

Informing, Reassuring, or Alarming? Balancing Patient Needs in the Development of a Postsurgical Symptom Reporting System in Cancer

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ABSTRACT: *After ambulatory surgeries, patients who recover at home have multiple questions about wound healing, symptoms and medication side effects, and recovery expectations. We conducted user testing and rapid application development of a newly developed symptom reporting system that supports home-based recovery by inviting patients to self-report symptoms in the days after surgery and then receive an immediate feedback report giving context for their reported symptoms. Findings showed that some participants primarily valued reassurance, whereas others prioritized receiving alerts about potential problems. Results also showed that most patients wanted feedback framed as comparing their progress to their expected progress, not to that of other patients. The final feedback report provided patients with actionable recommendations, small graphs showing their progress, and with short “gist” text interpretations. The system has been implemented, and recruitment is ongoing for a large clinical trial of its effectiveness for reducing adverse events and unnecessary emergency or urgent care visits.*

INTRODUCTION

Increasing numbers of surgeries, including cancer surgeries, are conducted as ambulatory procedures, with patients discharged the same day to recover at home.^{1,2} Such “short-stay” surgeries are less expensive than hospital procedures and may be welcomed by patients who prefer to avoid hospital stays. However, they also increase the self-care burden on patients and their families, who must manage postsurgical wound care, medications, rehabilitation exercises, and symptoms such as pain, swelling, sleep disturbance, or medication-related constipation.³ A particular challenge is for patients and caregivers to identify and respond promptly to relatively rare but extremely serious adverse events such as infection, while not overreacting to normal symptoms.

To help patients manage the postsurgical experience, clinical teams generally check in with patients by telephone in the days after surgery. It is possible, however, that patient-driven symptom reporting might be more effective in identifying adverse events and prompting appropriate and timely responses. In cancer, involving patients in reporting patient-reported outcomes (PROs) has been associated with better symptom control, improved quality of life and satisfaction, more appropriate use of supportive care, and even longer survival during metastatic cancer.^{4,5} Patient self-report has also been identified as an important opportunity to improve patient safety.⁶

At the Josie Robertson Surgery Center, an ambulatory surgery center at the Memorial Sloan Kettering Cancer Center (MSKCC), patient-reported symptom questionnaires are delivered through the patient portal for 10 days after ambulatory surgery as part of routine care. Symptoms that exceed a pre-specified threshold generate secure alerts to nurses, who call the patient. Early experience with this program suggested that most patients expect symptoms and are willing to tolerate them, but they become concerned when they don’t know whether their symptoms indicate a problem. To explore these issues, a team from MSKCC is implementing the “Ambulatory Cancer Care Electronic Symptom Self-Reporting (ACCESS) for Surgical Patients” (PCORI IHS-1602-34355) study, a randomized trial comparing the usual care to enhanced feedback, in which patients also receive an additional report giving more context for their symptoms, including whether they are within expected ranges or are cause for concern.

The current paper focuses on the human factors aspects of developing the ACCESS enhanced feedback report. Patients and families will adopt any newly developed system only if it is usable, and they will get value from it only

if results are presented in an intuitive and actionable fashion. Overall, consumer health information technology systems will be welcomed by patients and produce their intended benefits only if they are well adapted to the tasks that patients need to do as part of their self-management (or “illness work”).⁷⁻⁹ Our objective in the current project was to optimize the symptom feedback report, and especially the presentation of personalized results, through an iterative process of design with potential users, caregivers, and healthcare providers.

METHODS

System description: The ACCESS system is designed to deliver an online questionnaire to each patient each day for a minimum of 10 days after discharge; patients may choose to continue to report symptoms for up to 30 days if they would like the additional support. The questionnaire includes 20 items adapted from a validated self-report instrument, the Patient-Reported Outcomes Common Terminology for Adverse Events (PRO-CTCAE),¹⁰ as well as 3 additional questions to capture important post-operative problems and 2 questions about seeking urgent care or a doctor. The items assess symptoms such as pain, nausea, shortness of breath, fatigue, constipation, fever, chills, redness, and other symptoms relevant to the specific surgical procedure. For each, patients rate either symptom severity (from absent to very severe) or its frequency, as appropriate. Certain patient-reported items (such as high fever or shortness of breath) trigger an immediate warning to the patient to contact the surgical care team or visit an emergency department, with a simultaneous alert to the nursing team, who will then reach out to the patient.

