Improving Direct Notification of Abnormal Test Results Via Patient Portals

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2. Structured Abstract

**Purpose:** The goal of this mixed-methods study was to explore patients’ experiences and preferences when accessing test results via patient portals and create and evaluate a patient-facing laboratory test result interface prototype.

**Scope:** Online portals are being increasingly implemented to engage patients in their care. While portals provide patients access to their test results, little is known about how patients use these tools and what information is available.

**Methods:** We conducted semi-structured and structured interviews with eligible participants (adults who viewed a test result in their portal). Then, we created an initial test result prototype based on results from the semi-structured and structured interviews. Iterative design changes were made based on focus group sessions, expert consultation, and user testing.

**Results:** 46% of participants conducted online searches for further information about their test result. Patients who received an abnormal result were more likely to experience negative emotions than those who received a normal result (56% and 21%, P=0.003). Patients who received abnormal results were more likely to call their physician compared with those who received normal results (44% and 15%, p=0.002). Findings from our prototype system evaluation resulted in 6 iterations of the interface. Later versions of the interface fulfilled patient’s information needs, were perceived as usable, and encourage patient test result exploration.

**Key Words:** patient portal; test results; health information technology; medical informatics

3. Purpose

The goal of this proposal was to explore and improve how health information technology (IT) can be leveraged to help patients manage follow-up of abnormal test results. We first sought to identify patients’ needs, preferences and responses when receiving abnormal test result notifications through a patient portal. We then worked to develop a functional patient portal prototype based on patient support needs identified in the first part of the project. These goals are highly significant because failures to follow-up of abnormal test results lead to delays in diagnosis and treatment and may result in patient harm. Health information technology has been used to facilitate information exchange and has potential to address problems in outpatient test result management. While electronic health records can provide accurate, reliable delivery of abnormal test results to physicians, they cannot guarantee that appropriate follow-up action is taken. Thus, there is a need to explore alternate methods that involve patients in ensuring reliable follow-up.

We then worked to develop a functional patient portal prototype based on patient needs identified in the Aim 1 of the project. To develop patient-centered practices and design for test result management via portals, we needed to address many socio-technical variables that influence outcomes in this area, including technological (e.g., software, clinical content and user interface design) as well as non-technological factors (e.g., inter-personal communication, clinical workflows, processes, and procedures). Test results should be interpreted within a patient’s individual clinical context and personalized goals, and thus it is important to understand how patients will interpret and respond to test result information sent to them electronically without necessarily having the benefit of their clinician’s interpretation of their results at hand. Internet access provides a host of additional information resources that can hinder or facilitate these actions. Asynchronous communication (i.e., when sender and receiver are not engaged simultaneously) adds another layer of complexity. For example, patients may seek
information on the internet, which may or may not be reliable, prior to or instead of following-up with their physician. Thus, the study of patients’ preferences and responses related to test result notification via portals is essential to optimize design and implementation of notification systems.

Our specific aims were:

**Aim 1:** To understand patients’ needs, preferences and responses when receiving abnormal test results through patient portals.

**Aim 2:** To develop functional requirements for patient portals and socio-technical solutions (e.g., policies, procedures, and workflows) to address patients’ needs, preferences and responses to receiving abnormal test results through patient portals.

4. **Scope**

**Background:** Patients now have increased electronic access to their health information via portals. This access, in line with basic tenets of patient-centered care, could lead to better patient engagement and greater involvement in medical decision-making. Much of this increased access was stimulated by the implementation of national policies prioritizing patient access, such as the Department of Health and Human Services rule authorizing direct patient access to laboratory results and Meaningful Use Stage 2. There is thus an emerging need to identify patient needs and preferences when viewing their medical information to ensure it is meaningful, useful, and actionable to patients.

**Context:** Access to test results is an area of high interest to patients. Among the many patient portal functions, patients frequently cite test result access as most useful. Accessing test results provides an opportunity to foster patient involvement in care by preventing test results from being overlooked, a common patient safety concern. Further, portals that allow patients independent and unrestricted access may also help coordinate care between multiple physicians and avoid redundancy.

