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Title: Systematic Design of Meaningful Presentations of Medical Test Data for Patients

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Abstract

Purpose: To use an iterative, user-centered design process to develop and test visual displays of laboratory test results that make these data more intuitively meaningful for patients.

Scope: Although most patients have access to laboratory test results through patient portals of electronic records systems, results are commonly presented in difficult-to-interpret tables. While patients could use this information to guide self-management decisions or improve patient-provider interactions, they must first understand was these data mean.

Methods: After an initial multidisciplinary deep-dive brainstorming session, we developed a visual number line format for test result displays, received iterative patient feedback in user-experience design sessions, and conducted comparative evaluations of these designs in 7 large-sample, survey experiments of general public samples. We also conducted qualitative and quantitative assessments of healthcare provider beliefs about these designs.

Results: Visual displays informed by patient input can improve understanding of test results and increase patient sensitivity to result variations. Additional designs can incorporate novel features, such as disease-specific goal ranges or harm anchors, to make test result communications even more intuitively meaningful. Several designs are available in our free, online test result generator application (mylabresults.org).

Key Words: laboratory testing, test results, communication, patient education

Purpose

Drawing on research methodologies from design science, decision psychology, human-computer interaction, and health communication, we used an iterative research process to tackle the problem of how best to present laboratory test results to patients (e.g., Hemoglobin A1c test results to patients with diabetes) in order to make this information more understandable and useful. By making such results more intuitively meaningful to patients, we hope to promote communications that hold the potential of improving both patient self-management of chronic conditions and patient participation in medical decision making.

Scope

Direct patient access to medical test results is rapidly increasing through patient portals to electronic record systems. Once given access, patients use such systems first and foremost to view medical test results and value being able to do so. Yet, patients are now viewing medical test result data that they've either (a) never seen directly before or (b) only seen in the context of a clinical visit with a health care provider who could explain and interpret it.

Patients have many good reasons to want direct access to their test results. Direct access to results enables patients to seek out their results by themselves, thereby providing an opportunity for identifying actionable results and preventing unnecessary harm. Patients who receive test results directly may also have the opportunity to better prepare for future clinic visits or other patient-provider communications by preparing questions or seeking out other, relevant information. Such preparation benefits patients, but it also benefits the healthcare system by making visits more efficient. On a more day-to-day basis, patients can use their access to test results to evaluate their susceptibility to future health problems (e.g., by identifying whether they have particular risk factors) and improve self-management of their current health conditions.

Being an "informed" patient, however, doesn't mean being able to parrot back a number. It means understanding what test data means for the patient's sense of their health status and how it should influence future health decisions or behaviors. In that manner, patient access to such health data promotes a transfer of some of the responsibility for health management from care providers into the hands of patients themselves.

Yet, simply providing patients with access to medical test results might not result in improved outcomes. Many patient barriers to effective use of health information exist. In this project, however, we focused our attention on two specific issues that directly affect the capacity of patients to understand, interpret, and use medical test result data (as distinct from textual health information): insufficient patient numeracy skills and information evaluability problems. These barriers have important implications for the design of health information systems, especially those that aim to deliver medical test results directly to patients. Put simply, for many patients, "knowing" test results or risk estimates does not ensure that they understand what those numbers imply or what actions they need to consider. Such data can be literally "meaningless," and patients are likely to ignore confusing test results in decision making even when fully "informed."

We focused our project on the particular types of laboratory test results commonly presented to patients with diabetes. Patients with diabetes generally undergo regular hemoglobin A1c tests to assess blood glucose control, and these test values are often used by patients and providers alike to guide decisions about both medical and behavioral interventions. Yet, these patients

often receive many other tests as well, for reasons ranging from monitoring the effects of medications to assessing the impact of co-morbid conditions. As a result, this project examined how best to communicate a variety of different types of laboratory test results. This approach enabled us to test broadly generalizable principles of data presentation while simultaneously remaining grounded in the specific clinical context of diabetes. In other words, our research addressed a fundamental design problem that affects any patient who may receive laboratory test results as part of their care, regardless of diagnosis: If a patient cannot understand the meaning of the test results they receive, then they cannot use them to improve their health or their healthcare.

Methods

Our iterative research approach involved a three-stage research process that engaged an interdisciplinary team of health and risk communication experts, practicing medical professionals, and expert patients in solving the specific communications problems faced by diabetic patients who receive numerous types of test result data.

In Phase 1, we conducted an intensive "deep dive" design session (a methodology borrowed from design science) to identify discrepancies between patient needs for test result data and the formats in which such data are provided to patients, identify when low numeracy skills will be a barrier to patient interpretation and use of such data, and brainstorm potential solution concepts. This 2-day session combined the multidisciplinary team of investigators on this project with selected expert patients.

