Toward Better-Informed Healthcare Patients
A proposal submitted for the GRACA Grant Program

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Summary
This proposed research focuses on improving communication with healthcare patients via their personal health records, or PHRs. Enhancing this communication is critical, as significant benefits for the both the individual and the healthcare system as a whole are anticipated as patients become more involved and interested in their personal healthcare. PHRs are widely seen as a key means of increasing patient involvement and interest, but unfortunately today’s versions generally do not live up to expectations. Current PHRs simply do not communicate effectively with all patients, particularly those patients who have limited understanding of health data and/or limited abilities to work with numbers and graphs. Improved designs for PHRs are widely considered necessary for improving communication with those patients and fostering their personal involvement in their own healthcare. This proposed research explores alternate PHR designs and examines the degree to which those improved designs might improve information transfer to patients, particularly those who may not be best equipped to understand and process that information. The findings will provide improved understanding of patients’ needs and desires for interacting with their PHRs, will contribute to overall knowledge on PHR design, and will inform ongoing PHR redesign efforts in progress at the University of Nebraska Medical Center.

Motivation
Although the U.S. healthcare system is second-to-none in many ways, it does not provide consistent, high-quality medical care to all people (Institute of Medicine, 2001). The increasingly complex healthcare system of today is characterized by more to know, more to do, more to manage, more to watch, and more people involved than ever before (Institute of Medicine, 2001). The patient is increasingly seen as someone who can help reduce that complexity, with more active and engaged patients enabling the physician-dominated, largely one-way dialogues of today to be replaced with a more collaborative, patient-centered exchange of information in the future (Epstein and Street, 2011).

Directors at the National Institutes of Health share that vision, and suggest that reducing costs while improving overall patient health and healthcare in general will require migration to a system which is “more predictive, preemptive, personalized, and participative” (www.nih.gov/strategicvision.htm). Other researchers agree as well, with more active and more participative patients seen as key to enabling transformation of the U.S. healthcare system (Li, Gupta, Zhang, & Sarathy, 2014), and increased patient involvement seen as vital to increasing effectiveness and decreasing costs of the U.S. healthcare system (Tang, Ash, Bates, Overhage, & Sands, 2006). In short, all involved – from government agencies to healthcare providers to health information technology researchers – see the value and importance of increasing patient involvement and interest in their personal healthcare.

The Problem
Only patients themselves can actually increase that involvement, and in general they are not yet performing up to expectations. Although roughly 75% of patients say they see value in use of tools like PHRs to take a more active role in their personal healthcare (Kaelber, Ashish, Johnston, Middleton, & Bates, 2008), fewer than 10% actually utilize the PHRs provided to them (California Healthcare Foundation, 2010). Low utilization rates like this suggest that there are problems with the “usability” of today’s PHRs, and improving that usability is then key to improving PHR acceptance and use by patients.

There are several competing approaches to defining usability within the healthcare and HCI communities, but this research uses the International Standards Organization (ISO) version, which defines usability as follows: “The extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use.” (ISO, 1998).
In other words, usability of the PHR is determined by (1) how well it does what the patient needs it to do, (2) how well it does that without requiring excessive cognitive load or other effort from the patient, and (3) how pleased and comfortable the patient is with that process during and after the interaction.

Those factors of usability are lacking in the PHR systems of today, and addressing those shortfalls will be important to improving adoption rates. Professor Raj Ratwani, Scientific Director for the National Center for Human Factors in Healthcare, offered the following statement speaking to that concept in his recent testimony before the U.S. Senate Committee on Healthcare, Education, Labor, and Pensions (HELP) (Ratwani, 2015):

“The usability of . . . personal health records remains subpar, and is a significant challenge that we must overcome immediately. While some have suggested that low utilization rates of patient portals is based on lack of interest, we know that it is because in most cases the portals have not been designed using methods to optimize the system’s responsiveness to patient needs. There is overwhelming evidence that usability of health information technology systems . . . is crucial to adoption and effective use.”