Literature on patient access to test results through a patient portal is sparse but growing. Recent studies have found that very few patients experience negative emotions when viewing their test results on the portal. However, patients have trouble identifying when values are out of range in standard test result tables, especially patients with lower literacy and numeracy. It is not clear that patients are always able to interpret the meaning of their test results. This could be in part due to the test result report format and interface design. The issue of misunderstanding or misinterpreting test results can be framed as a lack of appropriate interface design that fails to provide patients with the necessary visual cues and information they need to comprehend each test result.

Recent studies have begun to explore patients’ information needs when interpreting their test results and how appropriate informatics tools can improve patient comprehension of health concepts. However, few studies have attempted to take the next step and use these information requirements to propose a new design for patient-facing interfaces or tools that promote patients’ comprehension of test results.

**Settings:** An academically affiliated private general practice, a primary care community clinic, a network of private-practice physicians, and an urban Veterans Affairs facility.

**Participants:** Adults (18 years or older) who viewed a test result through their portal.
Incidence/Prevalence: A recent systematic review of outpatient test result follow-up found a wide range of missed abnormal results, with 6.8% to 62% missed laboratory results and 1.0% to 35.7% missed radiology results, and thus many patients “fall through the cracks” of the health care system. Available data suggest that patient utilization of existing web-based platforms to access health information is low. Currently there are no national test result notification and interface design standards or guidelines for patient portals. Many portals may only provide a test result value with a range or flag to indicate significance, similar to the format received by clinicians. Patient portals lack interoperability and consistency in features and design across providers which can frustrate patients and limit use – only 15-30% of patients electronically access their health information.

5. Methods

**Study Design**

**Aim 1**

We used an exploratory mixed-method design to explore the patient experience of receiving test results through the portal. We initially conducted thirteen semi-structured interviews. We asked participants to walk through the process of receiving a test result via the portal and probed them with questions about their understanding of the results, information needs, and emotional responses. These questions included “What does the test result mean? Did your physician talk to you about why the test was being done? Did you have any concerns when you checked the result in the portal?” Interviews were conducted in person and by telephone, audio recorded, and transcribed verbatim. Based on our interview data and discussions with health information technology (IT) experts, we created a final structured interview. Structured interviews were administered by telephone and in person at the clinics in a private room, and were not audio recorded. All participants were provided a $25 gift card for their time. The local IRB committees at each site approved this study.

**Aim 2**

After establishing the initial patient-centered test result interface, we implemented a multimethod formative evaluation approach involving focus-group review sessions, expert consultations, and usability testing to uncover additional patient information needs and determine patient satisfaction with the test result interface. To recruit participants for the usability portion of the design evaluation, we contacted Aim 1 participants who identified themselves as open to participating in a related research project via email. Patients who consented to participate in this research were offered a $25 dollar gift card upon completion of their testing session. Ten semi-structured and three observations were conducted with current patient portal users who access laboratory test results. Data from interviews and observations were transcribed and used to construct a test result process map from the perspective of patient portal users. To identify task steps in the test result process, comments from interviews that identify different ways patients’ access or interpret test result information were grouped according to the information being processed in each step. For example, the task step entitled “Test result interpretation” was derived from different methods patients described to comprehend whether their test result was “good” or “bad”.

After creating the patient-based test result process map, interviews and observations were reanalyzed to determine shortcomings of the patient portal system that limited patients’ ability to access or understand their test results. Once relevant shortcomings were identified, they were incorporated into the test result process map to identify at which step each shortcoming occurred.
Data Sources/Collection

Aim 1
Data collection occurred between April 2015 and September 2016. Participants were approached in clinic waiting rooms, were informed of the study by their physician, or responded to posted flyers. This allowed us to recruit 43 participants. At one site, we obtained a list of all active portal users, and selected a random sample of 450 users. We sent a recruitment letter with opt out instructions and followed-up by telephone two weeks later. Thirty-nine agreed to participate. In total, 82 patients participated in the structured interview.

Aim 2
After establishing the initial patient-centered test result interface, we implemented a multimethod formative evaluation approach involving focus-group review sessions, expert consultations, and usability testing to uncover additional patient information needs and determine patient satisfaction with the test result interface. During the iterative evaluation and re-design phase we incorporated principles and suggestions from relevant interface design literature to improve the usability of the test result interface. In general, the focus group review sessions occurred during early versions of the interface design, but the expert consultations and user testing sessions shared significant overlap.

