

Increasing Patient Engagement: Patients' Responses to Viewing Problem Lists Online

A. Wright^{1,2,3}; J. Feblowitz^{1,2,3}; F.L. Maloney²; S. Henkin^{1,2}; H. Ramelson^{1,2,3}; J. Feltman²; D.W. Bates^{1,2,3,4}

¹ Division of General Internal Medicine, Brigham & Women's Hospital, Boston, MA;

² Partners HealthCare, Boston, MA;

³ Harvard Medical School, Boston, MA;

⁴ Harvard School of Public Health, Boston, MA

Keywords

Personal medical records, health information technology, patient portal, patient satisfaction, patient survey

Summary

Objective: To characterize the opinions, emotions, and actions taken by patients who viewed their electronic problem list via an online personal health record (PHR).

Materials and Methods: An online survey of patients who viewed their problem lists, as maintained by their healthcare provider, in a web-based PHR linked to an electronic health record for the first time.

Results: A total 3,649 patients completed the survey, yielding a response rate of 42.1%. Patient attitudes towards the problem list function were positive overall, with 90.4% rating it at least somewhat useful and 86.7% reporting they would probably or definitely use it again. Nearly half (45.6%) of patients identified at least one major or minor problem missing from their list. After viewing the list, 56.1% of patients reported taking at least one action in response, with 32.4% of patients reporting that they researched a condition on the Internet, 18.3% reported that they contacted their healthcare provider and 16.7% reported changing or planning to change a health behavior (patients could report multiple actions). 64.7% of patients reported feeling at least somewhat happy while viewing their problem list, though others reported feeling sad (30.4%), worried (35.7%) or scared (23.8%) (patients could report multiple emotions). A smaller number of patients reported feeling angry (16.6%) or ashamed (14.3%). Patients who experienced an emotional response were more likely to take action.

Conclusion: Overall, patients found the ability to view their problem lists very useful and took action in response to the information. However, some had negative emotions. More research is needed into optimal strategies for supporting patients receiving this information.

Correspondence to:

Adam Wright, Ph.D.
Brigham and Women's Hospital
1620 Tremont St.
Boston, MA 02115
617-525-9811
Email: awright5@partners.org

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1. Introduction

In recent years, the popularity of the electronic personal health record (PHR) has grown substantially [1]. Since 2008, the proportion of patients in the United States who use a PHR has increased from 3% to 10% [2]. This trend is likely to continue as the result of increased funding for health information technology under the United States Health Information Technology for Economic and Clinical Health (HITECH) Act, which creates financial incentives for healthcare providers who share clinical data with patient electronically [2].

The Markle Foundation's Connecting for Health (CFH) framework divides PHRs into two categories: tethered and untethered, defining an untethered PHR as, "an electronic application through which individuals can access, manage, and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment" [3]. A key differentiating factor for an untethered PHR is that the data is under the patient's control, not the healthcare provider. Tethered PHRs, by contrast, contain "subset of data compiled by a patient's provider and offered to the patient, often through the provider's website" [4]. A tethered PHR may include a patient's medications, allergies, laboratory results, vital signs, immunizations, family history, social history, and a list of the patient's healthcare providers [2]. Some systems incorporate additional functionality such as appointment requests, prescription renewals, secure communication and access to the patient problem list and visit notes [5-8].

Increased PHR use is expected to facilitate communication between healthcare providers and patients, reduce redundancy and improve care delivery [9]. Among both patients and healthcare providers, there is substantial support for increased information sharing [8, 10]. Approximately two-thirds of both patients and physicians agree that patients should be able to view and download their health information online [11], and in a recent survey 84% of physicians believe patients should be able to update some or all of their standard information in their health record, including their personal medical history [12]. In addition, studies have shown that patients participate more in their healthcare when features such as health maintenance reminders and medication management are available for them to view [13, 14].