For the enhanced feedback report, all the patient-reported data are collected and analyzed to derive expected recovery trajectories for patients stratified by surgical procedure and postsurgical day. These cohort data are then used to inform the patient how the patient’s status compares to others with the same surgery on the same postsurgical day. For example, a patient might report moderate pain on the first day after surgery, and a dashboard graphic would illustrate this while also explaining that this amount of pain is typical on the day after surgery. The cohort data are also used to provide a projection several days into the future. For example, it could show that patient-reported pain disappears, on average, by the seventh day after surgery. The ACCESS enhanced feedback report is being studied in an ongoing randomized controlled trial scheduled to include 1700 patients.

The ACCESS system was designed for ambulatory cancer surgery for breast, head and neck, gynecologic, and urologic cancers. It is delivered through the electronic patient portal and is accessible in web browser and mobile device formats.

Methods overview: User-centered design is a broad label describing the integration of usability and user characteristics, goals, and workflows into design and development to maximize the utility and usefulness of the final product.^{11,12} We applied this perspective by conducting interviews, focus groups, and iterative prototyping a rapid application development process¹³⁻¹⁵ in the design of the ACCESS enhanced feedback report. Initial specifications were developed by the research team in collaboration with MSKCC surgeons and nurses and the project’s Advisory Board, which includes stakeholders such as clinicians, researchers, hospital leadership, former patients and caregivers, and advocates from cancer support groups. The specifications were developed into initial wireframe mockups by MSKCC informatics staff. Then, in an iterative rapid application development process, patient participants and advisory groups were invited to discuss cancer patient needs for postsurgical information and support, to review the system mockups, to provide feedback about potential utility and usability, and to brainstorm novel ways of presenting information to make it more useful and patient-centered.

Patient interviews: Patients were recruited from practices of surgeons practicing in the outpatient surgery center. We conducted 30- to 60-minute interviews with patients; interviews were conducted either in focus group format or as individual interviews, depending on the participants’ preferences and schedule. The inclusion criteria were: recent experience with any ambulatory cancer surgery, either as a patient or as a close caregiver for a patient, and fluency in English. A semi-structured discussion guide was developed to invite participants to discuss their own experiences of cancer surgery and home-based recovery, to examine paper or electronic mockups of the ACCESS questionnaire and enhanced feedback report to consider whether or not it might be useful for themselves or others in similar position, and to provide feedback including novel ideas for visualizations or alternate ways of delivering information.

Advisory board: Interspersed with the patient interviews, the Advisory Board, whose membership includes patients, caregivers, and representatives of community patient advocacy organizations, met multiple times to review versions of the ACCESS questionnaire and dashboard. The entire Advisory Board met monthly during the early phases of the project and contributed to several iterations.

Core development team: The core development team, consisting of the coinvestigators as well as developers, informaticists, and participating clinical researchers, also met weekly throughout the 2-month rapid application development process for in-depth discussions and revisions to the ACCESS system. At each development meeting, nurse informaticists and nurses who worked directly with the patients were also invited to attend and provide feedback from their experience working with this population. About 10 accepted the invitation and participated in one or more meetings.

Data collection, rapid data analysis, and iterative versioning: Data collection and analysis was conducted in a highly abbreviated cycle in order to accomplish rapid application development within the 2-month development window.¹⁵ The prototype was initially developed by the core development team, which then met weekly for 6 weeks to incorporate the feedback described below. An early version focused narrowly on the statistical model was greatly modified after input from researchers applying lessons from the numeracy and health communication literatures and clinicians providing perspectives from working with patients. This finalized prototype was then presented to 2 patient focus groups (each n = 5) held on consecutive weeks. The Advisory Board discussed additional revised versions at 2 consecutive meetings. Finally, 3 individual patient interviews were conducted. Focus groups were recorded, and a research team consisting of clinicians, research assistants, and a developer observed live by video link. For the individual interviews, discussions were audiorecorded and field notes were taken. For the advisory board meetings, data collection was done through field notes, and participants were also invited to make sketches and mark up printouts. After each data collection session, the second author prepared a summary, including verbatim transcription of some comments as well as emerging suggestions for themes, for weekly presentations to the core development team, which discussed common themes and selected actionable recommendations for immediate implementation in time for presentation to the next individual or group. Although we did not conduct a formal qualitative data analysis for thematic saturation, we did note that patient feedback converged, and we stopped recruiting patients after the final 3 consecutive patient interviews did not raise any new issues. The final summary of themes was prepared by the first author after review of field notes and memos taken during all data collection as well as the weekly summaries and meeting notes.