The final method conducted during the evaluation of the patient-centered test result interface was a usability test that required patients to use the prototype test result interface to navigate to and interpret three different test results: an abnormal lipid profile test result, a hepatitis B surface antigen test result that suggested getting an immunization, and a liver function test that was within normal limits. All testing sessions took place in either the research office in a private room or the patient’s preferred location. Prototype tests were conducted using a laptop computer and computer mouse to ease navigation of the computer interface. For each testing session, Axure was used to generate an HTML-based interface for participants to navigate during the testing session, Camtesia software was used to capture participants’ cursor behavior while using the prototype and obtain an audio record of verbal comments, questions, or concerns participants made about the prototype during the testing session.

After consenting to participate, a vignette was read to patients to provide context for why they are using the prototype and to outline the task they needed to accomplish during the testing session. During the testing session, participants were asked to “think-aloud” while navigating the display by periodically reporting what they were looking for, anything that surprised them about the interface, or anything that violated what they expected to find. After finishing the testing session, participants were asked to fill out two questionnaires. First, a brief post-session questionnaire pertaining to the information participants needed to comprehend each test result. Second, participants were asked to judge the usability of the interface using the System Usability Scale. After completing the questionnaires, participants were asked if they had any final questions, comments, or concerns about the interface or the testing session.

Interventions
None

Measures
In Aim 1, the structured interview assessed four domain areas: 1) participant characteristics, 2) physician and patient actions on test results, 3) patient perceptions of receiving results via the portal, and 4) portal concerns and suggestions for improvement. Participant characteristics we assessed included gender, age, race/ethnicity, chronic conditions, internet comfort, portal use frequency, 10-item version of the Patient Activation Measure (PAM) and length of time as a
portal user. Physician actions included: did the physician communicate reason for test, if s/he would call to report result, if s/he told the patient to check the portal, and whether the physician explained the result in the portal. Patient actions included whether or not participants conducted online research, sent secure messages, called the physician following receipt of the result, and discussed the result with family/friends. Patient perceptions included how the patient knew the result was normal or abnormal, had the test been done before, why was it ordered, expectations about the result, whether the patient understood the result, and feelings upon seeing the result. We also included three open-ended questions to allow participants to explain in detail problems they experienced receiving test results via the portal and suggestions for improvements.

In Aim 2, we measured usability of our portal prototype using the System Usability Scale (SUS) survey. Additionally, video and audio recordings were used to create “time stamps” that describe the amount of time participants spent on each screen of the interface. Elapsed time was calculated for each test result presented in the prototype interface (Lipid profile, HBV, and LFT) along with the total time participants spent using the interface.

Limitations

Aim 1
We experienced challenges in recruiting eligible patients despite our inclusion of four clinical settings. Consequently, we used multiple methods to bolster enrollment. At all of our sites, we found semi-structured interviews took longer and were perceived as burdensome to patients. To boost sample size and recruitment, we used a shorter, structured interview guide based on our semi-structured interview data. Additionally, during recruitment we found that while many patients had signed up for a portal account, they had never logged in to their account beyond set-up to view a test result. Finally, our results may not generalize to all types of patients. Our sample consisted of a large majority of patients that reported being comfortable with the internet and predominately scored on the higher levels of PAM, Level 3 taking action or Level 4 maintaining behaviors.

Aim 2
Aside from having a small sample size, the main limitation of the user testing portion of our evaluation is the lack of a homologous “stimuli” to test with participants. In the current study, we chose to refrain from making interface improvements at predetermined times during the design cycle. In other words, we decided to incorporate relevant design recommendations on an "as needed" basis. This methodology likely increased the speed at which the interface could be produced at the cost of rigorous experimental design. Due to the limitations imposed by the design of the current study, the value added by this research is in the explicit description and illustration of methods that explain how design requirements were incorporated into the design of an interface, and how the evaluation and testing of the interface honed its functionality.