However, physicians are more likely than patients to express concerns about PHR use and less likely to anticipate benefits [15]. Providers tend to be more receptive to sharing laboratory results and other electronic health record (EHR) data than allowing patients access to more detailed information such as visit notes [15]. In a large survey of patients and physicians, nearly all patients supported increasing access to visit notes while the reaction by physicians was far more mixed [8].

Healthcare providers' worries about patients viewing their problem lists are diverse [16, 17]. A particular concern is that patients may be upset if they see diagnoses they don't agree with, or that are stigmatizing, such as mental health issues or sexually transmitted diseases. Anecdotally, many healthcare providers have interacted with patients who became upset after finding they have a specific diagnosis, which likely colors these perceptions.

In addition to provider concerns, many other challenges related to sharing health information contained in the EHR through a patient's PHR have also been identified, including: concerns about cost and security of these tools, problems assigning rights and responsibilities among various actors in the health system, liability issues, and tension between provider and patient expectations [18]. While many provider concerns have been addressed in previous studies [18], additional research is needed to characterize the value and consequences of sharing more clinical information with patients via PHR.

In this study, we conducted an online survey of patients who used an electronic tethered-PHR to access their health information online. Our primary goal was to characterize patient opinions, responses and actions taken while using a new PHR function that allows them to view their problem list online.

2. Methods

2.1 Setting

Partners HealthCare is a large integrated delivery system in Boston, Massachusetts that includes approximately 6,000 healthcare and 8 hospitals. Partners HealthCare began offering a tethered PHR, Patient Gateway (PG), to patients in 2002. Patient Gateway is a tethered PHR, enabling patients to access information from Partners' homegrown electronic medical record, known as the Longitudinal Medical Record (LMR). The majority of Partners' outpatient practices use the LMR, which allows healthcare providers to record clinical information in both coded and free-text form. Practices are enrolled in Patient Gateway, where advisement and recruitment of patients into Patient Gateway takes place. In 2013, PG had more than 440,000 active patient accounts, enrolling about 4,500 patients a month. Patients can register at their healthcare provider's office or online and may receive instant access via a knowledge-based authentication process or may be sent an access key by postal mail. After logging in, patients have access to specific clinical information from the LMR (e.g. allergies, medications, laboratory results) and can receive communications from their healthcare providers such as results letters, summaries of their visits and requests to complete pre-visit forms. Patients can also request appointments and referrals, communicate with their healthcare provider via secure electronic messaging, request prescription renewals, pay their health bills, and access a health information library. The amount of data shared with patients have increased over the past several years, from general electronic messaging with healthcare providers, appointment scheduling and referrals, and refill requests in 2004 [19], to laboratory results in 2007 [20], and more recently the sharing of problem and procedure lists. Despite a decade of sharing data with patients, a number of healthcare providers at our organization expressed concern about the recent expansion of the PHR that made problem and procedure data available to patients.

Beginning June 1, 2011, patients with an active PG account were able to view their problem and procedures lists via Patient Gateway (referred to as the "Condition and Procedure" list in the PHR). These lists mirror those recorded by healthcare providers in the LMR (► Figure 1). The LMR uses SNOMED internally to represent patient problems; however, synonyms are available to healthcare providers. For example, the SNOMED concept "malignant neoplasm of breast" can be added to the problem list, or the provider can choose to add "breast cancer" to the problem list instead. Both synonyms map to the same SNOMED code, but the synonym chosen by the provider is the one that will be displayed in both the provider and patient view. In addition to coded problems, healthcare providers have the option to enter uncoded free-text problem list entries in the LMR; however, these entries are not viewable in Patient Gateway. Both problem and procedure lists could be viewed in the new module; however, our analysis focused on problem list items.

2.2 Survey development and administration

In order to assess the impact of the new PHR problem list function, we designed and deployed an online survey to characterize patient opinions of this feature. We first conducted a review of current literature on personal health records to identify salient issues for further investigation. Based on this research, we established the following aims of the survey:

1. to assess how useful patients found the problem list,
2. to determine how accurate they felt that their problem list was and
3. to determine whether viewing the problem list influenced their emotions, their health behaviors or their interactions with their healthcare providers.

