

# A National Web Conference on Optimizing the Presentation and Visualization of Health Data for Patients and Providers

## Questions and Answers

May 30, 2017

### QUESTION:

Since your data display had a lot of colors in it, how would you address patients who are color blind?

### ANSWER:

**Brian Zikmund-Fisher:**

The color scheme that we showed you relies on the stoplight color scheme: red, yellow, and green. We ran a study to explore color perceptions and different color schemes, in part because one of our patient partners had asked whether labeling something red indicates that this is a particularly risky thing, or has a negative “you’re a bad patient” connotation.

The displays that I showed you all rely on redundant cues. That means you can put them into grayscale with no color, and all the extra information is still there. In the blocks version, you have clearly-defined blocks with clearly-defined labels right next to each one of them that provide information about borderline, low, etc.—even if you don’t have the colors.

On the color-gradient version—in which the colors are changing continuously—we added an arrow to indicate “high from here up” or “low from here down.” We added that because we wanted to make sure that someone who has color perception difficulties would still have a clear signal as to when they reach a higher risk level. The design process must balance the visual power that color cues provide people who perceive the full spectrum of color against the needs of those who can’t.

### QUESTION:

Have you thought about flipping the scale, so the optimal value would be on the right-hand side? In other words, have you thought about not always putting zero to the far left?

### ANSWER:

**Brian Zikmund-Fisher:**

This research question got an enormous amount of discussion in our research group, but we decided not to pursue a study on this question because we had competing priorities. I think it’s an interesting idea. It would require people to get used to the idea that left is bad, and right is good, even though the numbers will be going upward for some tests and downward for other tests.

Industrial information displays often do things like this to facilitate people’s scanning down a set of displays to find things that are potentially concerning. It may be appropriate to think about developing displays that would do that for either patients or clinicians. You would then have to worry about whether the user would walk away knowing in which direction their values should be going. If you have confusion because you flipped the scales, that might undermine the benefits of the display.

**QUESTION:**

Have you done anything with displaying longitudinal data?

**ANSWER:****Brian Zikmund-Fisher:**

I didn't include longitudinal data in this presentation. However, we did run a study that looked at the issues involved with presenting past data: Do you want to present only one past result? Do you want to present multiple past results?

There are a variety of graphical displays that can be used to present multiple past results, but you run into the simplicity versus complexity problem. If it's a nice monotonic trend, it's relatively easy to develop displays that make sense; but in the real world, values often bounce around. It's not trivial to figure out how to design a display that is simple and easy to understand, yet provides historical data context and trend information.

**QUESTION:**

Have you tested data displays with physicians as well as with patients?

**ANSWER:****Brian Zikmund-Fisher:**

The physician context is interesting for two reasons. One is: How do physicians respond to these displays for their own use? The second is: How do physicians respond to the idea of patients having these types of displays?

We've focused more on the second question. I have data from a survey of physicians in which we showed them the displays that I showed here and explored their perceptions of which ones they would prefer to give patients and to what degree they have concerns about those displays. I mentioned some of those issues at the end of my talk.

There's an interesting application of these types of displays or other variants of them for physician-focused electronic record system displays. However, the characteristics of a patient display may not be the optimal designs for physicians.

We can use physicians' experience and training so that we don't always have to present the same thing that we would present to a naïve patient who doesn't have experience with these test results. However, the idea of placing a value on a potential visual range has been incorporated in a lot of dashboard systems for a variety of clinical data, and I would love to see it done more often.

**QUESTION:**

Have you tested other more interactive models that allow patients to interact with the data—such as hovering over the line with more details, or having a drill-down menu? Have you tracked or tested patients' interactions with these models?

**ANSWER:****Brian Zikmund-Fisher:**

We have not yet done major studies in this grant exploring interactivity. I have done a series of research studies looking at interactivity in a related but different context, which is health risk communication.

The results of that work have been mixed. In exploring risk communication, we've discovered that the more patients are focused on figuring out what they're supposed to do or what they can do in the interactivity, the less they focus on processing the basic visual image. This distraction can inhibit their ability to take away information from that visual image. We found that giving people an interactive graphic led to worse processing than giving them a static graphic.

I have mixed feelings about this kind of context. There is some potential value for interactivity, especially when it allows people to see historical data and trends. However, I'm concerned that a graphic that looks cool and captures people's attention might distract them from processing the meaning of their test value. Figuring out the right balance is not going to be easy.

**QUESTION:**

Have you thought about a way for data to be accessed through an API (application program interface) by various databoard apps so that practitioners and patients can select the app or tool that meets their needs?

