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SAN ANTONIO BREAST CANCER SYMPOSIUM
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Session PS1 - PS1. Poster Session 1

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P1-16-03. Hear our voice: Patient-driven solutions to increase participation in clinical trials

December 11, 2019, 5:00 PM - 7:00 PM | Hall 1

Authors
Marina Kaplan. LBBC, Atlantic Beach, FL

Disclosures
M. Kaplan: None.

Abstract
Background: The rate of participation in clinical trials is dismally low, slowing the process of drug development and increasing cost. Patients living with metastatic breast cancer (MBC) are often willing to participate in clinical trials, but are frequently faced with insurmountable barriers. There is a dire need for studies identifying actionable patient-driven solutions to help ensure that opportunities to participate in clinical trials becomes more equitable, attractive and feasible for a larger, more diverse pool of potential participants. **Methods:** A mixed-methods design including in-depth interviews and online surveys was used to identify barriers and solutions to participation in clinical trials. Sixty-one participants were invited to be interviewed using purposeful stratified sampling (patient race, age and geographic location; community and academic center oncologists and administrators; researchers and research staff; payers). Interview questions were designed to collect feasible solutions to barriers. Convenience sampling was used to recruit MBC patient survey participants. Online surveys were fielded via nine MBC social media groups reaching approximately 1,500 patients living with MBC. Survey questions included demographics, trial experience, perception of benefits/disadvantages and barriers to trial participation, and ideas for solutions to the barriers. In addition, a short social media poll on trial participation was used. **Results:** A total of 496 women living with MBC completed the online survey. The mean age of survey respondents was 53 years old and mean number of years with MBC was 4.6 years. Respondents generally reported positive attitudes toward trial participation: The opportunity to get innovative treatments, helping others with MBC and contributing to research were rated as extremely important. Potential disadvantages included fear of side effects, possibility that trial drugs may not be effective and financial toxicity. Significant barriers included strict eligibility criteria, broad exclusion criteria and lack of trials nearby. All patients responding to a social media poll indicated they would consider participating in a clinical trial. Fifty-two participants were interviewed. The most frequent themes from patients were suggestions to address rigid eligibility and exclusion criteria by consistently including patients in research design, protocol development and policy decisions. Patients felt that trials should reflect the “real world”, and that opening up eligibility criteria would increase diversity and the number of potential participants. A dominant theme from rural and community-based oncologists was the need to address geographic, logistical and financial barriers using more “portable” multi-institution trials, providing transportation and adequate reimbursement for patients’ expenses. Clinicians in academic described exclusion criteria as a significant barrier for heavily pretreated MBC patients. Health care administrators discussed solutions to high costs associated with trials. Payers shared innovative solutions to out-of-network payment barriers. **Conclusions:** Most patients with MBC are willing to participate in clinical trials, and many are highly motivated to do so. MBC patients generally recognize the benefits that trials can offer and are willing and able to help address the barriers to trial participation by working collaboratively across the board. Multiple sectors of health-care are ready and willing to work together. It is in all our best interests to hasten the development of new treatments, and the time is right to implement a collaborative, systematic solutions-based approach that will make it feasible for more MBC patients to participate in clinical trials. This patient led study shows how this can be done..