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Review article

Prioritizing the patient voice in the development of urologic oncology research

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Abstract

Prioritization of patient and stakeholder engagement in the research process has been realized through increased funding and policy directives at the government level. Particularly, patient engagement in the preparatory research stage has driven development of patient-prioritized research questions. In this article, a successful example of patient-centered research prioritization is reviewed, and effective strategies and opportunities for patient engagement in urologic oncology research are described.

Keywords: Patient-centered care; Urologic neoplasms; Patient participation; Engagement

1. Background

Over the past century, clinical research has lacked meaningful patient participation. Fortunately, a slow shift in perspective has incorporated patient-reported outcomes in clinical trials, and the patient voice is beginning to shape the development and execution of research studies. The incorporation of patients, caregivers, and community members into research is defined broadly as patient and service user engagement. Engagement is now recognized as a meaningful way to facilitate research development and execution with the end-user in mind: patients.

Engagement of patients and important stakeholders in research can (and should) occur during all stages of the research process. The 3 stages of the research process create a general framework for which engagement can be defined: preparatory (research design), execution (research conduct), and translational (dissemination and implementation) [1]. Patient participation in the preparatory research stage involves agenda setting, prioritizing research topics, and selecting relevant research questions. Understandably, navigating the preparatory research stage can be complex and challenging. The perceived level of education required to develop clinical research projects has historically created a natural barrier to patient accessibility and involvement. However, active restructuring of the preparatory stage through engagement work has identified new patient-priority topics and focused limited research funds to research with the greatest patient impact. In this article, we focus on this critical initial stage of research development and discuss how the patient voice in research prioritization can be successfully achieved within urologic oncology. Several techniques described herein can also be used as key principles for success when engaging patients and their caregivers in all 3 stages of the research process.

The emerging importance of patient engagement is largely owing to changes in funding and policy directives that have placed new emphasis on the patient voice. In 2010, the Patient Centered Outcome Research Institute (PCORI) was founded as part of the United States Patient Protection and Affordability Care Act. The PCORI mission is to help patients make informed health care decisions and improve health care outcomes by producing evidence-based research guided by patients, caregivers, and the broader health care community [2]. Since inception, PCORI has funded more than $1.6 billion in patient-centered research activities and $327 million dollars in 2016 alone. A subset of this funding was used to specifically support patient engagement efforts that emphasize research prioritization,

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termed the Eugene Washington PCORI Engagement Awards. Per PCORI, Engagement Award projects must strengthen the capacity and ability of patients and other stakeholder communities to actively involve in the research development process [3].

Numerous patient engagement projects have since been published across multiple specialties [4–6]. Descriptions of successful patient engagement efforts regarding research prioritization create an opportunity for further development of effective patient engagement strategies in other fields. Despite growing interest in patient engagement across multiple disciplines, very little has been written about patient engagement in the context of research prioritization, especially in the setting of urologic oncology. Herein, we describe our experience with patient-centered research prioritization in bladder cancer. Our hope is that future engagement endeavors can build from the lessons learned, with the ultimate goal of further promoting development of an effective strategy for patient-centered research prioritization within urologic oncology.

2. Patient engagement within urologic oncology: An example

Our efforts for patient-centered research prioritization in bladder cancer began with the development of the Bladder Cancer Advocacy Network (BCAN) Patient Survey Network (PSN). The PSN was designed as an online repository of engaged patients and caregivers interested in research prioritization and design. Bladder cancer patients and caregivers were recruited through the existing BCAN online community, advertisement, and e-mails to online community members. Participants who joined the PSN completed a survey reporting general demographics, as well as clinical and cancer-specific characteristics. All participants were asked to include their e-mail address for future correspondence to continue ongoing research prioritization efforts, and also asked if they could be contacted for research opportunities in the future. In this way, a repository of subjects and contact information was created on which to draw future recruitment for research involvement. Over the span of 2 years, 1,382 patients and caregivers enrolled in the PSN and responded to the data-collection survey. Patients participated in prioritizing research topics that were then delivered to funding agencies such as the National Cancer Institute, PCORI, the Agency for Healthcare Research and Quality, and others. Through the 2-year development period, several challenges and opportunities were realized.

3. Keys to success within research prioritization efforts

3.1. Engaging the patient and caregiver

Patient identification and engagement in research prioritization is challenging. First, recruitment requires several varied strategies to extend reach to a broad representation of the patients target population. Recruitment for the BCAN PSN was multifaceted. Recruitment began with advertisement within an existing online community affected by a single disease process, enabling quick enrollment. In general, technology-based recruitment of patients through online (or telephone) mechanisms has been more successful for oncologic patient recruitment than in-person efforts [7,8]. However, broad recruitment strategies remain important and necessary. Additional recruitment was needed to expand diversity of the BCAN PSN using existing support groups at urologic oncology treatment centers, survivorship programs, annual meetings, and word-of-mouth promotion from community and academic specialists. These recruitment strategies allowed for co-ordination of patient care visits with PSN participation, identified as an important recruitment and retention tool for research participation by patients and caregivers [9].

Engaging hard-to-reach or vulnerable populations can pose additional recruitment challenges. Diversity was a priority (and a challenge) in development of the BCAN PSN. Black and Hispanic groups were targeted during recruitment of participants, using online and print advertisement in locations with larger proportions of minority patients. Improving representation of underrepresented populations can benefit from specific methodology such as snowball sampling. Snowball sampling uses a chain-referral method in which initial participants are encouraged to recruit others from their social network. Snowball sampling has been shown to be an effective way to engage patients whose perspective is overlooked owing to accessibility barriers, and therefore even more crucial [10]. Additionally, multimodal advertisement strategies facilitate broad recruitment efforts. Print advertisements (in addition to electronic and social media campaigns) include those without internet access (e.g. low-socioeconomic status and older age). Using telephone and mailing recruitment can also expand the diversity of a patient network. Finally, translation of surveys and recruitment materials in additional languages can further expand diversity. During the second year of the BCAN PSN, advertisement and surveys were translated (and back-translated to ensure accuracy) into Spanish to expand reach.

3.2. Developing and prioritizing research questions

Following recruitment, the next step requires effective engagement of enrolled patient and caregivers within the network. The key to effective engagement in research development requires patient involvement as early as possible in the research process. The BCAN PSN focused on research prioritization to identify research questions that most align with patient preferences. Engagement before research questions are chosen allows patients and stakeholders to steer research agendas and provides value and context for research question development [1]. To