**ANSWERS:**

**Genevieve Melton-Meaux:**

At a broad level, that's a great idea. If we're talking about a very straightforward task, that is likely a great approach. It gets a little more complex when we're talking about trying to understand multiple things about a patient during an ambulatory visit. During that visit, you might need more information than you had anticipated. Therefore, you may have to go to other parts of the electronic health record (EHR).

Giving users the freedom to interact with the patient chart in a different way is a great idea and a valuable thing. That may bring some nice innovation toward how we are able to provide care.

**Brian Zikmund-Fisher:**

Whether we're talking about displays or about navigation, aligning the steps or the displays to the user's purpose is where the ballgame is at. As Genevieve said, you may need one thing for straightforward situations, and something else for complicated situations. This is a pattern we see over and over again. The danger is that in our desire to make things easier for ourselves, we believe that there can be one-size-fits-all answers. Often, however, one size fits all doesn't actually fit all.

**QUESTION:**

Have you considered voice interaction for the navigators?

**ANSWER:**

**Genevieve Melton-Meaux:**

We have not used voice interaction, but there are some prototypes out there that use voice navigation. If sections of the notes are easily identified, that could be a way to avoid scrolling.

**QUESTION:**

The visualizations that you presented would require significant development by EHR companies that are not already using that model. Can you estimate the cost and the willingness of vendors to take this path?

**ANSWER:**

**Genevieve Melton-Meaux:**

It varies from vendor to vendor. The vendors that have a good market share are less excited to go to this type of model. With some of the work that's happening at a national level around certified health information technology, vendors are going to be pushed toward this model.

**QUESTION:**

From the provider's perspective, getting patients to react less to mildly out-of-range values can prevent unnecessary calls. How would you reframe this from the patient's perspective?

**ANSWER:****Brian Zikmund-Fisher:**

I see a clear patient value to these displays. As a patient, we are constantly exposed to unfamiliar data. We know these data are important, but we do not know what they mean or how to use them.

Furthermore, being a patient involves substantial feelings of lack of control. I believe most patients would welcome the opportunity to be able to discriminate between better and worse test results, both because it would reinforce the need to act (when appropriate), and because it would provide relief and greater confidence when the results can and should be handled through routine interactions with clinicians. I certainly appreciate when a clinician explains to me that a non-normal value is not something I need to expend my scarce mental resources worrying about.

Let's go back to the story I told at the beginning of the presentation, about the time my doctor discussed my bilirubin level with me. That discussion made me anxious, even though—as it turned out—I didn't need to be. If she had interpreted my results, I wouldn't have had that negative experience.

That's not an uncommon story. Patients, especially those who are worried about their condition, seize upon whatever information is provided by their doctors or through the patient portal. If the values make them worry about stuff that they **don't** need to worry about, that's unnecessary harm—and I'm using the word "harm" intentionally. We can and should try to prevent that harm.

Interpreting results also has benefits for the healthcare system. However, I look at it primarily from the patient's standpoint. I want to know when I need to worry, and I want to know when I don't. I value when I'm given information that enables me to feel a sense of confidence.

## Additional Q&A Addressed Following the Webinar

### QUESTION:

Interpretation of most medical test results requires trend information for a patient, in addition to standardized norms. Have you studied how to graphically display results over time, such as in a line plot with ranges?

### ANSWER:

#### **Brian Zikmund-Fisher:**

As noted in the discussion, we have collected some (not yet published) data related to presenting past test results. Some of this uses line plots, while others place past data anchors on number lines. While it is premature for me to speculate on the findings, the challenges are clear: 1) The more past data one provides, the more complicated the task for the patient, and 2) Displays that clarify the trend also tend to divert attention away from the level of the test (i.e., how good or bad the current result is). The reverse of the last statement is also true: Displays that emphasize the meaning of the current test result tend to make it harder to see trends.

### QUESTION:

Many of the lab values that you've been discussing exhibit nonlinearity (e.g., the risk of bleeding with low platelet counts increases exponentially, with 10 k being the "elbow" of the nonlinear risk curve). Have you considered how to incorporate nonlinearity?

### ANSWER:

#### **Brian Zikmund-Fisher:**

Displays that include categorical labels and/or color cues to show risk can represent the nonlinearity of risk in these cases by showing how fast or slow one transitions from, for example, "borderline high" to "high" to "very high" levels. However, helping patients understand the true exponential nature of many risks is very difficult. Nonetheless, it is an important goal, since making extreme values even somewhat less extreme often corresponds to huge risk reductions, even when the patient has not come anywhere close to reaching the standard range or target goal ranges.