Potential Solution

Much of this shortfall in usability may be due to the complex data being presented in the PHRs and the difficulties that many patients have in understanding and interpreting what they are being shown. Medical data are some of the most complex and difficult to understand data one encounters (Shneiderman, Plaisant, & Hesse, 2013), and many patients have difficulty interpreting the meaning of what they see in traditional displays (Zikmund-Fisher, Exe, & Witteman, 2014). Visual-based displays (e.g., line graphs or bar charts) are often viewed as a better option for sensemaking in cases such as this (van Wijk, 2005; Fekete, Van Wijk, Stasko, & North, 2008), and multiple researchers have written on the positive effects of visualization specifically in the healthcare environment (e.g., Hawley et al., 2008; Torsvik, Lillebo, & Mikkelsen, 2013; Shneiderman et al., 2013; Landro, 2014).

Zikmund-Fisher et al. (2014) report on a web-based survey where they first measured each participant’s health literacy (how well that person understands health-related concepts) and numeracy (how well that person works with numbers), then asked each participant to review sample laboratory results and indicate what actions they would take based on that review. Results indicated that those scoring “Adequate” in both categories were more likely to identify lab tests out of the normal range than those scoring “Low” in both categories (77% vs. 38%). However, neither group seemed to know what actions were appropriate based on the abnormal results, and even nearly 1 in 4 participants with adequate skills were unable to even notice the abnormal reading in the first place. The results as a whole illustrate the difficulty in communicating complicated medical data to patients, particularly all patients, and these researchers conclude with (Zikmund-Fisher et al., 2014):

“Our results reinforce the critical role of health literacy and numeracy skills in enabling patients to take active roles in their health care. Being an “informed” patient requires more than having access to test results or being able to recite specific numbers. It means understanding what test data mean for evaluating one’s health status and how it should influence future health decisions or behaviors. Our data demonstrate that limited health literacy and numeracy are significant barriers to such knowledge translation tasks. Further research should investigate designs that help people better interpret the meaning of their numbers.” (emphasis added)

Proposed Research

This research will investigate several approaches to improved designs, specifically by including more visual-based displays into a survey design similar to that conducted by Zikmund-Fisher et al (2014).
Standard testing for health literacy (Chew et al., 2008) and numeracy (Fagerlin et al., 2007) will be conducted, as will an additional test for graph literacy (Galesic & Garcia-Retamero, 2011). The alternate displays will be chosen from among those identified as particularly noteworthy in the Health Design Challenge, a competition for redesigning the PHR supported by both the Department of Health and Human Services and the Veterans Administration (www.healthdesignchallenge.com). Many entries in that competition include displays based on graphical concepts – often enhanced by use of color, sorting, or other techniques to emphasize important information – so they provide a good source for displays which are both professionally designed and professionally evaluated. The ultimate test lies with the patients themselves though, so testing with representative patients is the focus in this research.

My primary, over-arching research question is:

**RQ: How can displays of lab results in PHRs best be improved to enhance patient understanding?**

It will be supported by two secondary research questions:

**RQ: Do patients generally prefer visual PHR displays over tabular (non-graphical) PHR displays?**

**RQ: If so, is that true across all combinations of numeracy and graph literacy for participants?**

Standard demographic information plus results of health literacy / numeracy / graph literacy surveys will first be collected, then participants will be given a scenario asking them to imagine themselves as a middle-aged cardiology patient responsible for reviewing their recent lab results in preparation for their upcoming annual checkup with their physician. Three alternate designs for display of lab results will be presented, and participants will be asked to rank order them against each other in order of preference for performance of three distinct tasks: (1) review of most current lab results, (2) review of lab results over time, and (3) determination of the risks posed by these lab results as shown. (Scenario wording and specific lab results will be developed with the assistance of the Department of Cardiology at UNMC.) Additionally, participants will be asked to identify specific likes and dislikes for each of the proposed displays so that further improvements can be made (if warranted).

**Project Timeline**

- February – April 2015: Collect additional background research, finalize displays and scenarios
- May – July 2015: Pilot testing with scenarios and displays (pilot with surveys already conducted)
- August – December 2015: Collect additional data via in-person / online surveys
- January – March 2017: Analyze data, present and publish results

**Student and Mentor Roles**

Student: Coordinate selection of alternate displays, coordinate development of scenarios and sample lab results, conduct pilot and actual studies, perform preliminary and final data analysis, coordinate collection of additional data (if necessary), coordinate publication and presentation of results

Faculty Advisor / Mentor (Dr. Ann Fruhling): Advise in development of displays, scenarios, and overall research plan. Monitor data analysis, participate in publication and presentation of results.