The complete survey instrument, which was created using the Partners Research Computing instance of the REDCap system [21], is included as ► Appendix A. This study was approved by the Partners Human Research Committee.

Patients were first asked "Do you recall viewing your condition and procedure list in Patient Gateway?" For patients who responded "No," the survey was automatically terminated at that point (after the survey application advised patients that this response would end the survey) and these results were excluded from analysis.

2.3 Data analysis

Following the close of the study, anonymous survey results were analyzed in aggregate. Partial survey responses were included in analysis with percentages adjusted for the number of individuals who answered the question. Data analysis was carried out using SAS system software version 9.3 (SAS Institute, Cary, NC). For questions using a Likert scale, responses are reported by scale item in tables and dichotomous results are reported in the text. Scales were dichotomized by converting positive answers to 1, and negative and neutral responses to 0. For all other questions, results are reported as percentages of survey respondents. We also evaluated the association between patient emotions and actions taken, and computed significance for each comparison using Pearson's chi-squared test. To account for multiple comparisons, we used the Bonferroni correction, adjusting the critical value for the test, α , by dividing it by the number of comparisons made.

2.4 Sampling Procedure

The survey opened on August 3, 2011 and recruitment closed on January 3, 2012. All patients who had viewed their problem list in Patient Gateway on or prior to August 3, 2011 received an invitation the evening of August 3, 2011 to participate in the study. From August 3, 2011 to January 3, 2012, patients received an invitation to complete the survey the evening after they viewed the problem list for the first time.

Survey invitations were transmitted via a secure clinical messaging function available in the existing PG system. Patients who did not complete the survey within 72 hours received a single automated reminder to do so. All survey responses were collected anonymously, so there was no way to associate the survey responses with the clinical data or demographic characteristics of the respondents stored in the EHR.

3. Results

A total of 8,676 patients were initially identified as having viewed their problem list in Patient Gateway. This group of patients was invited to complete the online survey via automated invitations. At the close of the survey, a total of 3,649 patients had completed the survey, yielding a response rate of 42.1%. Of these respondents, 93.4% (N=3,389) recalled having viewed the problem list and were included in our analysis.

Overall patient opinions regarding the problem and condition list functionality are shown in ► Table 1. 90.4% (N=3,062) of respondents reported that the feature was at least somewhat useful and 86.7% (N=2,935) reported that they would probably or definitely view their problem list again. They also found the problem list comprehensible, with 82.9% (N=2,806) reporting it as somewhat or very easy to understand.

Among patients reporting at least one medical condition, 62.7% (N=2,046) reported that all of their problems were on the problem list, while 18.7% (N=606) found at least one major missing condition and 18.6% (N=611) found at least one minor (but no major) missing conditions (the classification of major and minor was left to the patient) (► Figure 2). In addition to missing problems, patients also reported other issues with their problem and procedure lists, including conditions that they no longer had (17.5%, N=592), conditions that they never had (4.2%, N=142), conditions that they might have (8.0%, N=271), conditions that they were unaware they had (7.3%, N=247), and conditions or items that they didn't understand (7.1%, N=242); due to an error in survey programming, subjects were asked this question twice and were counted if they answered yes either time). In addition, a small number of patients reported that their lists contained an entry they did not think should be on the list because they considered it private (3.0%, N=103), or for other reasons (3.3%, N=113).

Overall, 45.6% of patients (N=1545) reported finding at least one error on their problem list (a minor or major missing problem, or a condition they never had or used to have but do not have anymore). However, of these patients, only 3.5% (N=54) had asked their provider to correct the error, while 11.8% (N=183) planned to make such a request later. In addition, 9.0% (N=140) felt that the

error was not worth correcting and 13.2% (N=204) did not know how to have an error corrected (► Figure 2).

