

Health Literacy and Usability of Clinical Trial Search Engines

Timothy Bickmore, Michael Paasche-Orlow, Maryam Aziz, Barbara Barry

Background/Research Question

Several web-based search engines have been developed to increase participation in clinical trials by allowing individuals to more easily find trials for which they may be interested in volunteering. However, these search engines may be difficult for individuals with low health and computer literacy to navigate. We conducted a usability study of the National Cancer Institute (NCI) clinical trial search engine with individuals who had varying health literacy levels.

Methods

Health literacy was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM). The sample was split into adequate and low health literacy groups, using a REALM score of 9th grade and above. Search engine skill was assessed using a single self-report scale measure (1="I've never used one." to 4="I'm an expert."). Satisfaction and ease of use were assessed using single item 7-point measures.

Participants were given three standardized tasks of increasing complexity to perform using the NCI search engine. For each task, participants were asked to find at least one trial that satisfied stated criteria (e.g., "Amy is a 66 year old appendix carcinoma cancer patient. She would like to participate in a clinical trial that is related to her condition. Location of the trial does not matter.").

To evaluate preferences and decision making processes, participants were shown three pairs of trial descriptions from the NCI site. For each pair the participant was asked to choose which of the two trials they would prefer, along with a justification, which was audio-taped and qualitatively evaluated.

Results

The study is ongoing. To date, twenty-three participants, aged 23-76 (mean 50.3), 65% female, have been recruited from an online recruiting site (n=14, all adequate health literacy) and an urban apartment complex inhabited primarily by older minority adults (n=9, 67% low health literacy). Participants with low health literacy scored significantly lower on self-reported search engine skill (Mann-Whitney $p < .05$).

Those with adequate health literacy completed 1.25 search tasks on average, while those with low health literacy failed to complete any of the tasks (Mann-Whitney $p < .05$). Participants with adequate health literacy scored the search engine significantly higher on satisfaction (4.3 vs. 1.4, Mann-Whitney $p < .05$) and ease of use (4.5 vs. 1.6, Mann-Whitney $p < .05$) compared to those with low health literacy.

When asked to read pairs of study descriptions and describe which trials they would prefer, participants with low health literacy focused primarily on discomfort and beneficence criteria gleaned from a single phrase they recognized, while disregarding most of the descriptions. Participants with low health literacy also demonstrated many misunderstandings of the study descriptions and misconceptions about clinical trials.

Conclusions/Implications

Current clinical trial search engines are not usable by individuals with low health literacy.