

AUGUST 2021

Ovarian Cancer Epidemiology, Healthcare Access and Disparities



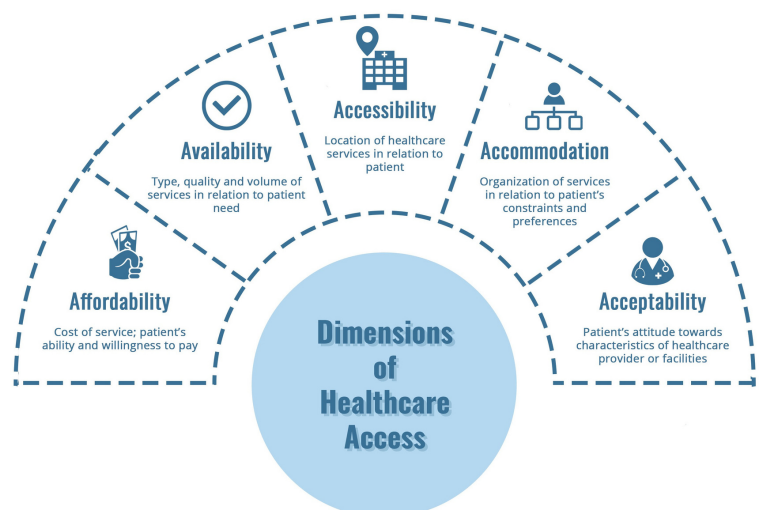
Dear ORCHiD Study Participant,

We appreciate the gift of your time in helping us understand how healthcare access affects the timing and quality of care for cancer patients. Because of volunteers like you, we are already learning how to make it easier for cancer patients to receive the best quality treatment. We are learning about the unique challenges faced by patients living in rural areas, without health insurance, with language barriers, and the need for strong support systems to help cope with treatment. We are learning about important changes providers can make to improve the care experience, e.g., better communication, empathy and respect, and addressing implicit bias that may affect the quality of care received by African-American and Hispanic patients.

Thanks to your participation in our pilot study, we have now launched our main study. We look forward to learning more about how to improve ovarian cancer outcomes for all patients, and we look forward to sharing the results of the study with you all!

The ORCHiD main study is currently recruiting 1,500 ovarian cancer patients from nine US states to understand how various dimensions of **Healthcare Access (HCA)**: *Affordability, Accessibility, Availability, Accommodation, and Acceptability* vary by race and rural/urban region, and how these factors, and biological changes, impact the timing and quality of cancer treatment

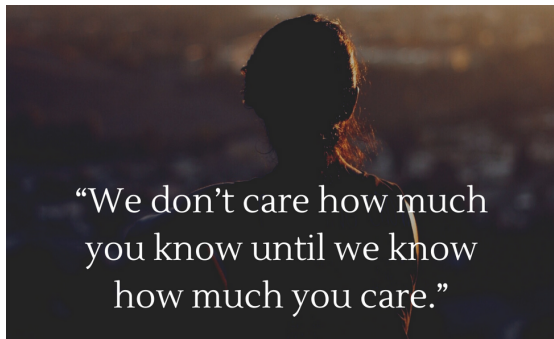
This information will help guide individual, clinical and policy changes to promote equity in cancer treatment, and guide tailored strategies to ensure the best health outcomes for everyone.



RESEARCH PROGRESS AND NEXT STEPS

FOCUS GROUPS

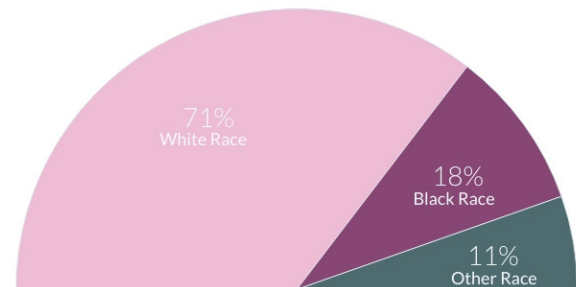
Thank you so much for your participation in this important phase of the study. The focus group interviews helped us learn that, overwhelmingly, issues of acceptability had the most impact on your care. Specifically, the trust that you had in your doctor and the need for providers to show empathy, compassion, and respect. A favorite quote of ours was *“We don't care how much you know until we know how much you care.”* We also learnt about the importance of accommodation with scheduling, wait times, and language accessibility. While we focused mostly on the five HCA domains, there were other aspects of your treatment that were commonly discussed, including the need for physical and emotional support as well as the importance of faith. These findings helped us develop a comprehensive survey that considered as many aspects of cancer care access as possible. We thank you again for your important contribution to the development of this study!



PILOT STUDY

Thank you for your participation in our pilot study. You helped us in pilot testing the survey instrument and recruitment protocol to detect any points in the study flow that require further optimization. This phase enhanced the quality and effectiveness of recruitment and data collection of the main phase of the study. This phase of the study was conducted between November 2020 and February 2021 and took place at both Duke University and The University of Alabama at Birmingham (UAB). We were able to speak with 105 cancer survivors by phone. Out of those, 75% consented to participate in the study. We gave the option to complete the survey by phone, electronically, or on paper. Of those that completed the survey (82%) and 43% also consented to participate in the Bio-specimen sub-study.

RACIAL DISTRIBUTION OF OUR PILOT STUDY PARTICIPANTS



KEY FINDINGS

- Everyone (100%) reported that they had surgery for their ovarian cancer
- Almost everyone (90%) completed full course of chemotherapy
- The median travel time from home to the site of surgery was reported as 1.25 hours. About 63% of participants reported that they were driven to their treatment location by someone else, while 32% drove by themselves .
- A little less than half of the participants (45%) reported having to dip into their savings account and sacrifice their family plans and vacations in order to afford treatment. About a quarter (23%) reported delay in paying bills.
- Most participants seemed pleased with providers' willingness to accommodate their schedules and needs
- About 70% of participants believed that they received the same medical care from doctors as people from other ethnic groups
- Almost all (96%) reported that the doctors have their best interest in mind.

WHAT'S NEXT

We are currently recruiting participants for our main phase from multiple states such as Kentucky, New York, Georgia, Maryland, Texas, North Carolina, California and Florida. Thanks to your support, we have finalized a comprehensive survey and optimized all the aspects of the study. We have two publications under review currently that describe aggregate findings from the focus groups and the methods we used for the study. We're excited to see what the next year brings!

A BIG THANK YOU!

Dr. Tomi Akinyemiju (Principal Investigator) & The ORCHiD study team