6. Results
Principal Findings

Aim 1
We conducted 95 interviews (13 semi-structured and 82 structured). Participants were 55.8% male, 65.3% white, average age 54.6 (SD 15.6), and 62.1% had one or more chronic condition. Almost three-fourths (71.6%) had been using the portal for 1 year or more, and 84.2% considered themselves comfortable with using the internet. A majority of patients (85.3%) scored high on the PAM measure in Level 3 and 4, suggesting overall they were more activated.
Most patients indicated that their physician explained why the test was being ordered (89.5%). Half reported that their physician told them to check their portal for the result (50.5%). However, 63.2% of the participants reported that their physician did not include a note or interpretation explaining the result.

Participants who received an abnormal result were more likely to call their physician than those who received a normal result (44.2% and 15.4%, respectively, p=0.002). Overall only a quarter of participants (25.3%) sent a secure message to their doctor regarding the test result, more commonly in participants with abnormal (32.6%) than normal test results (19.2%). Participants who sent a secure message reported that they did so for further explanation of the test result or to determine next steps.

About half of all participants sought information about their result from sources other than their physician—46.3% did online research and 51.6% discussed their result with friends or family. Participants explained that they conducted online research before or in addition to contacting their physician to look up unfamiliar terms or tests they encountered while viewing results, to look up a potential diagnosis, and to avoid bothering their physician. “I’ll sit down and Google it and see if I can figure it out that way before I bother [doctor name]…those doctors are swamped...” (P 1001) “If there’s a certain condition that is referenced by a certain test, I might just google it as a start...and learn more about whatever the condition is.” (P 1003) One participant indicated that the physician had included a “well explained” note but that she still searched online to for additional information, “I Googled it and then clicked on some of the researchy [sic] stuff...NIH has a little write up on heart diseases like a little pamphlet which explains what to do.” (P 2004)

While examining patient perceptions related to receiving a test result we found that a majority of participants indicated they knew why the test was being ordered (95.8%) and they had the test done before (84.2%) and 77.9% stated that they understood their result. In interviews, understanding the result meant different things. Some participants were able to discuss the meaning of the test, “This means that for instance with the cholesterol that I have elevated indicators that can increase the risk of heart problems, strokes, and that I should just really watch them and to reduce them” (P1006), while others understood the results in terms of behavior changes, “Basically...I would likely have to go on medication and change my diet at that point.” (P 2004)

Participants indicated they knew their result was normal or abnormal by looking at a visual cue such as a flagged or bolded value (61.1%), a physician told the patient (16.8%), personal medical knowledge (8.4%), and 8.4% didn’t know or looked up the test online.

Over half of participants with abnormal results (55.8%) experienced negative emotions, including confusion, concern, anxiety, fear, or frustration when viewing the result. In interviews, participants expressed nuanced emotions related to their current health status, personal experiences, and uncertainty. Some participants with chronic conditions managed their expectations about their tests results based on experience. “Well I mean I’ve been taking these blood tests for years and years and years...there really wasn’t anything unexpected.” (P1005)

Almost a quarter (21.2%) of participants who received normal results also experienced negative emotions. One participant expressed concern because she was unsure how to interpret a positive test result.

“I think some of them said negative and positive. But then I think for some of the tests that you’re supposed to be positive for an antibody. So if it says positive on it; you think
positive means like bad, right?...It said positive and I freaked and then I went to talk to my doctor about it. (P2005)

Half of participants with normal results expressed indifference (50.0%) and indicated they had existing personal medical knowledge about the test, a physician or nurse had called prior to viewing online results, or that a normal result was simply not a concern.

When investigating the types of problems patients reported while interacting with the portal we found that more than half of participants indicated that they did not have trouble checking their test results on the portal (60.0%). Patients commented on the time it takes for results to post on the portal, display and usability issues, password issues, and lack of test result explanation and portal education for patients. About half agreed that portals could be improved (52.6%). Suggestions to improve portals included: improving the display and usability (e.g., “Not good for computer "un-savvy" vets, requires you to go through a maze, a SEARCH feature would be VERY helpful”), include timely test result notification with explanation and follow-up instructions (e.g., “An explanation of the reference range and what the result might mean to me”), and additional functionality (e.g., “CT/MRI/imaging results on portal”).

Aim 2
User testing results
Fourteen patients volunteered to participate in the usability portion of this project. Participant ages ranged from 25 to 73 with an average age of 43 yrs. Most patients had some experience working in the health care domain (71%). All participants indicated they had some familiarity with the tests presented in the test result interface.

