



# CAROLINA ENDOMETRIAL CANCER STUDY

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## Thank You for Participating!

Your participation, the stories you tell, and the information you provide are so important. In the first survey, you shared a lot about your personal and family history and about some of your personal views. We want to follow up to see how your treatment and surveillance has continued, how your recovery is going, and overall how you are doing and feeling. This follow up survey will really help us gain a fuller picture of your treatment history and your road to recovery—your successes and your challenges. **We hope that you will continue to say, "Yes!"**

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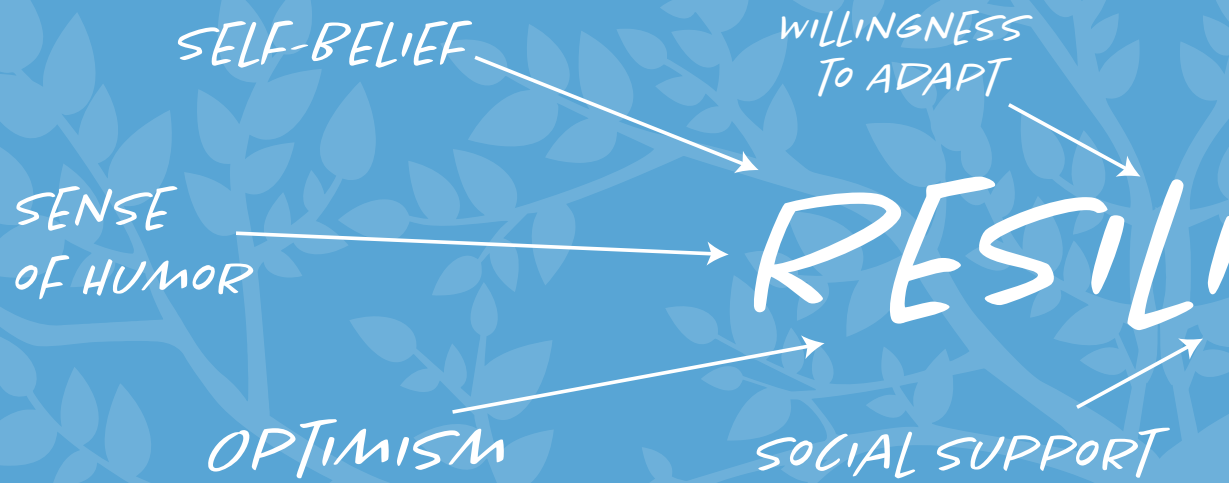


Greetings from the Carolina Endometrial Cancer Study! We hope you enjoy this edition of our study newsletter. Thank you for all the time and care you have invested in participating in the Carolina Endometrial Cancer Study. Our hope is to bring greater attention to the experiences of endometrial cancer survivors and ultimately improve endometrial cancer care and survivorship in North Carolina.

We believe our study will be an important information source across the nation—by enrolling participants from all across North Carolina, we can capture the experiences of participants in cities, small towns and rural centers—those with medical providers next door or hours away—and those who experience challenges in other parts of their lives beyond their cancer diagnosis that need to be taken into account. Your continued participation helps us understand experiences beyond diagnosis and initial treatment to learn how an endometrial cancer diagnosis can change lives even after treatment is complete, and what resources are most needed to survive and thrive after diagnosis.

In the meantime, we hope you will enjoy our latest newsletter. Inside you will find highlights of recent findings from endometrial cancer research across the country, and explanations about different parts of study participation and why we ask the questions we do in the Carolina Endometrial Cancer Study. As always, thank you for your continued participation in our study. We know your time is valuable, and we welcome your feedback and suggestions on how to make participating in the Carolina Endometrial Cancer Study best fit your life and responsibilities.

— *Andrew Olshan and Hazel Nichols*



## Inside the Study



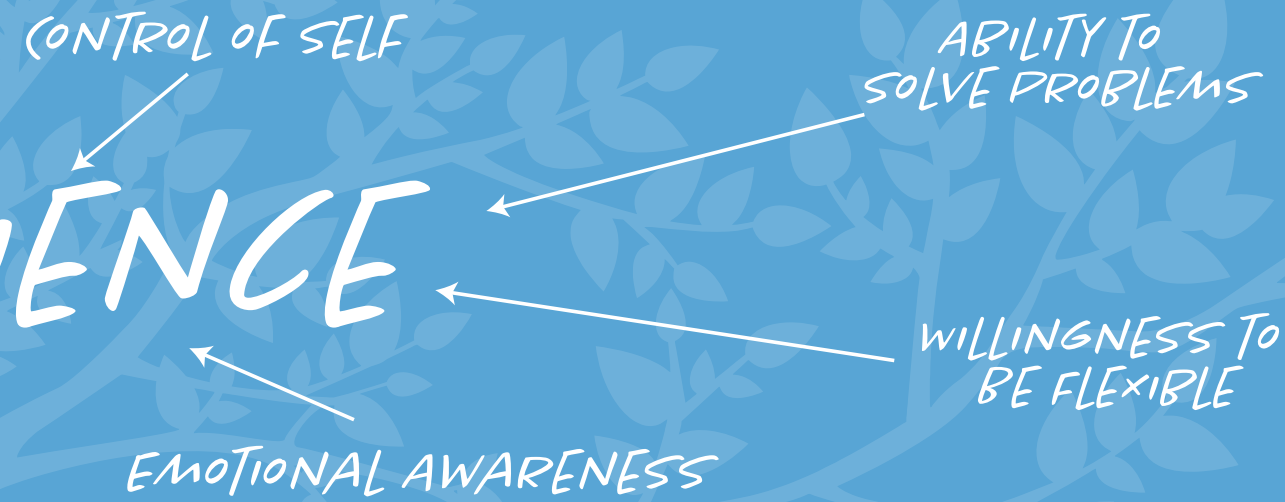
### Why do we ask for permission to obtain tumor samples?

