Is This Good or Bad? Redesigning Visual Displays of Medical Test Results in Patient Portals to Provide Context and Meaning

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Abstract

We describe an ongoing effort to improve communication of medical test results directly to patients by providing important contextual information about the test results in a graphical format that is well suited to online patient portals. We undertook an iterative, user-centered design process to explore ways to design meaningful representations of test results. We present findings from this process that have important design implications for communicating test results via online patient portals.

Author Keywords

Health Informatics

ACM Classification Keywords

H.5.2. User Interfaces: User-centered design

Introduction

Patient portals to electronic health records are poised to dramatically change how people interact with the health care system. A key function patient portals offer is the ability to view one's medical test results. Receiving the results of a medical test can put patients in a difficult

situation by requiring them to interpret what the test result means for their health and well-being as well as make decisions about what they should do in response to the result. Test results can be given in unfamiliar or confusing units using highly technical language and formats (see) that patients may be unable to easily understand. Furthermore, if the result is provided without also providing important contextual information such as whether the patient's doctor would consider the result "too high/low" or within an acceptable range, the result may carry little meaning to the patient.

Even when data are provided in clinic visits, busy providers often lack the time to explain what they signify and may lack training and skills in risk communication to effectively provide sufficient context for a patient. However, patients are increasingly accessing test result information via online patient portals [1]. These portals allow patients to see their test results and other personal health information by logging into the portal at any time [4], and also to send and receive messages with their providers [13]. While such portals offer tremendous value, they may make it even more difficult to provide necessary context to a test result so that patients can derive meaning from the information.

We have undertaken an iterative, user-centered design effort to develop graphical representations of medical test results that provide meaningful and useful context to patients when viewing the results. We have designed dozens of variations of a graphic for presenting results, and conducted in-person user tests to evaluate the designs and inform subsequent iterations.

Background

Need for context

One of the challenges in communicating test results to patients is that a test result is, to patient, an incomplete piece of information. Patients have a primary interest in their health risk associated with a given test result more than the number itself. A patient with a Hemoglobin A1c result of 6.0, which falls just above the "standard range" for that test, will be more interested in knowing what that value means for his or her health than simply knowing what the value is. Yet there has been a concern that providing test results without adequate context can create confusion or "undue anxiety" in patients [5].

In addition to lacking context, numbers by themselves can be difficult to interpret and patients can have varying levels of *health numeracy*, which is an ability to derive meaning from health-related numerical data [8]. Many patients have low health numeracy [2] and these patients have greater difficulty knowing what to do with test result data [9].

Fortunately, graphical representations of health information can help patients' understanding more than purely numerical representations [3], including patients low in numeracy. Therefore, we believe that a patient-centered design approach can be utilized to develop graphics that effectively communicate risk and provide meaningful context to test result communications.

Patient Portals

Previous HCI work has made important contributions to understanding and designing patient portals. Latulipe et al. [6] found that found that patients can be emotionally impacted by seeing medical terminology
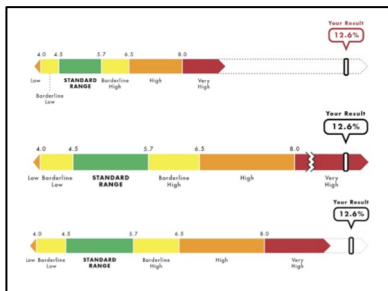
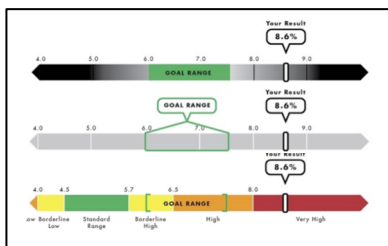Figure 3. Example designs for outlying values.

Figure 4. Example designs for presenting a goal range for the patient

and want their information to be contextualized to help them better understand it. Other work has looked at using portals to facilitate direct communication between patients and portals [13], and developing user-friendly explanations of health information and test results by automatically extracting natural language from web resources [14]. Milewski and Parra [7] suggested that patient portals should include visualizations of health data to help users understand their information and provide motivation to manage care.

Figure 1. Test result page in a current patient portal.

However, current patient portal designs do not provide the contextual information that is needed for patients to understand and act on test result information. Figure 1 is a screenshot of how test results are presented in a current patient portal used at our and many other institutions. Users can see their result, a "standard range" for that test (without any explanation of what "standard range" means), and the name of the units of the test (without explanation of the technical terminology). And since patient portals are designed to provide test results outside the presence of a clinician or other expert who can explain them, the lack of contextual information within a portal is particularly problematic for patient understanding.
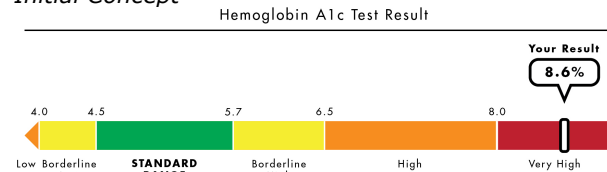
Design Goals

Initial Concept

Figure 2. An initial concept of the test result graph.