When asked if they thought any information was missing from the display, 21% of participants indicated that they wanted more information about their test results. Similarly, 36% indicated they would like to “Google” their results to retrieve relevant information about each result. In early testing (Version 2 & 3) of the prototype participants wanted to know more information about the details of their test results. However, in later versions of the prototype (> Version 5), participants were less concerned with using the internet to understand the details of their test results. Instead, they wanted more detailed information about medications and immunizations mentioned within the test result interface. One participant indicated that she would like context for the results: “If they were my test results, I might want more information about what's normal for someone like me - google "normal cholesterol/LFT" for someone like yourself.” (P3009)

When asked what they would do after viewing the test results, 64% of participants mentioned they would make some form of lifestyle change, such as consider starting cholesterol medication, getting a hepatitis B vaccine, adjusting their diet, or exercising more. In addition, 35% of participants anticipated that they would contact their physician to hear their interpretation of the test results and/or discuss potential treatment options.

SUS Scores
After the initial testing of Version 3 of the test result interface, SUS scores maintained a range of 82.5 – 100 throughout the design lifecycle of the interface obtaining a final average score of 92.

Time stamps
The total amount of time participants spent within the test result interface varied widely (M = 659.36 s; SD = 530.46 s). Some participants chose to thoroughly explore the details of the prototype interface while others preferred to focus solely on finding and interpreting the tests results as instructed at the beginning of the testing session. Thus, the total average of time spent viewing different screens of the interface portray the general amount of time spent within
that portion of the interface—regardless of version—and the standard deviation accounts for differences in version of the design and participant use of the interface. On average, participants spent more time viewing the lipid profile test result (M = 251.93 s; SD = 257.09s) than either the hepatitis B surface antigen test (M = 100.29 s; SD = 15.22s) or the liver function test result (M = 72 s; SD = 19.40s).

Outcomes
We developed and evaluated a patient-centered test result interface that was initially based on results from literature that elicited patient’s information needs for understanding laboratory test results. The SUS Score ranged from 82.5 – 100 with an average of 92.

Discussion
Aim 1
We conducted this study to better understand patients’ experiences accessing their test results through the patient portal. We found that more than half of participants did not receive explanatory information or result interpretation in the portal at the time they received the result and almost half conducted online searches about their result. While more than half of participants did not call their physician following receipt, participants that received abnormal results were more likely to call their physician than with those who received normal results. Finally, participants who received an abnormal result were more likely to experience negative emotions than those that received a normal result.

Despite increased access to patient portals, there are no nationally recommended practices or guidance for test result notification via patient portals. Previous work shows that both patients and physicians see benefit in providing patients with an interpretation(21;32) but little progress has been made to facilitate this. Only a third of participants received a note in their portal explaining the test result. Although three-fourths of participants indicated they understood their test results, almost half reported searching online for additional information—sometimes before contacting their physician, in line with previous work.(32)

Our work has several implications for policy and practice. Understanding test results is hard for most patients.(22) Providing an interpretation along with the test result at the time of portal release should be considered “best practice”.(24) Additionally, providing information about the test at the time of the order does not appear to mitigate patient online research. Several participants searched online for supplemental information even when they indicated they understood the result. Rather than discouraging patients from conducting online searches, they should be encouraged to use specific, vetted websites and search options provided within the portal. The portal should provide easy access to such high quality tools to support and educate patients.(31;44;45)

While previous literature on patient access to health information has shown reduced or no effect on anxiety,(31;46) our participants experienced negative emotions when accessing their test results online. This includes, feeling concerned, confused, anxious, scared, and/or frustrated. While we cannot know whether or not these emotions are related to receiving the result specifically via the portal, this finding suggests that we must invest in tools and resources to reduce this burden. Although the portal gives patients access to their health information, it might not be able to provide them with the appropriate information within the context of the patients’ health problems. Some patients might need additional personalized or contextual information, compassion or reassurance—something health IT cannot provide. For instance, almost half of our abnormal test results sample called their physician’s office and about a third sent a secure message about the abnormal test result. Some tests results, especially sensitive results, may
require additional support services or resources for patients. Patient navigators have been successful in reducing anxiety for patients who have received an abnormal mammography and are waiting for follow-up testing.(47) Thus, ideal test results notification via portals should include information about the purpose of the test, the result in context of a patient’s health, directions for next steps, and specific resources, including available support and educational services.(28;32;33;38) Current health policies should support these strategies.

