

Examining Current Practices of Participant Engagement in Cancer Genomics

Department of
Biomedical
Informatics



THE OHIO STATE
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Abstract: The Cancer Moonshot Initiative put a spotlight on using direct participant engagement to accelerate cancer research. Participant engagement has been adopted by several research networks studying cancer genomics, yet, their current practices of participant engagement are unclear. We conducted an environmental scan to answer three guiding questions about how ten research networks studying cancer genomics conceptualize, implement, and evaluate participant engagement. We found that participant engagement could be conceptualized as a continuum. The continuum ranged from: (a) transactions for recruiting and retaining study subjects to (b) ongoing relationships for informing and shaping the research process. Across the continuum was a growing emphasis on engaging diverse populations. Websites were a key engagement strategy for recruiting study subjects. Advisory boards were a key engagement strategy for informing the research process with most emphasis placed on informing recruitment processes. Metrics and methods to evaluate engagement were described, however, few studies evaluated engagement strategies. Compared to other fields of engagement there is an opportunity to engage cancer communities more throughout the research enterprise.

About the Speaker: Anne Schuster, PhD is an OSU Comprehensive Cancer Center funded Post-Doctoral Scholar and an active member of the Patient-Centered Outcomes Research Lab (PI-Bridges) within the Department of Biomedical Informatics. Prior to joining OSU in February 2021, Anne earned a doctorate in health services research from the University of Colorado in 2020 and a masters of health science (health economics) from the John Hopkins Bloomberg School of Public Health. Her research has spanned a range of topics including stakeholder engagement to promote advance care planning in high risk surgery cancer patients and end-user engagement to scale up a biomedical informatics tool for clinical trial accrual. Most recently, her research relates to the Participant Engagement and Cancer Genome Sequencing Network. It is a network established by the National Cancer Institute as part of the Cancer Moonshot Initiative and OSU serves as its Coordinating Center. Long-term, Anne is interested in advancing the science of engagement in cancer research with an emphasis on promoting diversity, equity, and inclusion.

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Friday, February 11th, 11:00am-12:00pm
Carmen Zoom