### QUESTION:

How would you consider this with more continuous data, such as heart rate or steps?

### ANSWER:

#### **Brian Zikmund-Fisher:**

Heart rate could be displayed similarly. The key issue with heart rate is adjusting the reference range for age. However, steps don't have a natural reference point. As a result, the question is not whether you can show steps on a line (you can), but what reference points are most helpful to encourage whatever behavioral response is desired.

### QUESTION:

How did you quantify the evaluation results of the various design models for the purpose of comparison and analysis?

### ANSWER:

#### **Brian Zikmund-Fisher:**

I'm not sure I fully understand the question. If you are asking about the characteristics of the outcome measures used, then the answer is: We used several different outcome measures, ranging from a question about the urgency of a result, to a question about how quickly to contact a healthcare provider about a result.

**QUESTION:**

It makes sense to add additional anchor values. However, do you think that adding values at which “practitioners may become concerned” may also lead to complacency on the part of a patient to reach more desirable results?

**ANSWER:****Brian Zikmund-Fisher:**

That’s an inherent tradeoff that is associated with the question of purpose. If the test is being ordered for self-management purposes **and** the patient has repeated experience with a test, then the concern you raise might well be important. The additional anchor provides a “good enough” type of reference point that might, in theory, limit motivation to continue to act. By contrast, if the test is being ordered for monitoring purposes, the patient is not familiar with it, and the expectation is that the test would be normal, then the situation is very different. In this case, the additional harm anchor provides guidance to help patients interpret how concerned they need to be about an unexpected result.

**QUESTION:**

Have you considered presenting change of value information (e.g., higher, lower, same as previous) along with current reading?

**ANSWER:****Brian Zikmund-Fisher:**

Yes, we have explored that idea in our other (not yet published) studies. The challenge (both good and bad) is that a result that is better than previous may not be good, and a result that is worse than previous may still be OK. Figuring out whether patients should be focused on the change in result vs. the absolute level of the result is an important issue that likely varies from one situation to another.

**QUESTION:**

On Slide 25, if the standard range is defined by lines at 150 and 400, what does the green shading mean? Is it meant to imply a zone of ambiguity? How did you determine the limits of the green shading?

**ANSWER:****Brian Zikmund-Fisher:**

The green is a proxy for the “goodness” of the result. Therefore, the entire standard range is green. However, results that are just barely out of the standard range are not that much riskier than those inside the range. Therefore, after some preliminary testing, we made the green fade to the background color (e.g., gray) as values move further from the standard range. This question raises the issue of how we should determine the limits of the green area. This is indeed a challenge, and one that combines data with clinical judgment. In our studies, we based these decisions on the advice of several participating clinicians.

**QUESTION:**

Lay readers may think higher is better, even if the exact reverse is true (e.g., an A1C result). How do you respond to this issue?

**ANSWER:****Brian Zikmund-Fisher:**

The question of how to clearly communicate whether higher values represent better or worse is one of the most challenging issues in this domain. For example, we want lower low density lipoprotein (LDL), but higher high density lipoprotein (HDL).

Color coding and labels can serve as communication tools. For some tests (e.g., ALT), nearly all the non-normal values are above the standard range. In that case, we let the color coding convey the fact that higher is worse. Other tests have poor outcomes if one is too low or too high, and the graphics can display that too.

The core message is that we need a clear target reference point for each patient. Once patients have that, they can determine whether their result is above or below the target and know in which direction they should move.

**QUESTION:**

Do you think the patient's story is lost in the data display? Should we try to reconcile the knowledge gaps?

**ANSWER:**

**Brian Zikmund-Fisher:**

I'm not sure I understand the concept of the "patient's story" in this context. These test results are explicitly about one point in time. Historical data expand the time range, but they still don't represent in any way the totality of a patient's story.

**QUESTION:**

There are ties between how health data are presented and how we communicate nutritional data on food. Have you looked at the user experience with other (perhaps non-healthcare) data to see how they track?

**ANSWER:**

**Brian Zikmund-Fisher:**

There are many applications of the data visualization principles we are exploring. One application is nutrition data. Another we have started to explore is patient reported experience measures (PREM), or patient reported outcome measures (PROM). The most work in this area has been done in human factors engineering, especially as it relates to optimal design of instrument control panels (e.g., airplane cockpits).

**QUESTION:**

Is there any work underway to standardize harm barriers? Is the only answer complex configurability?

**ANSWER:**

**Brian Zikmund-Fisher:**

There may be efforts to standardize harm anchors. Since that would require consensus from clinicians of various types on the many different situations in which a test might be ordered, we considered this question well beyond the scope of our expertise.