these highly utilized information resources. In future real-world portal designs, proper attention should be given to avoid unintended consequences (eg unnecessary anxiety) of sharing negative non-contextual results to patients; consequences demonstrated in prior literature.⁵² Participants’ concerns about the accuracy of PROMIS measures (well-known scales to the health and research communities) may require additional justification of utility to the general public. These concerns could be alleviated by giving additional information about the origin, nature, and robustness of PROMIS measures. This information could be personalized for participants including a summary for those who only want an overview, and greater depth for those who need more detail. A frequently asked question (FAQ) section could outline what PROMIS scores can and cannot tell participants.

Future directions would include evaluating how this information may be valuable to the healthcare team in determining how to best care for patients. Methods explored in this study could also inform new mechanisms for patients to report their outcomes in common diseases, such as depression, anxiety, and pain, in an objective way that may help providers take better care of patients. The population surveyed in our study was primarily white, which limits the generalizability of our findings as significant cultural differences may exist in the perceived acceptability and usability of a portal in minority populations.^{53–55} Future research based on this preliminary study should take this into account.

Several limitations were present in this study. First, a Research-Match population has the potential for biases. Identification of participants was based on self-reported conditions, but we were encouraged that individual results from various PROMIS domain scores were directionally consistent (eg anxiety and/or depression group scored significantly higher on the anxiety domain compared to the healthy group). We chose a single, combined diagnosis of (anxiety and/or depression) for the “medical conditions” cohort, which could limit the generalizability of our findings in a larger general population with multiple other chronic medical conditions. In this study, we did not collect information related to participant’s educational level or assess and control for health literacy levels, which may limit generalization of our findings to all populations. System/Feature options were derived after intentionally showing a finite set of options, rather than other qualitative methods to gather broader ideas, which may have narrowed our results. Our initial set of features were based on others that have been described in the literature.⁴³ Finally, as most of our feedback for participants and providers was qualitative, we did not power the study to determine absolute measures of health domain information for each of our participant cohort groups. We instead focused on ensuring populations were large enough to collect meaningful input on the potential value of patient-provided information in planning future health portals.

CONCLUSIONS

This study helps demonstrate that both healthy individuals and those with chronic medical conditions want to use a portal to share health-related information, as do healthcare providers. By including both patient and provider communities in our study, we were able to explore and elicit bi-directional benefits, barriers, and required considerations for patient-provided information system design and evaluation. While literature has demonstrated that there are benefits, barriers, and opportunities for patient-reported portals,^{17,42,43,52} we add to the informatics literature by engaging healthy people, patients with a chronic medical condition, and healthcare providers about a single patient report portal. We discovered specific benefits (eg improved engagement, patient-provider communication and decision making), barriers (eg lack of incentives and need for personalization of data collected, information resources, and data presented to the patient and provider), and opportunities (eg goal setting, integration into the workflow and tools available to patients and providers can lead to a usable patient report portal) for this patient report portal. Generalizable information from this study can be used by future implementation teams considering collection, storage and use of patient-generated health data in mainstream healthcare services and care.

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COMPETING INTERESTS

None.

CONTRIBUTORS

RMC, DC, and PAH were involved with the conception, design, and data collection of the study. RMC, DC, DC, RNJ, DWB and PAH were involved with the analysis of the study. All authors were involved with the writing and editing the manuscript.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

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