IRB review: The MSKCC Institutional Review Board declared this project exempt (waiver X17-009). No individually identifiable information was collected from participants.

RESULTS

A total of 13 patients were interviewed. They had experience with surgery for breast, uterine, prostate, bladder, and lung cancers, ranged in age from 35 to 70 years old, 9 were women. Nine were white, 2 were black, 1 was Asian, and 1 was unknown race. In addition, the 25 Advisory Board members participated in the iterative feedback (including an additional 5 patient partners, 3 men and 2 women, all white), as did the core development team, which included nurses, surgeons, informaticists, and biostatistics staff members.

For the initial enhanced feedback report, graphics were developed on the basis of best practices and evidence about communicating risks and probabilities (such as the probability of experiencing pain or constipation at three days postsurgery).¹⁶⁻²⁰ For pain and fatigue, line graphs were developed to illustrate the probability over time (for example, the fact that the number of patients reporting pain declined every day over 10 days).²⁰ Every numerical concept was accompanied by an actionable interpretation or “gist”²¹ to make sure the take-home message was clear (e.g., “this is nothing to worry about,” or “it is important to seek medical help”).

Also, several pictograms (stylized human figures) were tested to illustrate concepts such as pain, in light of evidence that pictograms can be helpful to reinforce or illustrate concepts and actions, especially with lower literacy audiences.²² However, most of the graphics were removed during the iterative design process and replaced with simpler line graphs to show the patient’s estimated future progress (for example, how quickly the symptom was

expected to disappear; Figs. 1 and 2). Text was also shortened to focus on actionable explanations of the “gist”²¹ of the message and what to do next. In addition, some of the detailed information from earlier iterations was removed; for example, an early version that specified “3 out of 10 people reported pain” was replaced with a more general statement about whether this degree of pain was expected or unexpected. The alerts, which were triggered as soon as a patient reported serious or out of range symptoms, contain simple and direct language to seek medical assistance and were made actionable with the inclusion of the appropriate telephone number; an exclamation point icon was added for reinforcement (Fig. 3).

Three themes from the interviews helped guide the redesign process.

1. Give me information about me, not about my cohort

Patients appreciated personalized and actionable messages. The top requests were whether or not their recovery was normal, and whether they should call the clinical team for help. “It’s the idea of knowing what to expect,” one woman said.

There was a strong negative reaction to early mockups that compared the patient’s individual experience to that of patients similar to them (messages such as, “The amount of discomfort you are experiencing is similar to what other patients are reporting at this stage”). Some participants objected to this framing because they did not think they were genuinely similar to other patients who were described as being “patients like you.” For example, one woman said, “I feel that with my pre-existing conditions, I don’t feel like my recovery fits into this.” Others disliked it because they said it made them feel as if they were “competing” with or being judged against other patients. “If I am reading this and I am worse than everyone else, I am going to be really upset,” one woman said. At least one participant said information about other patients was not relevant: “I might be self-centered but I don’t care that [other] people are doing better or worse.” The negative reaction also extended to icon arrays designed to show the frequency of a particular condition (such as 3 colored stick figures out of a line-up of 10 stick figures); one participant explained that it reminded her unpleasantly of the graphics she had seen in a decision aid during her treatment decisions.

Patients preferred later mockups that were revised to compare the patient’s course to what was expected for that patient. However, both mockups relied on the same statistical analysis that estimated the patient’s “expected course” from data from other patients.

2. Reassure me, but scare me

Participants expressed strong and competing desires to be reassured and to be alarmed.