We developed an initial concept of a graphic intended to provide important contextual information indicating the risk and severity of a given test result. We used color and labeling to communicate the severity of the result and also to indicate a standard range for the test. We have used primarily diabetes-related tests such as Hemoglobin A1c (a measure that approximately represents average blood glucose over the past 3 months) as the example test in our design examples and in the user tests. We designed the graphics keeping patient portals as the most important application, although we note that these graphics can be used in educational materials and decision aids.

In initial planning discussions (which involved researchers, clinicians, as well as people with type 1 and type 2 diabetes) and in some early quantitative studies of these designs we identified three important issues that we felt would be important for contextualizing the test result and helping users derive meaning in their decision making. One issue was how to represent outlying values. People with diabetes may have values that extend well outside the standard range for Hemoglobin A1c and other tests, and in previous work we found that displaying a very broad scale is not ideal [10]. We wanted to be sure that the
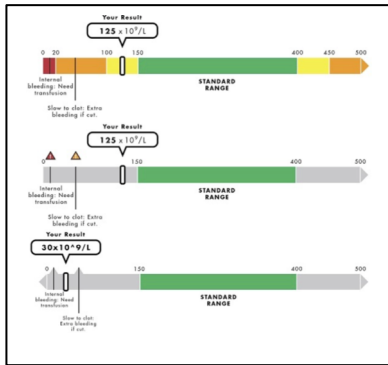
Figure 5. Example designs for communicating points of harm

visualization would be flexible enough to clearly indicate to users how their results compare to standard ranges for a particular result and what that comparison means for their health. A second issue was how to visually present a short-term goal of the patient or the clinician. Since the standard range for a test result may not be a meaningful or realistic goal for someone with diabetes, we wanted the visualization to be able to communicate to the user a personalized goal range. A third issue dealt with communicating the potential for harm at various points in the spectrum of possible test results and helping users with unsafe values appropriately interpret their risk for harm based on the result, as well as relieve anxiety for users with results that are outside of a standard range but not at a point at which they should worry excessively.

Method

We have undertaken an iterative design process in which we produced several variations of a visualization and then qualitatively assessed its cognitive and affective effects via think-aloud protocols and cognitive interviews in user-centered design sessions. These sessions were intended to provide qualitative feedback about various design concepts in preparation for large-scale quantitative studies of the most promising ideas. In these sessions, we presented users with prototypes of several different variations of the design and solicited feedback. Each prototype graph was presented within a patient portal (see Figure 6) and a hypothetical scenario. After conducting two to four sessions, we reconvened and adjusted the designs.

We conducted three waves of user tests, with each wave focusing on design strategies for one of the three

primary design goals listed above. We recruited 18 participants for the sessions. Participants had a median age category of 50-59, and 47% were female. The majority of participants had some familiarity with diabetes, either as patients themselves or as friends/relatives of a diabetes patient.
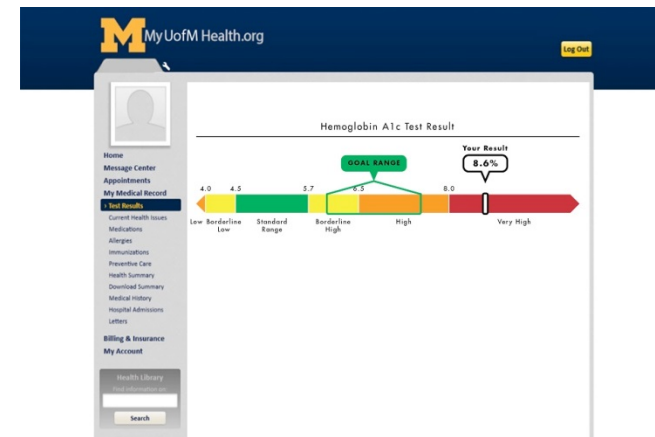

Figure 6. An example of a prototype that was shown to participants.

Results

Color, emotion and meaning

Graphs can have an impact on users both in terms of understanding of the test result but also in terms of the emotional response to the information. Color was effective at communicating information about risk, but color also created strong emotional responses to the graphs. These emotional responses must be considered carefully in the design of patient portals to help patients make good and informed decisions with the information that is provided.