Patients also reported a range of emotional reactions to viewing their problem lists (► Table 2). For each emotion, patients were considered to have felt the emotion if they provided a score of 3 (somewhat) or higher. 76.5% of patients reported at least one emotion (patients could report feeling multiple emotions). 64.7% of patients (N=2,172) reported being at least somewhat happy, 30.4% reported being at least somewhat sad (N=1,017), 35.7% reported being at least somewhat worried (N=1,198), 23.8% reported being at least somewhat scared (N=795), 16.6% reported being at least somewhat angry (N=556), and 14.4% reported being at least somewhat ashamed (N=479).

Patients reported taking a variety of actions in response to reviewing their problem list. These are summarized in ► Figure 3. Overall, 56.1% (N=1,901) of patients took at least one action after viewing their problem list. 32.4% (N=1,098) of patients researched a condition on the Internet, 12.9% (N=437) discussed a condition with a family member or friend, 12.0% (N=406) changed a health behavior, 10.6% (N=359) sent a message to their provider, 6.8% (N=231) made an appointment with their provider, 5.8% (N=197) planned to change a health behavior, 5.2% (N=177) called their provider, and 4.2% (N=142) researched a condition somewhere other than on the Internet (patients could report more than one action).

Patients' emotional responses were also related with their actions upon viewing their problem list (► Table 3). Emotional activation was generally associated with a greater likelihood of taking action. Patients who reported being at least somewhat worried or scared were more likely to take every one of the eight actions we asked about. The biggest absolute effects were seen in researching conditions on the Internet, with large increases for patients who reported being sad, worried or scared. Smaller absolute increases were seen for actions involving contact with the healthcare system (calling, making an appointment or sending a message); however, since the baseline rates of these actions were low, the relative increases were large, with scared patients being three times more likely to call their healthcare providers than those who were not scared (10.5% vs. 3.5%). Most associations were statistically significant, even after applying the Bonferroni correction for multiple comparisons, which reduces α from 0.05 to 0.0010417 for the 48 comparisons.

4. Discussion

These results suggest that patients have highly favorable opinions of the PHR problem list function overall. A large majority of respondents rated the problem list as highly useful and easy-to-understand and reported that they were very likely to use it again.

A key finding of the study is that patients frequently identified errors and omissions on their problem lists (at least from their perspective). Our prior research has also corroborated that problem lists frequently omit important problems [22], so patients may be a potential untapped resource for improving the problem list, at least among those sufficiently activated to view their own problem list.

However, only a minority of patients who found errors on their problem list had taken any action to correct them. At the time of the survey, our PHR did not allow patients to suggest corrections to their problem list, except through a general provider message. Previous research on the effect of a PHR-linked medications module on medication safety and accuracy has shown an association between documented and patient-reported medication regimens and reduction in potentially harmful medication discrepancies [14], and similar research has shown that patients can provide helpful and accurate information about health measures [23]. We now allow patients to suggest problem list changes through a pre-visit form; however, to date, this functionality has only been implemented at a small number of Partners HealthCare practices. We plan to roll the pre-visit form out to more practices, and are considering new features to allow patients to suggest problem list changes outside of a planned visit.

A second key finding of our study was that patients frequently took action in response to seeing their problem list. Most of these actions were self-help, such as researching a problem on the Internet. Patients were much less likely to seek contact with their healthcare provider. About 1 in 8 patients reported changing a health behavior after viewing the information in their problem list. This

was an unexpected finding but demonstrates the potential benefit of providing patients with access to the problem list managed by their healthcare providers.

A third key finding of our study was that patients experienced few negative emotions after viewing their problem list; they were most likely, in fact, to report feeling happy. Patient who experienced emotional responses were more likely to take a range of actions, including changing health behaviors, contacting healthcare providers, researching conditions or discussing conditions with a friend or family member. Of the emotions, sad, worried and scared were most associated with increased action. Angry and ashamed had fewer statistically significant associations; however, these emotions were relatively uncommon. Happy was associated with some increases in action; however, fewer were statistically significant than for sad, worried or scared.