On one hand, many interviews suggested that an important purpose of this ACCESS enhanced feedback report would be to calm anxiety after surgery. “What I’m looking for after surgery is to be comforted and reassured,” one person said, using words that were repeated by many other patients during their interviews. These patients particularly valued receiving feedback that their symptoms were what would be expected at this stage of their recovery. These participants also recommended changes whenever the dashboard language or visualizations seemed too frightening (for example, in a version that used a large red exclamation point icon to draw attention to an alert). Many of these patients also sought confirmation that the current online system would be considered an adjunct to, not a replacement for, nurse telephone conversations and clinic visits, which they found to be important personal connections. To address the goal of reassurance, the initial name of “symptom tracker” shown in the ACCESS enhanced feedback report was replaced with the term “recovery tracker.”

On the other hand, other participants wanted to make the alerts even more alarming to ensure that patients took them seriously. Many patients had stories about being reluctant to ask for help. One woman had experienced a serious infection after her surgery but had not recognized the severity of her symptoms and did not go to the emergency room until her daughter insisted. Another experienced breakthrough pain when her medications ran out but did not feel that she could contact the clinical team after hours. Reasons for not contacting the clinical team included concerns that they might be “bothering” the clinical team with unimportant issues, and unwillingness to admit weakness. “The male species does not do things like this. We do not call [the doctor],” one man joked. Interestingly, several female patients said that it was women who were most likely to act tough and refuse to call the doctor. Most patients said they would value clear, personalized guidance about when to seek help. “I would not hesitate to call the

doctor,” one woman said. “I am not fooling around with infection or chills. The doctor and nurse practitioner won’t pooh-pooh me. They are not going to be upset I called. But I do live with a boyfriend who will not call the doctor. So I know other people are not like that!”

In light of this lack of convergence about reassurance versus alarm, the core development team made a final decision to prioritize reassurance. This was largely because the ACCESS system was designed to trigger an alert to the clinical care nurse, who was expected to contact the patient even if the patient was not alarmed enough by the message to act on it.



Fig. 1: Early mockup version showing a patient-reported symptom that is moderate but within the expected range. Overall, participants liked the reassurance of being told that there was nothing to worry about. However, most did not like the visual and text suggestions that they were similar to other patients, and thought the icons might be confusing or interpreted as condescending or judgmental.

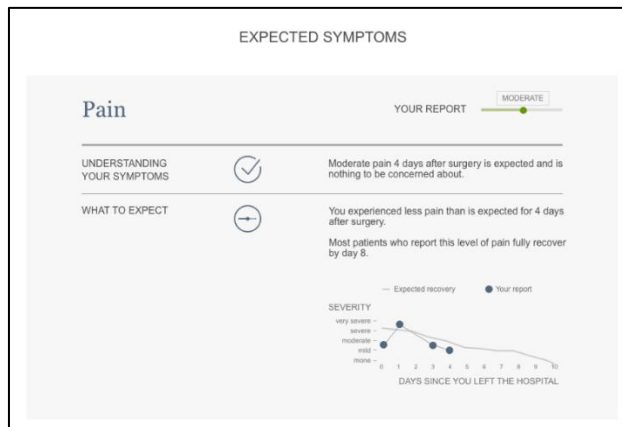


Fig. 2: Later version, with more personalized and actionable text. The patient’s status is compared to what is expected 2 days after surgery, not to what other patients have experienced. Icons have been removed.