Aim 2
The current study describes the design of a patient-centered test result interface that was initially based on results from literature that elicited patient’s information needs for understanding laboratory test results. After developing the initial interface, we used an iterative design process to evaluate and hone the design.

Results from participant responses to the post-session questionnaire suggest the early versions of the test result interface (Version 3 – Version 7) failed to fulfill patient’s information needs. Since participant information needs from the literature were incorporated into the initial test result interface, participant’s desire for more information suggests providing the content necessary to assist patient’s with interpreting their test results only addresses a portion of patient’s concerns. When comparing early versions of the patient-centered test interface to later versions of the interface, the content being presented was relatively unchanged, but considerable effort was dedicated to making design features less confusing and easier to navigate (e.g., improving the “clickability” of buttons by making them look like hyperlinks). The difference in the way information is presented between early and later versions of the patient-centered test result interface suggests the content frequently identified by information elicitation strategies must be appropriately “built” into an interface for users to understand the information being presented. This finding coincides with previous literature discussing interface design for complex domains.(48)

Regardless of the version being tested, participants found the interface to be quite usable. Based on Bangor and Kortum’s(49) summary of scoring using the SUS, the prototype test result interface presented in the current study has maintained scores within an “acceptable” range of use.

Given the differences in each participant’s approach to the interface, it is difficult to determine whether the amount of time spent viewing different portions of the interface were due to flaws in the design of the interface or to differences in patient’s thoroughness while using the interface. However, we anticipate the extra amount of time spent viewing the lipid profile result is likely due to the result of this test being abnormal and that most participants chose to view the results of the lipid profile test first. Viewing the lipid profile test result first provided an opportunity for participants to learn the dynamics of the interface (e.g., how the details of each result are presented), which likely accounts for the reduced variability in the amount of time participants took viewing Hepatitis B and liver function test results.

One interesting finding we observed that may also account for the amount of time users spent viewing results on the interface is that, as the interface became more useable, participants spent more time learning about their test results within the display. As opposed to earlier versions of the interface where patients’ screen behavior suggested difficulty navigating the display to obtain the information they wanted to find, participants testing later versions of the display exhibited screen behavior that was less indecisive and more directed at exploring features of the interface. Though this finding is somewhat anecdotal, we anticipate that as the design of the prototype interface became more user friendly, patient’s comfort with using the
system increased; thus, they were more willing to explore different features provided by the display. Future research should explore this hypothesis further.

Conclusions

Aim 1
Our findings suggest that current online portals are not designed to present information on test results in a meaningful way. Providing patients access to their test results via portals is insufficient by itself to meet patients’ needs. To facilitate patient engagement, this step should also be accompanied by strategies to help patients interpret and manage their test results. Given the absence of national guidance, findings from this study could be useful for strengthening policy and practice in this area.

Aim 2
There are numerous studies identifying patient’s information needs to assist with comprehension of medical information. However, without conducting appropriate research to operationalize patient’s requirements through the design of patient-facing interfaces, the value of requirement elicitation research is significantly diminished. The current study attempts to explain how information obtained from requirements elicitation studies can be operationalized to assist with the design of a patient-facing, prototype test result interface. Results of the evaluation suggest patients perceive the interface as usable and as fulfilling most of their information needs when it comes to interpreting lipid profile, hepatitis B surface antigen and liver function test results.

Significance
Communication of test results via patient portals is an important topic and abnormal test results that are lost to follow up is a significant problem. This study sought to explore patients’ experiences when accessing and view test results through a patient portal. Given the absence of national guidance, findings from this study could be useful for strengthening policy and practice in this area.

Implications:
The information gained by carrying out this study will lay groundwork for future work to enhance communication of test results via patient portals. There are overwhelming benefits from improving test result communication via patient portals in terms of preventing loss to follow up results and improving patient understanding and engagement.

7. List of Publications and Products
In preparation or under review:

Abstracts:


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