The study has several limitations. First, our results are likely not generalizable to all patient populations. Patients who responded to the survey are likely to represent a particularly active group, since they

1. have a PHR account,
2. used their PHR account to review their health information,
3. opened the survey invitation and
4. completed the survey.

Thus, these results may reflect a subset of patients who are more engaged with healthcare information technology and their own healthcare needs. Our prior research has demonstrated that PHR users differ in significant ways from the patient population as a whole [24], and we anticipate that regular users who respond to surveys may differ further. Second, because the survey was collected anonymously, we could not compare patient's health records with their survey responses or characterize the demographic characteristics of respondents, including the subject's emotional status prior to viewing the problem list. This limits our ability to draw conclusions about the patient population using the new problem list function and whether the emotional response was due to reviewing the problem list, or more closely related to the content of the problem list or the patient's current mental status. Third, our survey instrument was designed pragmatically and has not been formally validated – because there is limited literature in the area of patient access to problem lists, we adopted this pragmatic approach; however, further studies to validate and refine the instrument would be useful. Finally, this study was limited solely to patients' opinions of a single PHR function. Additional research will be needed to understand the utility of other PHR functionality, to plan for future expansion and to characterize healthcare providers' opinions of patient PHR use.

Our study has several important implications for designers of PHRs. First, we found that, at least in our sample of highly-activated individuals, patients took action in response to their problem list. This supports the idea of an “informed, activated patient” in Wagner's chronic care model (CCM) [25]. These patients sometimes, but not always, communicated with their healthcare provider – to the extent that these interactions were positive, they may contribute to Wagner's concept of “productive interactions” with a “prepared, proactive practice team”, which are key for coordinated chronic illness care. Designers of PHRs, especially those which provide patients with rich clinical information, should keep care coordination and patient-healthcare provider interaction at the fore. The second implication of our study is that patients had significant emotional responses to viewing their PHR data. Though many of these responses were positive, some were negative. PHR designers and healthcare providers should design both software and communication processes that respect the potential for emotional interaction. We believe that patients should be provided with accurate and complete information – not oversimplified or unnecessarily abridged –but that this information should be delivered in a supportive and sensitive way, using a combination of person-to-person and technological means. The third implication of our study is that patients may be able to improve the accuracy of data in the EHR by viewing it in the PHR. This is important for patient safety and quality, and extensions into other data elements that patients may be able to review should be explored.

5. Conclusion

These results suggest that patients find the problem list highly useful and easy to understand. In addition, the electronic problem lists appear to be capable of motivating contact with healthcare providers, patient self-education and changes in health behaviors. However, our results also indicate that accuracy is a significant issue in problem documentation and patients are unsure how to respond to errors, and while most patients had positive responses, others expressed negative reactions including worry and fear. Healthcare providers and organizations should work to expand patient access to problem lists and improve the accuracy of problem documentation.

Clinical Relevance Statement

Our findings suggest that providing problem list information to patients through their personal health record is well-received by patients. Additionally, patients may be able to identify potentially significant gaps or errors in their problem lists, which could lead to improved problem list accuracy. Furthermore, patients who viewed their problem lists reported engaging in potentially beneficial health behaviors related to their problems.

Conflicts Of Interest

The authors declare that they have no conflicts of interest in this research.

Protection Of Human 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 approved by the Partners Human Research Committee.