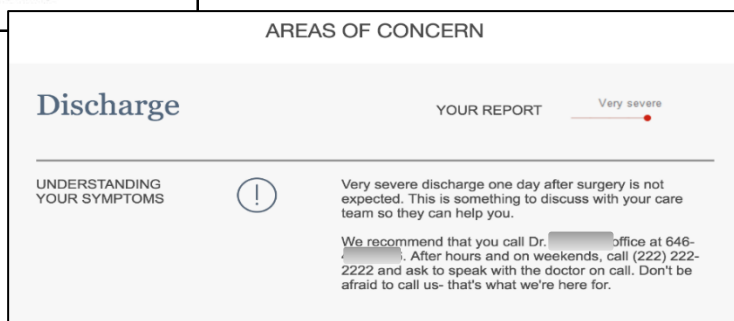
3. Don’t judge me

In their warm-up discussions about their own cancer experiences, patients expressed a strong need to understand whether their recovery was “normal,” because that helped them decide whether to call the care team or even go to the emergency room. However, when viewing the mock-ups, they disliked the use of the term “normal” because it seemed judgmental. Patients had a more positive reaction to terms such as “as expected,” “as planned,” or “on track” to express the same concept. Some participants also expressed concern that the pictograms (miniature stick figures) designed to convey concrete health-related concepts such as discomfort or constipation might be viewed as judgmental, patronizing, or less than respectful; these images were ultimately removed from the displays. Finally, as noted above, graphics that placed the patient’s own self-reported health status in the context of the recovery status of their cohort were disliked by a subset of participants who thought that they conveyed the concept of competitiveness or judgment, or even a “test.” This was a particularly strong concern when the graphic showed that the patient’s pain or functional status was worse than expected at this stage of recovery.



Fig. 3: An alert informing the patient that their symptoms require medical attention. The initial screen summarizes results and provides instructions and phone numbers; the second screen below provides additional detail.

In light of patients' desire for reassurance as well as clarity, the alert calls symptoms "out of the expected range" (left) and "not expected" (below) rather than a more alarming term such as urgent or serious. Also, to provide a positive incentive, patients were encouraged to contact the doctor's office "so they can help you" (below). In light of patient interviews suggesting that they did not want to "bother" their doctor, we added the final sentence, "Don't be afraid to call us – that's what we're here for."



DISCUSSION

The concept of adding normative feedback reports to an existing online self-report system in which patients report postsurgical symptoms was welcomed by samples of cancer survivors and caregivers, who considered it a potentially valuable support for their home-based recovery. An iterative rapid-cycle development process was completed in support of a clinical trial designed to assess the value of normative feedback. In this process, early mockups developed on the basis of clinician researcher specifications were reviewed, critiqued, and expanded upon by patients, a development team of informatics and researchers, and a stakeholder advisory board.

In the qualitative interviews and stakeholder meetings, many patients expressed needs for comfort and reassurance, while others had a strong interest in making sure the information was alarming enough and informative enough to prompt immediate attention when warranted. As a result, in the final versions, we used fonts, images, and language designed to convey a reassuring tone for all reports within normal or unproblematic ranges. The alerts for patients who needed medical attention used simple and direct language, included the appropriate telephone number to call, and were illustrated with an exclamation point icon for emphasis.

Initial prototypes, driven by clinician researcher and informatics specifications, were numbers-heavy. This was because one novel aspect of the project was to leverage the existing systematic collection of postsurgical symptoms to provide patients with normative recovery trajectories. The initial proposal was to show some of these data back to patients, explained as being based on "patients like you." However, we found that the patient users did not welcome the implication that they were being compared to other patients, or that their recovery trajectories were derived from the experiences of other patients. In addition, some of the more detailed numerical information did not seem particularly relevant to most of the patient users; instead of knowing that 2 people out of 10 experienced a problem, they wanted to know the actionable step of whether the problem should be considered expected/normal or not. The emphasis on actionable interpretations of the meaning of a number is consistent with other risk communication findings showing that people make decisions on the basis of the "gist," not the number itself.^{21,23} It is also consistent with findings that simplifying graphs to focus on a single message (i.e., by omitting redundant survival and mortality information) are likely to be more useful than more complex ones for patient problem-solving and decision-making.^{17,24} However, we opted not to remove all numbers in light of other research suggesting that at least a subset of highly educated and numerate patients were likely to be information seekers who would welcome numbers.²⁵

Research, development, and implementation of PRO systems is evolving rapidly in light of growing evidence of their value. A large randomized trial showed that symptom monitoring via an online PRO questionnaire was associated not only with better quality of life in metastatic cancer but also with longer overall survival (median 31.2 compared to 26.0 months, $p = .03$).⁵ However, web-based systems may not be feasible for patients who lack access to computers or the Internet in their daily lives.²⁶ In a multi-national study of advanced prostate cancer, this limitation was addressed by putting tablets in the clinic to let patients report PROs while onsite.²⁷ Alternately, health systems may need to develop systematic procedures to collect PROs through paper and telephone as well as electronically.²⁸ The ACCESS system is currently available through the online patient portal in web browser and mobile device formats. In light of evidence that patients without computer access or technology literacy are likely to be the ones most in need of support,²⁶ it could be valuable to explore additionally administering ACCESS questionnaires via paper, telephone interview, or automated interactive voice response systems.

