

Collecting Non-Clinical Data to Address Disparities in Cancer Prevention: Lessons from the Field

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Background

Research on how women at high-risk of breast or ovarian cancer make riskreduction choices is still developing, and rarely addresses minority and underserved populations (Padamsee et al. 2017). Early findings indicate that African American women face additional burdens at every stage of the decision-making process (Padamsee et al. 2018). Comprehensive research with diverse samples is imperative to understanding women's risk-reducing choices in order to (a) facilitate health-protective decision making and (b) reduce cancer health disparities.

A high proportion of high-risk women in all racial-ethnic groups – and the majority of high-risk African American women – do not receive clinical care related to their cancer risk. Better understanding and support of riskreduction behavior among these populations therefore requires that researchers develop and utilize methods to enroll participants from a broad range of settings, instead of solely from the clinical populations commonly used in risk-reduction studies.

Non-Clinical Recruitment Experience

The Daughter, Sister, Mother Project designs and implements studies of diverse women at high risk of breast or ovarian cancer, using multiple research methodologies. Non-clinical recruitment methods include contacting women through social media, online volunteer databases, and community organizations. We have recruited high-risk African American and White women from non-clinical environments to collect both qualitative and quantitative data.

Our recruitment methods have successfully enrolled larger and more varied samples than are often possible from these populations, including a set of 50 semi-structured interviews (40% African American, 60% White), and a set of 1040 lengthy survey responses (~35% African American, ~65% White). Our experience developing and using these methods has illuminated challenges and solutions that may be useful in other research.

Related Work & Acknowledgments

The Ohio State University Comprehensive Cancer Center – James Cancer Hospital. 2019. The Daughter Sister Mother Project. https://cancer.osu.edu/research-and-education/labs-and-facilities/padamsee-group/daughter-sister-mother-project Padamsee TJ, Wills CE, Yee LD, and Paskett ED. 2017. Decision Making for Breast Cancer Prevention among Women at Elevated Risk. Breast Cancer Research 19:34. https://doi.org/10.1186/s13058-017-0826-5

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Risk Prediction Modeling

- Because the individual risk level of women recruited through non-clinical methods is usually unknown, risk prediction modeling must be built into the data collection process
- Telephone screening by trained research staff allows risk prediction modeling before study enrollment and replaces the risk-level information that would pre-exist participant recruitment in a clinical setting
- Incorporating risk-prediction modeling into a data collection instrument requires technical integration with proprietary modeling software or substantial investment in original programming
- Collecting risk-related information within a survey instrument makes it possible for participants to complete a survey in one interaction, but requires risk-prediction modeling and sample trimming after data have been collected





Challenges and Solutions in Non-Clinical Recruitment



Ongoing Connections

- Some African American women not already involved in high-risk clinical care are also hesitant to become involved in health-oriented research
- Trust can be built by nurturing connections with community organizations and by fostering ongoing two-way contact with a research team
- Long-term collaboration can be advanced by facilitating access to necessary health care resources, and by retuning useful information to the communities from whom we learn it





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