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Fig. 1 Screenshot of the Personal Health Record Condition and Procedure List

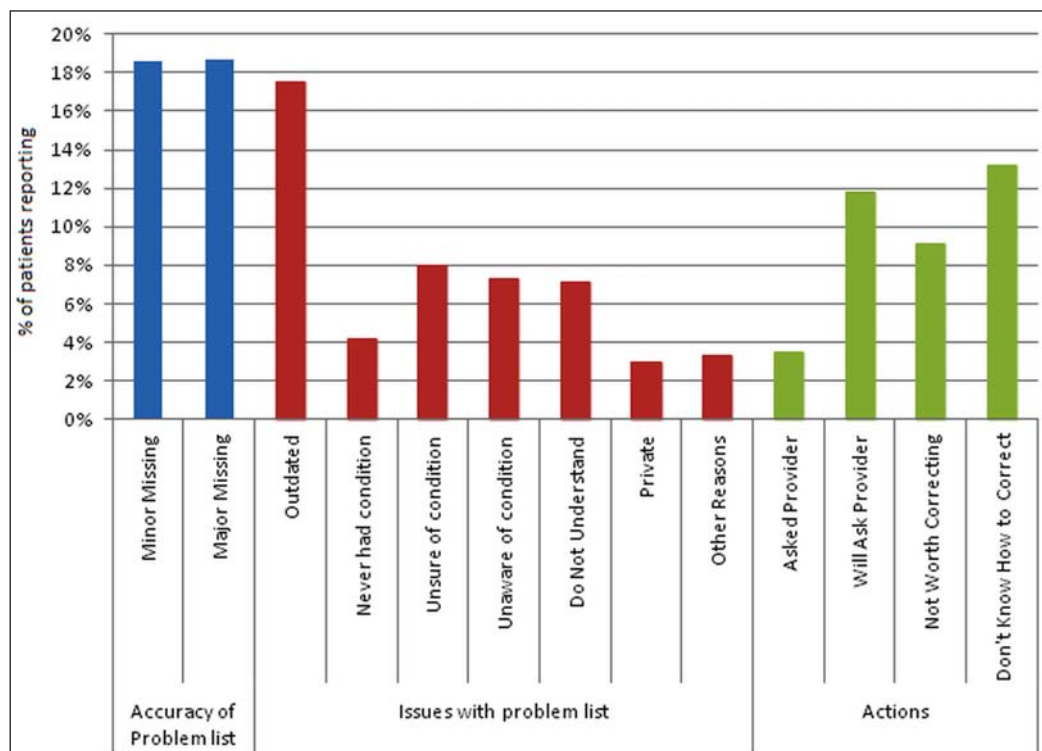


Fig. 2 Reported Accuracy, Issues, and Actions based on Personal Health Records Problem List

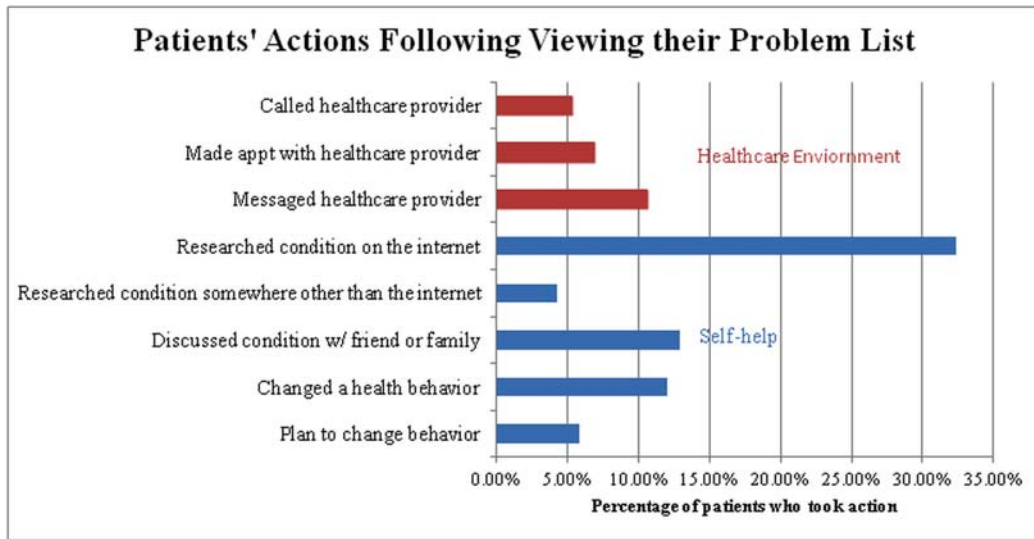


Fig. 3 Various Actions to Viewing the Personal Health Record Problem List

Table 1 Patient opinions regarding the condition and procedure functionality in the PHR

