



Research Week 2020

Public Perception of Predictive Cancer Genetic Testing and Research in Oregon

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Keywords

Qualitative, focus groups, marketing, outreach, recruitment, disparity, rural, heritable, pathogenic variants, genetic testing

Abstract

Nationwide efforts are engaging communities in large genetic studies to better estimate the population-wide prevalence of some heritable cancers that have medical recommendations, however, effective communication about benefits and risks of both personal genetic testing and participation in bio-repositories remains challenging in some communities. To successfully engage an Oregon population in longitudinal research that includes predictive genetic testing for pathogenic or likely pathogenic variants associated with an increased risk for cancer, researchers conducted 35 focus groups with 203 adults (two of which were held in Spanish) in 24 of Oregon's 36 counties to better understand knowledge and attitudes related to genetic testing and willingness to participate in longitudinal genetic research. While participants at most focus group sites (33 of 35) described "concerns about outcomes" as barriers to predictive genetic testing, the desire to learn about health risks in oneself to inform personal or family medical decisions buffered fears for many participants, with 33 of the 35 sites citing "families" (e.g., children, close relatives, extended family members) as key motivators for participation in genetic research. Participants, particularly in rural areas, highlighted critical factors for research recruitment, such as trust, personal interaction, public education about genetic research, and clear communication about study goals and processes. Our statewide findings reflect that public interest in predictive cancer genetic testing and cancer genetic research can surpass lack of knowledge of the complex topics, particularly when benefits for self and family are emphasized and when study considerations are well articulated.

