

# Educating patients improves knowledge and attitudes about participating in research

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A five-center national study led by Neal Meropol, MD, and a team of researchers from Case Western Reserve University School of Medicine and University Hospitals Case Medical Center demonstrated that a little information goes a long way in encouraging cancer patients to enroll in clinical trials, a decision that could be potentially lifesaving.

The findings, which appeared in the December 21st, 2015 issue of *Journal of Clinical Oncology* (JCO), showed that among 1,255 [cancer patients](#) taking part in an educational program, 21 percent of patients chose to enroll in cancer [clinical trials](#). Traditionally, less than 5 percent of cancer patients choose to participate in clinical trials, according to the American Cancer Society.

"Unfortunately, although clinical trials are critical for advancing [cancer treatment](#) and ultimately serve as the basis for new standards of care, very few patients participate," said lead author Neal J. Meropol, MD, Professor of Medicine at Case Western Reserve University School of Medicine, and Chief, Hematology and Oncology, University Hospitals Case Medical Center Seidman Cancer Center. "We want to close the patient knowledge gap and positively affect their attitudes toward clinical trials."

In this study, a tailored video education program, PRE-ACT (Preparatory Education about Clinical Trials), was compared to information delivered as simple written text. PRE-ACT videos were more effective than text at improving knowledge, and decreasing

negative attitudes that serve as impediments for patients to take part in clinical trials.

Half of the patients received PRE-ACT, which delivered tailored video education based on their individual knowledge gaps and attitudes, while the other half received written information about clinical trials that was not specifically chosen based on their responses to an initial survey.

"Although both the PRE-ACT videos and the written materials improved participants' knowledge, reduced attitude-related barriers, and improved their preparation to consider clinical trials as a treatment option, we found that PRE-ACT was better than the written information in reducing barriers," said Dr. Meropol.

Participants rated the Web-based video educational program significantly higher than the text-based education material in satisfaction with the amount of information presented, the way the information was presented, and the feeling of being more prepared for them to consider clinical trials for cancer treatment.

PRE-ACT, developed by Dr. Meropol and collaborators, is a tailored intervention where patients access a Website to take an online survey. The survey gauges the individual patient's knowledge and attitudes about clinical trials, and then, based on that patient's answers, video clips are presented addressing their specific concerns.

For example, patients sometimes worry that they will receive a placebo rather than active treatment, so one video clip explains how placebos are used ethically in cancer studies, and the fact that very few studies will include a placebo without any active treatment. The videos also help patients clarify their preferences in terms of quality of life or length of life.

"By identifying knowledge gaps and negative attitudes and addressing those before patients meet their doctors to discuss cancer treatment, the patient will be better prepared to make a good decision about whether a clinical trial will be an appropriate option for them," said Dr. Meropol, also Associate Director for Clinical Research, Case Comprehensive Cancer Center. "We hope PRACT will result in increased participation in clinical trials by cancer patients through improving knowledge and attitudes and facilitating treatment decision-making."

For the study, researchers sought a robust sample of patients representing a variety of race, ethnicity and socioeconomic backgrounds. Therefore, they enrolled patients from five centers: University Hospitals Seidman Cancer Center, Cleveland Clinic Taussig Cancer Institute, Barbara Ann Karmanos Cancer Institute in Detroit, Robert H. Lurie Comprehensive Cancer Center of Northwestern University in Chicago, and Fox-Chase Cancer Center in Philadelphia.

Dr. Meropol has partnered with the American Society of Clinical Oncology to make PRACT widely available to [cancer patients](#) worldwide at <http://www.cancer.net/PRACT>. The development of this Web-based program was supported by the National Cancer Institute (NCI), according to Dr. Meropol.

During the course of their research, investigators did uncover another surprise finding. Video clips meant to address concerns about the costs of clinical trials treatment actually caused a spike in worries about out-of-pocket costs of clinical trials. These financial concerns generated yet another paper that appeared in the same JCO edition as the main paper.

"What was a surprise is that giving people information about costs in general terms made them more anxious," said Dr. Meropol, the senior author of the financial concerns paper. "It was not surprising to us that these concerns actually affect distress, add to decisional conflict, and

interfere with decision-making. This finding highlighted for us that communication about costs is both necessary and challenging. It indicates that we need to be sensitive to patients' cost concerns as they navigate decisions about cancer care."

Next steps in research include developing new tools to assist patients with financial navigation. Additionally, the NCI is funding a project led by Dr. Meropol and Barbara Daly, Ph.D., Professor of Nursing, to develop a Web-based educational program for oncology nurses to help them in their discussions with patients about participation in clinical trials.

Provided by Case Western Reserve University

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