Question	Response n (%)				
	Not at all		Somewhat		Very
	1	2	3	4	5
How useful was it to view your condition and procedure list?	109 (3.2%)	215 (6.4%)	902 (26.6%)	1415 (41.8%)	745 (22.0%)
How likely are you to review your condition and procedure list again in the future?	40 (1.2%)	96 (2.8%)	315 (9.3%)	1023 (30.2%)	1912 (56.5%)

Table 2 Emotional responses to viewing the problem list

Emotion*	Not at all		Somewhat		Very
	1	2	3	4	5
Happy	894 (26.7%)	289 (8.6%)	1238 (36.9%)	539 (16.1%)	395 (11.8%)
Sad	1960 (58.6%)	368 (11.0%)	781 (23.4%)	159 (4.8%)	77 (2.3%)
Worried	1666 (49.7%)	489 (14.6%)	765 (22.8%)	310 (9.3%)	123 (3.7%)
Scared	2159 (64.5%)	391 (11.7%)	552 (16.5%)	151 (4.5%)	92 (2.8%)
Angry	2558 (76.5%)	228 (6.8%)	402 (12.0%)	58 (1.7%)	96 (2.9%)
Ashamed	2687 (80.5%)	174 (5.2%)	346 (10.4%)	65 (2.0%)	68 (2.0%)

* Patients could report more than one emotion.

Table 3 Actions taken by patients with an emotional response of somewhat or greater

	Happy	Not Happy	Sad	Not Sad	Worried	Not Worried	Scared	Not Scared	Angry	Not Angry	Ashamed	Not Ashamed
Called healthcare provider	5.6%	4.4%	7.8%	4.1%	8.3%	3.5%	10.5%	3.5%	8.1%	4.6%	5.6%	5.1%
p-value	0.14	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	0.68	
Made appt with healthcare provider	7.6%	5.3%	8.4%	6.0%	9.9%	5.0%	10.6%	5.6%	9.0%	6.3%	7.1%	6.7%
p-value	< 0.01	0.01	0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	0.03	0.03	0.76	
Messaged health-care provider	11.7%	8.7%	12.9%	9.6%	13.6%	9.0%	14.8%	9.3%	13.2%	10.1%	9.8%	10.8%
p-value	0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	0.03	0.03	0.50	
Researched condition on Internet	33.8%	30.1%	39.4%	29.5%	42.7%	26.9%	40.4%	30.1%	34.8%	32.0%	35.1%	32.1%
p-value	0.02	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	0.22	0.22	0.19	
Researched condition somewhere other than the Internet	4.6%	3.5%	6.7%	3.1%	6.8%	2.8%	7.2%	3.3%	6.0%	3.9%	6.7%	3.8%
p-value	0.09	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	0.02	0.02	< 0.01	
Discussed condition w/ friend or family	13.7%	11.8%	16.9%	11.4%	19.2%	9.6%	18.2%	11.5%	12.8%	13.1%	12.9%	13.1%
p-value	0.11	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	0.89	0.89	0.92	
Changed health behavior	13.2%	9.8%	13.3%	11.4%	15.9%	9.8%	14.9%	11.1%	9.9%	12.4%	12.3%	11.9%
p-value	< 0.01	0.09	0.09	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	0.11	0.11	0.88	
Plan to change health behavior	6.9%	3.9%	7.8%	5.0%	8.8%	4.2%	7.8%	5.2%	6.5%	5.7%	6.5%	5.7%
p-value	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	< 0.01	0.42	0.42	0.55	

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