

CANCER CLINICAL TRIALS EDUCATION: INSIGHTS FROM PATIENT EXPERIENCES AND PREFERENCES

Background

Clinical trials offer cancer patients access to innovative treatments, quality care, and hope for a better future. Yet, participation rates across adult cancers remain low. Education is a target intervention. The following research examines patient experiences, beliefs, and preferences related to cancer clinical trial participation.

Methods

In 2015-16, the Cancer Support Community conducted an online survey with the goal of developing an educational program that would increase clinical trial awareness and participation. Survey responses from 506 cancer patients were collected. Most respondents were female (85.5%) and Caucasian (84.8%). The average age was 58.7 years old. Nearly half (47.2%) were diagnosed with breast cancer. Of the respondents, 48.3% were currently receiving treatment.

Results

Most (81.4%) had heard of clinical trials prior to diagnosis. While 36.3% had participated in trials, 52.5% never considered it. Results found that 56.7% had discussed clinical trials with their healthcare team during treatment, but only 20.2% felt that their goals and concerns were meaningfully addressed. Additionally, 93.1% reported that more time with their doctors to discuss clinical trials would be “somewhat” or “very” helpful. Websites with clinical trial information were shared with just 34.4% of respondents. Survey results indicated that 91.9% felt that a website including clinical trial information would be “somewhat” or “very” helpful. Specifically, 60.2% of respondents reported that a website with patient narratives would be “very” helpful. While, 60.9% felt that tools to help locate clinical trials would be “very” helpful. Most had not been offered or couldn’t independently locate videos (80.7%) or illustrations/images (73.8%) explaining clinical trials. Of the respondents, 94.0% reported that speaking directly with a clinical trial participant would be helpful. Yet, this was only offered to 10.3% of patients.

Conclusions

Findings were used to develop content for educational products and programs delivered by CSC for those potentially eligible for clinical trials. Survey data highlight the importance of providing information relevant to eligible participants across multiple formats.