A modest drawback to the standardized survey measures (patient-reported outcome measures or PROMs) used in the ACCESS system is that, while they are simple to collect and analyze, they provide only discrete and categorical Likert-scale responses, which have limited nuance and detail. Recently, several groups have begun working toward ways for patients to share photographs of postsurgical wound healing and other types of information.^{29,30} Including such additional types of patient-generated health data (PGHD) could also be a useful future expansion of the ACCESS system.

Limitations: A relatively small group of patient participants contributed to the project; larger samples may have identified more diversity in patient perspectives. Only limited sociodemographic information was collected, so we do not have systematic information about participant education level or technology skills. Because of the emphasis on rapid application development, qualitative data were summarized and presented to the development group by a single researcher rather than being systematically reviewed and coded using team-based qualitative data analysis methods. The ACCESS symptom self-reporting system is available online only, which is likely to restrict its use among patients with less computer proficiency or lacking computer access because of low socioeconomic status or advanced age. The portal adoption rate among MSKCC's ambulatory surgery patients is about 85%, which is considerably higher than averages reported elsewhere.³¹⁻³³ This may limit the generalizability of the current study to other patient populations with lower rates of portal adoption.

Conclusion: After ambulatory surgeries, patients who recover at home must self-manage wound healing and other aspects of recovery. We conducted user testing and rapid application development of a newly developed online system that supports home-based recovery by inviting patients to report their postsurgical symptoms and status, and to receive immediate feedback over a minimum of 10 days after surgery. Our qualitative work revealed needs for reassurance/comfort as well as needs for appropriate alerts to encourage patients experiencing adverse events seek medical help. It also showed that patients wanted their feedback to appear personal rather than cohort-based. This human factors project helped inform the development and implementation of the ACCESS enhanced feedback report, currently being studied in a randomized controlled trial of 1700 patients.