In Phase 2, we conducted comparative evaluations of proposed designs using (a) user-experience design sessions, and (b) an iterative sequence of large-sample, multi-factorial, randomized-controlled experiments using both general public and clinician samples obtained from different Internet-based panels. These iterative testing process facilitated continuous revision and improvement to visual designs in order to identify what formats make test data most meaningful and useful for facilitating informed patient decisions about medical care.

In Phase 3, we took our identified test results communication "best practices" and developed and programmed a test results "display generator" application that we have made available to patients via a free website (http://mylabresults.org). We designed this application to facilitate the possibility that it could, in the future, be integrated with existing electronic health record systems and other applications.

Results

Specific Aim 1 of this project involved an intensive "deep dive" brainstorming session (A) to identify discrepancies between diabetic patients' needs for knowledge about test results and the formats in which data are provided to patients, (B) to identify when and how low numeracy skills will be a barrier to patient interpretation and use of such data, and (C) to brainstorm potential solution concepts for development and testing in Aim 2. The "deep dive" was successfully completed on May 20-21, 2014, with attendance from all but 1 study team member (including 2 patient consultants) as well as support staff and an incoming post-doctoral fellow. We used two design students as visual recorders and ended up with over 60 giant sticky notes of drawings, design ideas, and notes plastered to the wall of the conference room. Discussions ranged from assessment of numeracy barriers to the subtle ways that different labels can unintentionally convey a sense of "bad patient" when describing an out-of-range test result. These findings were crucial inputs into the design processes implemented in Aim 2.

Under Aim 2, we conducted comparative evaluations of proposed designs using (a) user-experience design sessions, and (b) an iterative sequence of 7 large-sample, multi-factorial, randomized-controlled survey experiments of general public samples along with 1 qualitative study and 1 quantitative survey of healthcare provider beliefs about these designs.

- Study 0 was a pre-study examining patient perception of the meaning of different color schemes by patients with diabetes. Our results suggest that a red-yellow-green stoplight color scheme may increase sensitivity to changes in test value over other color schemes without significantly increasing negative perceptions (a concern since red might have been seen as implying negative things about the patient).
- Study 1 was our first multi-factorial study that multiple design elements of the visual displays (e.g., the presence or absence of categories) tested on 4 different types of laboratory tests and randomized to be at different test result levels. We included control conditions of tabular displays modeled after those currently used by online electronic health record portals. Our results showed provided preliminary evidence that visual displays could result in better sensitivity to changes in test results than tables.
- Study 2 examined different approaches to visually showing outlier data points (extremely high/low values). The results suggest that people treat outlier values as essentially equal, regardless of how far "out" of the regular scale the value is.
- Study 3 examined how best to present goal ranges to patients in situations where the patient's goal is different than the standard (normal) range. Importantly, we found that while adding goal ranges to the standard range was helpful, it was even more helpful to use a simpler design that removed the standard range and only included the patient's disease-specific goal.
- Study 4a tested the impact of providing harm anchors, i.e., reference points that describe possible harms at different non-normal levels of a test result. The findings suggested that harm anchors were not particularly important to evoking concern about extreme test values but might be most useful for helping patients known that a slightly out-of-range value is not particularly concerning. It also provided evidence that anchors that described how bad a value was were not particularly reassuring, even when the value had not reached that level of harm
- Study 4b both (a) collected additional data comparing visual display designs (now refined based on our earlier data) with tabular presentations and (b) demonstrated clearly that harm anchors and other visual cues could reduce patient concern about slightly out-of-range values that are not clinically concerning. This data collection integrated designs from several previous studies as well as new designs. Results (a) confirmed that number line displays were superior to tabular displays, especially in increasing patient sensitivity to variations in results outside of the standard reference range, and (b) demonstrated that providing a harm anchor ("Many doctors are not concerned until here") was particularly effective an reducing patient concern about out-of-range but near-normal test values.
- Study 5a involved conducting 9 qualitative interviews with clinicians about the visual displays developed up to that point in the project. These interviews supported the general design approaches taken in the web studies but suggested several important caveats, including the potential need to tailor displays to patient characteristics, especially if the display is to include a defined target goal range. Clinicians also expressed concern that the harm anchor design might reassure patients for relatively small deviations from normal but that it might also inhibit action in other situations.
- Study 5b was an internet-administered survey of primary care clinicians recruited through a clinician-specific social media / survey research company that examined clinician

perspectives about the visual designs developed in this project. Results confirmed many of the impressions of the Study 5a qualitative interviews, including (a) general interest in visual displays, (b) concern from a minority of clinicians about particular displays, and (c) both interest and concerns seemed highest for the harm anchor displays.

