Category: Trial Recruitment & Community Outreach and Engagement – Completed Project

Exploring the Perceptions and Satisfaction of Princess Margaret Clinical Trial Participants

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1. Background

While assessment of patient satisfaction with clinical care has become standardized at most large health care institutions, there is limited comparable systemic evaluation of patients' experiences in a clinical research context. The incorporation of participant feedback and perspectives into clinical research programs has been shown to improve quality, outcomes, and patient protection. Aligning research goals with patient needs can help increase recruitment and retention, decrease implementation issues, and create programs that are more responsive to patient needs.

2. Goals

An exploratory project was initiated to evaluate the feasibility of obtaining feedback from clinical trial participants at Princess Margaret Cancer Centre about their satisfaction with, and perceptions of, their clinical trial experience. The objectives of this initiative were to elucidate the relative importance of various factors affecting clinical trial accrual, retention, and withdrawal among clinical trial participants, and to provide information on the experiences of participants about their clinical trial involvement.

3. Solutions and Methods

A validated patient satisfaction survey was mailed to 308 surviving patients who enrolled in a clinical trial between November 1, 2019 and March 1, 2020. The survey was designed to evaluate research participants' experiences, and to assess a range of topics, including motivation to participate in, or withdraw from, research; the informed consent process; and interactions with the research team. A descriptive analysis of the aggregate results was performed. Frequencies were calculated for categorical variables, while mean and median values were determined for continuous variables.

4. Outcomes

Twenty-eight percent of participants completed the survey. Participants assigned high ratings to their overall research experience, with a median score of 9 out of 10. Ninety-four percent indicated they would "definitely" or "probably" recommend research to their friends and family. Ninety-three percent of participants indicated they did not experience any pressure to participate in a trial and 92 percent reported they were treated with courtesy and respect at all times. The most influential motivators for clinical trial participation were access to new treatment, research center reputation, and a desire to help others. In rating factors influencing participant retention, the highest ratings were assigned to accessing new treatment and quality of life improvement. The decision to withdraw from clinical trials was most heavily influenced by side effects and pain, followed by interactions with the study team, and not receiving test results. Obtaining a summary of research results was the most likely variable to influence future study participation.

5. Lessons Learned

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Evaluating the experiences and satisfaction of the Princess Margaret Cancer Centre clinical trial patient population is feasible. The exploratory findings show that the majority of participants were very satisfied with their experiences and highlighted actionable items to consider in order to improve participant recruitment, retention, and satisfaction. The perception of Princess Margaret's institutional reputation was a highly rated factor influencing the decision to participate in clinical trials. The feedback derived from participants provides an opportunity to assess existing local practices, identify gaps, and implement quality improvement modifications. The results of this pilot study will serve as a baseline and reference point for ongoing program evaluation.