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REFERENCES

1. Hollenbeck BK, Dunn RL, Suskind AM, Zhang Y, Hollingsworth JM, Birkmeyer JD. Ambulatory surgery centers and outpatient procedure use among Medicare beneficiaries. *Medical care*. 2014;52(10):926-931.
2. Hollenbeck BK, Dunn RL, Suskind AM, Strobe SA, Zhang Y, Hollingsworth JM. Ambulatory Surgery Centers and Their Intended Effects on Outpatient Surgery. *Health Serv Res*. 2015;50(5):1491-1507.
3. de Kok M, van der Weijden T, Kessels AG, et al. Patients' opinions on quality of care before and after implementation of a short stay programme following breast cancer surgery. *Breast*. 2010;19(5):404-409.
4. Kotronoulas G, Kearney N, Maguire R, et al. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J Clin Oncol*. 2014;32(14):1480-1501.
5. Basch E, Deal AM, Dueck AC, et al. Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. *JAMA*. 2017;318(2):197-198.
6. Vincent CA, Coulter A. Patient safety: what about the patient? *Qual Saf Health Care*. 2002;11(1):76-80.
7. Ali S, Hafeez B, Ancker JS. Applying a task-technology fit framework to adapt an electronic patient portal for patient work. *Applied Clinical Informatics*. in press.
8. Corbin J, Strauss A. Managing chronic illness at home: Three lines of work. *Qualitative Sociology*. 1985;8(3):224-247.
9. Ancker JS, Kern LM, Abramson E, Kaushal R. The triangle model for evaluating the effect of health information technology on healthcare quality and safety. *JAMIA*. 2011;18:749-753.
10. Basch E, Reeve BB, Mitchell SA, et al. Development of the National Cancer Institute's patient-reported outcomes version of the common terminology criteria for adverse events (PRO-CTCAE). *J Natl Cancer Inst*. 2014;106(9).
11. Norman DA. *The Psychology of Everyday Things*. 1984.
12. Norman DA, Draper SW. *User-Centered System Design: New Perspectives on Human-Computer Interaction*. Hillsdale, NJ: Lawrence Erlbaum Associates; 1986.
13. Rosson MB, Carroll JM. *Usability engineering: scenario-based development of human-computer interaction*. San Francisco: Morgan Kaufmann; 2002.
14. Sanders EB-N, Brandt E, Binder T. A framework for organizing the tools and techniques of participatory design. Proceedings of the 11th Biennial Participatory Design Conference; 2010; Sydney, Australia.
15. Gerber AM, Alta van der, Alberts R. Practical implications of rapid development methodologies. *Proceedings of the 2007 Computer Science and IT Education Conference*. 2007.
16. Ancker JS, Senathirajah Y, Kukafka R, Starren JB. Design features of graphs in health risk communication: A systematic review. *Journal of the American Medical Informatics Association*. 2006;13(6):608-618.
17. Zikmund-Fisher B, Fagerlin A, Ubel P. A demonstration of "less can be more" in risk graphics. *Med Decis Making*. 2010;30.
18. Zikmund-Fisher B, Ubel P, Smith D, et al. Communicating side effect risks in a tamoxifen prophylaxis decision aid: The debiasing influence of pictographs. *Patient Educ Couns*. 2008;73.
19. Galesic M, Garcia-Retamero R, Gigerenzer G. Using icon arrays to communicate medical risks: Overcoming low numeracy. *Health Psychology*. 2009;28(2):210-216.
20. Trevena LJ, Zikmund-Fisher BJ, Edwards A, et al. Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers. *BMC Medical Informatics and Decision Making*. 2013;13(2):1-15.
21. Reyna VF. A theory of medical decision-making and health: Fuzzy trace theory. *Medical Decision Making*. 2008;28:850-865.
22. Yin HS, Dreyer BP, van Schaick L, Foltin GL, Dinglas C, Mendelsohn AL. Randomized controlled trial of a pictogram-based intervention to reduce liquid medication dosing errors and improve adherence among caregivers of young children. *Arch Pediatr Adolesc Med*. 2008;162(9):814-822.
23. Reyna V. A theory of medical decision making and health: Fuzzy-trace theory. *Med Decis Making*. 2008;28.
24. Zikmund-Fisher B, Fagerlin A, Ubel P. Improving understanding of adjuvant therapy options by using simpler risk graphics. *Cancer*. 2008;113.
25. Gurmankin AD, Baron J, Armstrong K. The effect of numerical statements of risk on trust and comfort with hypothetical physician risk communication. *Medical Decision Making*. 2004;24(3):265-271.
26. Veinot TC, Mitchell H, Ancker JS. Good intentions are not enough: how informatics interventions can worsen inequality. *Journal of the American Medical Informatics Association*. 2018.
27. Chi KN, Protheroe A, Rodríguez-Antolín A, et al. Patient-reported outcomes following abiraterone acetate plus prednisone added to androgen deprivation therapy in patients with newly diagnosed metastatic castration-naïve prostate cancer (LATITUDE): an international, randomised phase 3 trial. *The Lancet Oncology*. 2018;19(2):194-206.
28. Chenok K, Teleki S, SooHoo NF, Huddleston J, Bozic KJ. Collecting Patient-Reported Outcomes: Lessons from the California Joint Replacement Registry. *eGEMS*. 2015;3(1):1196.
29. Gunter R, Fernandes-Taylor S, Mahnke A, et al. Evaluating Patient Usability of an Image-Based Mobile Health Platform for Postoperative Wound Monitoring. *JMIR mHealth and uHealth*. 2016;4(3):e113.
30. Sanger PC, Hartzler A, Lordon RJ, et al. A patient-centered system in a provider-centered world: challenges of incorporating post-discharge wound data into practice. *J Am Med Inform Assoc*. 2016;23(3):514-525.

31. Fraccaro P, Vigo M, Balatsoukas P, Buchan I, Peek N, van der Veer S. Patient portal adoption rates: A systematic literature review and meta-analysis. *Studies in Health Technology and Informatics*. 2017;245:79-83.
32. Ancker JS, Nosal S, Hauser D, Way C, Calman N. Access policy and digital divide in patient access to medical records. *Health Policy and Technology*. 2017.
33. Ancker JS, Barron Y, Rockoff M, et al. Use of an electronic patient portal among disadvantaged populations. *Journal of General Internal Medicine*. 2011;26(10):1117-1123.