- Study 6 was planned to address the potential for screen size (e.g., computer vs. mobile device) to affect interpretation of displays. However, in the end we did not run a separate study on this question and instead focused on analyzing screen size data collected in multiple other web-based studies.
- Study 7 was the final primary data collection for Aim 2, and it focused on communicating how test results might change over time. We tested number line displays vs. line graphs, the impact of including more vs. fewer past results, and the effect of presenting past data in a forward vs. backward (in time) sequence. At this writing, analyses of these data are ongoing. However, preliminary analyses demonstrated that past data do indeed strongly shape perceptions of current results and that, under some circumstances, the scaling of the range of values displayed can also influence perceptions.

Aim 3 involved incorporating the identified test results communication best practices into an online test results "display generator" application. The prototype generator was developed based on iterative feedback from study team members using a user-centered design perspective. The generator is now freely available at http://mylabresults.org.

Overall, our work demonstrated that the tabular format currently used in patient portals to electronic health record systems is not the optimal approach to display laboratory test results to patients. We developed and tested multiple designs that used visual features such as distinct color-coded categories, color gradients, harm anchor threshold points, visually displayed target ranges, and historical data points.

Across all of our studies, our findings showed that patient sensitivity to variations in test result values depends heavily on providing the type of contextual information that is most relevant to the characteristics of a particular test and the needs of an individual patient. For example, patients already diagnosed with certain conditions should have disease-specific reference ranges instead of (not in addition to) standard ranges. Patients who are receiving results that are outside of the standard reference range but not clinically concerning need additional contextual cues (e.g., harm anchors, or category labels) to reassure them or else they risk unnecessary calls to their doctor's office or unneeded trips to the hospital.

The takeaway message from this project is that laboratory test result data can be made more useful for patients through careful visual design and inclusion of relevant (but not excessive) contextual cues. These designs could easily be incorporated into electronic record systems that are used by millions of patients each year to access their test results electronically. However, translation of this design work into improved health outcomes will require convincing developers of record systems to do the up-front work to incorporate these approaches into their systems. Once incorporated into patient-facing communications on a broad scale, however, these designs hold the potential to improve patient understanding of test results, patients' ability to manage their health conditions, and patient-provider interactions around medical decision making.

List of Publications and Products

To date, we have published one manuscript in the *Journal of the American Medical Informatics Association* comparing visual displays versus tabular displays based on the Study

4b data. Two additional manuscripts are under review a) based on Study 3 on the effect of providing goal ranges and b) on the use of harm anchors to minimize concern about clinically unconcerning nearly-normal values using additional data from Study 4b. Additional papers planned include a paper on clinician perspectives about these displays (from Study 5b data), a paper on the effects of different screen sizes (using data drawn from multiple studies), and a paper on the impact of past data on perceptions of current test results (from Study 7 data).

Publications
1. Zikmund-Fisher BJ, Scherer AM, Witteman HO, et al. Graphics help patients distinguish between urgent and non-urgent deviations in laboratory test results. J Am Med Inform Assoc 2017;24(3):520-528. PMID: 28040686

Presentations
1. Zikmund-Fisher BJ, Scherer AM, Fagerlin A, Klasjna P, Tarini BT, Exe NL, Larkin K, Witteman H. Test results in line graphs instead of tables: less confusion without distortion. Oral presentation to the Society for Medical Decision Making, St. Louis, MO, October 19, 2015. *(Top-Ranked Abstracts Session)*

2. Scherer AM, Witteman HO, Fagerlin A, Klasjna P, Tarini BA, Exe NL, Larkin N, Zikmund-Fisher BJ. Block it out! Presenting test results with clearly defined categories increases understanding of results. Oral presentation to the Society for Medical Decision Making, St. Louis, MO, October 19, 2015.

3. Scherer AM, Witteman HO, Solomon J, Fagerlin A, Exe NL, Zikmund-Fisher BJ. Improving understanding of test results by substituting (not adding) goal ranges. Poster presentation to the Society for Medical Decision Making, Vancouver, BC, Canada, October 23, 2016.

4. Zikmund-Fisher BJ, Scherer A, Witteman HO, Solomon J, Exe NL, Fagerlin A. Providing harm anchors in visual displays of test results mitigates patient concern about nearly normal values. Oral presentation to the Society for Medical Decision Making, Vancouver, BC, Canada, October 24, 2016. *(Top-Ranked Abstracts Session)*

5. Zikmund-Fisher BJ. The pros and cons of infusing cancer patients with statistics and test results. Oral presentation to the American Association for the Advancement of Science (AAAS), Boston, MA, February 20, 2017.

6. Zikmund-Fisher BJ, Scherer AM, Solomon J, Witteman HO, Exe NL, Fagerlin A. Physician preferences and concerns regarding visual displays of laboratory test results for patients. Poster presentation to the Society of Medical Decision Making, Pittsburgh, PA, October 24, 2017.

Products
1. mylabresults.org. Accessed October 16, 2017. *(free, online, test result display generator)*