Studying the genetic material in your tumor cells is one of the most important strategies to help us better understand endometrial cancer. We compare the genetic material from tumor cells with your germline (non tumor origin) cells, which is why we also ask for a saliva sample. By doing this comparison, we can look at certain changes in the genes to see if these changes are related to your cancer diagnosis, progression, and treatment.

### What do we do with the tumor samples after you give permission?

When your tissue was removed during a biopsy or surgery, it was first examined by doctors so they could better understand your disease. This helped your doctors and you make informed decisions about your diagnosis and treatment. Often after this happens, there is leftover tissue, and with your permission, some can be made available for research purposes. CECS will only use part of your stored tissue, and we return the rest to your healthcare facility. This is so that it will be available to guide any treatments you might need in the future. Any samples that we collect will be stored indefinitely in a university or affiliated storage facility.

If you also gave your consent for your tissue to be used in future studies, then when researchers from universities, hospitals, and other health organizations approach CECS about using our data as part of their studies, then those researchers may be given access to the samples that CECS already collected. But before all that can occur, UNC's Institutional Review Board (IRB) and CECS's own researchers will review every request, analyze the proposed study for scientific merit and good design, and only then decide if CECS samples are appropriate for use.



**Why do we ask for permission to review medical records after the survey is completed?**

Your medical records provide critical information to inform our research. Our goals are to study survivorship after endometrial cancer, understand differences in outcomes, and ultimately improve the lives of people with endometrial cancer in North Carolina and nationally. To do this, it is important for us to look at changes in your cancer or its treatment, and this information is only recorded in your medical records.

**How can we improve the Carolina Endometrial Cancer Study?**



Our study team wants to hear from you about your experience! If you have feedback that you would like to share with us, please scan the QR code to provide feedback on your participation and ways for us to improve this study. We know your time is valuable, and we can't thank you enough for your contributions to this important research project.







*Minimizing the time between diagnosis and treatment initiation is critical for preventing the spread of cancer.*

## ENDOMETRIAL CANCER RESOURCES:

### American Cancer Society

1-800-ACS-2345  
[www.cancer.org](http://www.cancer.org)

### National Cancer Institute

1-800-4-CANCER  
[www.cancer.gov](http://www.cancer.gov)

## We'd Love to Hear from You!

We would love to feature you in our next newsletter. If you have a short (<100 words) story, a brief poem, or a work of art that tells something about your journey with endometrial cancer or perhaps you're willing to be featured in an interview, e-mail the study coordinator, Adam Gardner, at: [cecs@unc.edu](mailto:cecs@unc.edu).

## New Research Highlights



A recent study from UNC examined survival among U.S. women with endometrial cancer for up to 12 years after diagnosis. In the early years after endometrial cancer, endometrial cancer survivors have a higher risk of dying than women in the general population. However, once women survived at least 4 years from their diagnosis, risk of dying became similar ( $\leq 5\%$  difference) between endometrial cancer survivors and the general population. The study also reported that it took longer for Black survivors to return to having a similar risk of dying to the general

population—Black survivors had to live 8 years past their diagnosis. Better understanding of what drives survival after endometrial cancer is a key part of our goal to improve the lives of endometrial cancer survivors in North Carolina. **Website:** [pubmed.ncbi.nlm.nih.gov/33737298](https://pubmed.ncbi.nlm.nih.gov/33737298)

Minimizing the time between diagnosis and treatment initiation is critical for preventing the spread of cancer. Researchers at the University of Washington conducted interviews with White and Black women diagnosed with endometrial cancer, with an objective to identify possible factors related to care delay. The study authors identified 4 areas that have the potential to contribute to care delays: 1) knowledge of endometrial cancer and its symptoms, 2) prior negative healthcare experiences, 3) other health issues (prior or concurrent), and 4) dismissive healthcare provider response. We are collecting data on these factors so we can explore endometrial cancer care experiences in North Carolina. **Website:** [pubmed.ncbi.nlm.nih.gov/34862064](https://pubmed.ncbi.nlm.nih.gov/34862064)

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PROGRAM ON TRANSLATIONAL RESEARCH  
IN ENDOMETRIAL CANCER DISPARITIES

The Carolina Endometrial Cancer Study is conducted by the Lineberger Comprehensive Cancer Center in affiliation with the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill. It is funded by the University Cancer Research Fund of North Carolina and the Lineberger Comprehensive Cancer Center.



LINEBERGER COMPREHENSIVE  
CANCER CENTER

**Please contact us with any questions about this study at 1-866-927-6920.**