**Project Deliverables**

Deliverables from this proposed project will inform and support my dissertation research in Information Design / Visualization in the College of IS&T as well as an ongoing PHR redesign effort in progress at UNMC. Specifically, the verified and fully analyzed data will show the specific preferences for PHR design as related to presentation of lab results. These data will form the basis for my dissertation, and the results will inform specific approaches utilized in the ongoing PHR redesign effort at UNMC.
Budget Justification

I am requesting $5,000 to support this research, but will make do with whatever can be provided.

Grant funds will be devoted to collecting the data during the research, and will be spent on some combination of the following options:

- **In-person data collection:** Data collection will include as much in-person interface with the participants as possible as that allows for the highest quality interaction. This also requires a significant time commitment, so it may not be advisable to focus solely on this method. Completion of the necessary surveys and scenarios is estimated to require between 30 and 60 minutes for each participant. Local participants will be compensated with a $5 gift card for their time, so I estimate the cost for each local participant at $5.

- **Locally-supported online data collection:** Collecting adequate data using in-person methods alone may prove problematic – particularly given the planned schedule – so it may be necessary to do some data collection online to supplement the in-person portion. To support that locally, I will need to hire an assistant to help build the surveys in Qualtrix, investigate and implement hosting the surveys on the university servers, and assist with collection and analysis of the data. I estimate this to be 100-150 hours of work at $12 an hour, for a total cost of $1200 - $1800.

- **Professionally-supported online data collection:** I have made preliminary contact with Survey Sampling International (SSI) in Shelton, CT to discuss their potential participation in this project. SSI specializes in conducting surveys of this type. They contact and recruit their own participants, provide incentives for participation, and balance the sample (geographically, demographically, etc.) to my specifications. Costs vary based on the extent of the survey and the degree of balancing required, but generally range about $7 - $8 per participant. This is slightly more expensive than the other options, but I see it as a bargain.

Given those options, I propose using $1,000 for local data collection (roughly 200 data points, including the pilot study) and $4,000 for professionally-supported data collection using SSI. It is slightly more expensive to work with SSI, but they essentially guarantee success in collecting the data and are able to complete the entire process in a much shorter time period than either of the other two methods. Therefore, I feel the extra cost is more than warranted. Available money might be shifted between these two approaches as the experiment unfolds and more information becomes available.

Note: I can also support any combination of the other two options if there are objections to spending the grant funds in this manner. I can still get the data using those methods, it will just take a little longer.
References


January 19, 2016

Dear GRACA Reviewers,

I fully endorse the GRACA research project Alvin Tarrell submitted entitled "Toward Better-Improved Healthcare Patients". Alvin is in his final phase of completing his dissertation research and his data collection relies heavily on patients in our community, state and country. The financial support he is seeking to enlist the assistance of a professionally supported online data collection organization as well as participant incentives will help him reach the depth and breadth he needs to validate and generalize his findings. His research is poised to make a significant impact on increasing the quality of healthcare for patients and to help them better understand their current health status and interpret their results.

Although, Alvin works full-time and is a part-time student, he has shown tireless dedication and support to a related project where Dr. John Windle (PI), UNMC Chief Cardiologist and I (co-PI) are involved from the National Institutes of Health, Agency for Healthcare Research and Quality (id: 1R01HS022110-01A1) grant called, “Optimizing the Electronic Health Record for Cardiac Care”. For the past year he has attended our weekly research discussion meetings as well the patient focus groups. The NIH project has afforded AI to survey dozens of patients to help build an understanding of the current graphicity and numeracy aptitude levels of patients with acute illnesses and who may or may not have experience using electronic patient health records applications. This data has helped Alvin develop his research questions and design his dissertation research study.

I sincerely hope the committee will fund this worthwhile project. I will be available as needed during the summer to support and guide Alvin. We will communicate on a weekly basis and discuss his progress and findings. The end goal of his study will be to complete his dissertation and submit at least one manuscript to a prominent Health Informatics journal.

If you need additional information or have any questions, please contact me at afruhling@unomaha.edu or 402-554-4968.

Respectfully submitted,

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