Figure 7.

Figure 8.

Figure 9.

Color coding using the stoplight theme worked well for helping participants understand what a result means for their health. As P2 stated, "I automatically know just at a glance that this is in the danger zone because of the color code." Similarly, designs that did not use color to communicate risk led to confusion. For example, P15 stated "I can only assume this gray is to ignore" in response to Figure 10. But a result in this area should not be ignored as it is outside the standard range.

While color was effective at helping participants understand the test result, it also triggered varying emotional responses to the result. Many participants commented on how the color of the graph made them feel as the viewed it. P1 stated that "the red, which is like a color of danger, makes me feel [nervous]." Looking at Figure 7, P12 stated that the graph felt "cold and statistical." As there are times that a strong emotional response may be desirable (such as a patient with a dangerous test result who needs the emotion to trigger action), and others where it is undesirable (e.g. a patient with a slightly out of range result that experiences unnecessary anxiety), an important future goal is to explore designs that effectively trigger appropriate emotional responses for varying contexts.

Information density vs. minimalistic design
Adding contextual information about test results prompts users to want to seek additional information, such as more detailed explanations or instructions from a doctor. For example, P8 wanted more text explaining the result, stating "it needs … an explanation, of maybe some things that we could do."

This creates an additional design tension because a patient portal cannot feasibly provide all of the necessary nuanced information to a patient. And when some additional text was provided in the third wave of designs, it created clutter and distraction.

P15: *It's busy. It's way too busy for me.* (Figure 8)

P16: *I would like it … without, what would you call it, diamond shape or whatever on top, you know, because it's distracting from the numbers* (Figure 9)

Participants stated a clear desire for simplicity and minimalism in the design to make the graphs easier to interpret. Yet at the same time, they wanted access to more information, as well as greater readability through larger fonts and graphs. The limited space available for a graph such as these in a patient portal, particularly when considering designing for mobile applications, presents a considerable challenge going forward.

Information Source Confusion
Providing contextualized and individualized test results requires aggregating information from multiple sources, such as the result value itself, a patient's doctor or others who determine what the "goal range" should be or where the harm anchors may reside, or other sources such as published research that determines what the standard range is. But the graphs aggregate this information into a single, unified interface and users may not be aware of all the sources that go into it without explicit markers [12]. Users' perception of source credibility or relevance may be affected by their understanding, or lack of, the sources of the information in the result graphic.
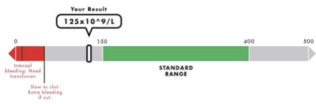
Figure 10.

For example, when looking at a graph that indicated a personalized goal range for the patient (Figure 11), P10 stated "What belongs to the graph needs to be clear, what's related to me demarcated." Users have a need to understand which characteristics of the graph have been set by a doctor or provider and which are coming from other sources.

Others wanted to know what the doctor thinks about the result. P12 said "If it is out of the goal range and [the doctor] thinks it is still good, it would be nice to have like a smiley face or an indicator … that 'you did even better than we expected.'"

Patients prefer receiving troubling test result information directly from a doctor face-to-face [11]. Our participants expressed a desire to immediately communicate with their doctor when seeing troubling results. As examples:

P5: *I would call my doctor and ask if I'm going to die*

P6: *I would probably call the doctor's office to see how soon I could get in.*

Figure 11

Patients may have varying conceptualizations about how they should use a patient portal in managing their own health. While some may view the portal as simply an additional or alternative source of information, others may treat it as an extension of a doctor's visit or as a form of asynchronous but direct communication between the patient and doctor. However, doctors often want to reduce communication regarding non-serious results, so this represents another conflict between different types of users.

P10 stated that she wanted the graph to have text that said "you are here, your doctor wants you here" in order to make the graph "seem more personalized." Words make the graph feel more like a communication channel, and even an asynchronous communication channel is more understandable to a user.

P8 felt that it was wrong to provide a serious test result online. "Somebody should be with me. … I would call my doctor and say 'what the hell are you sending me this stuff for. I thought I was just going to get some results.'"

This type of response suggests an expectation that doctors are closely overseeing the results and managing the information that goes into the portal, but that may not necessarily be the case.

Conclusion
Graphically communicating test results in a meaningful way presents several difficult design tensions. Concepts such as using color or text to convey important contextual information can be effective for their specific purpose, but may also conflict with other important goals for the graphic such as triggering appropriate emotional responses or supporting clear communication between doctors and patients. We hope to build on this work and develop new approaches to resolving these tensions.
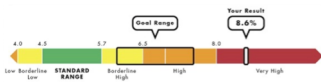
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