Sometimes the most important things you hear in a usability session sneak up on you. It starts with a single comment, and then grows into one of those big “ah-ha” moments that come along every once in a while when you are doing user research.
This project was user-centered research into how cancer patients and their families looked for information about cancer and its treatments, as well as how to search for clinical trials. It was part of ongoing work to improve the U.S. National Cancer Institute (NCI) website (http://www.cancer.gov/).

One of NCI’s goals is to increase participation in clinical trials, as part of a broad mission to improve understanding, treatment, and prevention of cancer. Clinical trials provide patients access to up-to-date and new treatment options and contribute substantially to the knowledge of, and progress against, cancer. Both patients and researchers benefit from clinical trials: patients, from early access to additional treatment options; medical researchers, from a larger pool of patients and the data each contributes. A central feature of the site is the clinical trials search feature, which lets the general public and healthcare professionals search a large database of over 5,000 active trials.

We prepared for exploratory usability sessions with a literature review and comparative audit of more than a dozen cancer-related websites. The literature review included journal articles on patient attitudes towards clinical trials and interviews with cancer information specialists, oncology nurses, and research managers about how they talk to patients about the possibility of participating in a clinical trial. The audit reviewed websites that provide information about clinical trials, many using the same national database of clinical trials as the NCI website.

From these two efforts, we identified three issues that might show up when we watched patients, friends, and family members use the Web to search for clinical trials that would be a good fit for them:

• General barriers to participation. There is a rich literature on the reasons why people are unwilling to join a clinical trial, including the fear of being an experimental “guinea pig.”

• The challenges of medical terminology. Clinical trials are tests of treatments that often have those long, polysyllabic tongue twister names. They involve difficult concepts like randomization, and come in phases. (Or is that “stages”? Even the term “clinical trial” is part of a specialized medical vocabulary.

• Access and eligibility. Clinical trials are carefully controlled experiments, so participation is limited to people who meet strict eligibility criteria. Also, they are conducted at specific geographic locations which might not be convenient for the patient.

All of these issues (and more) showed up in our usability sessions. But so did a single, overwhelming user need that we had not anticipated—our “ah ha” moment. Cancer patients are not looking online for information out of general interest. They have a deep, personal, urgent need for the information. They are, not to mince words, worried that they might die. They want information that will help them, that is about them, that speaks directly to their condition and their lives.

We talked to one patient about her experiences investigating clinical trials, as part of her search for treatment when her adrenal cancer recurred and spread to her lungs. She was well-educated, actively involved in her treatment, and had learned a lot about her type of cancer. This is how she described one experience:

“I had actually contacted one person. It was very interesting speaking to him on the phone because even as he was talking to me, the patient, he was saying, ‘Well, you know, statistics we’ve had,‘[he was really excited] ‘One person it worked completely but she still died. But then we had one other person who had partial remission and then some surgery and she’s been living for four years and that is great for adrenal cancer.” He’s talking about this all excited as a researcher and I’m going, ’I’m sorry, I’m about to start breathing into a paper bag. I realize this is exciting research for you but I’m the patient on the phone.’ It was good I was able to contact him, but he wasn’t exactly warm and fuzzy.”
It sounded obvious at first. After all, guidelines for writing for the Web tell us that good writing speaks directly to readers, using plain language and concepts and terminology that are meaningful to them. Good health communication works hard at this, trying to present information that is accurate, authoritative, and usable. But, when you look at clinical trials information (and perhaps most medical websites) from this new perspective, it’s easy to find the mismatch: they talk about the statistics, the research, and the details of the disease. What this patient wanted was information that would help her make a decision about her medical condition.

How to Describe a Clinical Trial

One of the biggest differences between the sites we reviewed was how they presented the description of the clinical trial. Two sites, EmergingMed.com (http://www.emergingmed.com) and CancerHelp UK (http://www.cancerhelp.org.uk) use short, easy to read text. CancerHelp UK is careful to define not only medical terms, but to explain the goals and other facts about the clinical trial in simple, clear text. We expected participants to prefer this format. They didn’t.

In the usability sessions, we asked participants to use the clinical trials search feature on several different sites. Then, at the end of the session, we showed them three different paper prototypes of a clinical trial description. They were a blend of good features we identified in the comparative review:

- A short narrative style written in clear, basic English with terms (such as “randomized”) defined in the text
- A version that used terse, professional language, and presented the information in a structured list.
- A simplified medical style for the main text with a quick reference section at the top and structured headings.

We used a real clinical trial description, selecting the order and format for the information. Because many web sites have access to the same database, we were able to find different writing styles to use. Surprisingly, few people preferred the first version. They felt that they had to “work too hard” to find key information in the text, and had trouble telling whether they might be eligible to join the trial. Participants strongly preferred the two versions structured with bullet points—even the one with more professional medical terminology. They said that this format seemed shorter and more succinct. We were also surprised that even people who struggled with the terminology sometimes preferred the professional version. Possibly, having fewer words to read—even if those words are more difficult—is part of the advantage.

One reason they liked the more professional version is that it listed the eligibility criteria up front. For many of the participants, the most important thing is to be able to quickly determine the goals of the trial and whether it might be a treatment option for them. As one participant put it, “Well, this [first prototype] is a nice clear explanation. But, I do love having the eligibility criteria.”
How to Read a Clinical Trial Search Results List

This focus on their own medical details and situation worked well for patients reading the clinical trial descriptions, but it worked against them when scanning a list of clinical trial results. No matter how good or poor their grasp of medical terminology, participants tended to know the medications and treatments they had experienced. Some had cheat sheets. Some could not pronounce the words, but they all recognized their own medications.

These words become anchors for patients. As they read, they scan the pages for those words. This strategy works well in most situations, such as looking up information about a newly prescribed medication. In searching for clinical trials, however, it works against them because prior use of a medication or treatment often disqualifies them from the trial. This is more than a problem with the user-interface design—it's a mismatch of mental models. In real sites and in our mockups of search results, the more clearly the treatment being tested is identified, the more likely participants were to pick trials for which they were not eligible.

One solution, used by several sites, is to change the entire concept from searching a database to finding a match. These sites ask patients to fill out detailed medical questionnaires, and use this information to identify clinical trials for which they might be a match. Patients accepted this, and were willing to complete long forms, as long as they didn’t have to reveal personal information that did not seem relevant. Unfortunately this solution relies on good algorithms (or human intervention) for useful results. In the case of rarer cancers, they can often return either no options or options with no obvious connection to the patient’s medical situation. They also fail to meet the goal of many long-term cancer patients and survivors—to see the breadth of research being done on their cancer.

From this project, we learned that patients have real, personal concerns about their health, and that medical information only becomes compelling to them when it directly answers their questions and enables them to make decisions. It is not enough to simply present the right information to patients; medical information must also have the right tone, recognizing the gravity of the patient’s situation, and must present the information in the right format, so patients may quickly find it and act upon it.

ACKNOWLEDGMENTS: This project was conducted at the National Cancer Institute’s Operations Research Office by Holly Massett, Ph.D. (director), Nancy Atkinson, Ph.D., Christy Mylks, Whitney Quesenbery, Colleen Ryan, M.A., and Sandra Saperstein, M.A.

DEDICATION: Laura Snyder, my friend and colleague, contributed to this project. Although her participation was intended only as a pilot session, her insights proved to be key to the project. Laura was diagnosed in 2002 and died in July 2007. She never gave up the fight. To the end, she maintained that “life is good.”

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