

For Study Participants

The Carolina Head and Neck Cancer Study (CHANCE-2):
A Population Cohort to Investigate
Head and Neck Cancer Epidemiology and Outcomes



A MESSAGE FROM THE CHANCE-2 TEAM

Thank you for your participation!

We want to express our sincere gratitude to you for participation in CHANCE-2. You are a part of an important study aimed at better understanding the best treatments for head and neck cancers and how to reduce adverse outcomes and improve quality of life for patients. Working with individuals with these cancers is the best way to learn more about these important questions. We hope information from this study will reduce head and neck cancer occurrence, improve treatment, and increase survival rates for future generations.



WHAT TO EXPECT FROM YOUR FOLLOW-UP CALL

One of our callers will be contacting you to obtain information about any additional treatment, biopsies, surgeries, or other procedures you may have had since we last spoke with you. We will also be asking questions about your lifestyle and health status. This survey may last about 10-15 minutes. After completing the survey we will send you a \$20 gift card as a small token of our appreciation.



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MEET THE PRINCIPAL INVESTIGATOR



Andrew Olshan, PhD is a Distinguished Professor of Cancer Epidemiology at UNC's Gillings School of Global Public Health. He is also Associate Director for Population Sciences at UNC's Lineberger Comprehensive Cancer Center. Dr. Olshan is the principal investigator of the CHANCE-2 as well as the principal investigator for multiple epidemiologic studies of adult and childhood cancers and reproductive and pediatric outcomes. He led the first CHANCE study, conducted in North Carolina from 2002-2006. Recent research led by Dr. Olshan focuses on the impact of lifestyle, behavior, and

socioeconomic factors in breast cancer and cancers of the head and neck. He is looking forward to collaborating with oncologists, surgeons, cancer biologists, and other scientists to reduce head and neck cancer occurrence and improve outcomes for patients.

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PEOPLE BEHIND THE SCENES

The CHANCE-2 support team includes phone interviewers, medical record abstractor, and research assistants who work behind the scenes to make calls, send mailings, and obtain medical records and survey data. Our team members are thrilled to be part of the CHANCE-2 team and are dedicated to the success of this important research.

Heather Tipaldos, MS, CRA (right) is the Project Manager of CHANCE-2. She is responsible for its day-to-day administration, managing staff and coordinating enrollment and data collection for CHANCE-2 participants.



Pamela Mack (left) is a Telephone Interviewer for the CHANCE-2. She has been involved in various capacities of research at UNC since 2010, but immensely anticipates the unique conversations she has with all participants, in which she gathers important health information to aid in the study.



Linda Shaw (left) is a Telephone Interviewer of CHANCE-2, helping to collect the valuable information you contribute. Linda has been involved in cancer research at UNC since 2010. She really enjoys getting to know participants in the study and hearing about their experiences.

Michele Smith (right) is one of CHANCE-2's research assistants. She sends out thank you letters to participants, requests medical records, and enters health information into the database. She has been involved in cancer research at UNC since 2010.



Erin Lutz (right) is a Telephone Interviewer for CHANCE-2. She has worked in health research at UNC since 2010. Erin is a dental hygienist and was a faculty member at UNC School of Dentistry for ten years prior to her research involvement. She enjoys the opportunity to connect and gather important information about your head and neck cancer experiences.



Susan Campbell (left) is the study's Medical Records Abstractor. She extracts head and neck cancer data, as well as treatment and health-related information, from participants' medical records.

Shanice Borden (not pictured) is a research specialist for CHANCE-2. She is responsible for its day-to-day coordination and is excited to learn new ways to carry out the work we do in a way that positively impacts the participants.



TRAVEL TIME TO YOUR DOCTOR: WHY DO YOU ASK THAT?!

- How many miles do you travel to see your health care provider?
- How long does it take to get to your health care provider?
- How do you usually get to your health care provider?
- Was there a time in the past ten years that you wanted to see a doctor but could not due to transportation issues?

These are just a few of the questions we ask that at first may seem odd to include in an interview about head and neck cancer. The study you are enrolled in, CHANCE-2, was preceded by a first phase of the CHANCE in 2002-2006. The first study also recruited men and women with head and neck cancer living in central North Carolina. CHANCE-2 hopes to build on information and findings from the first study. One of the many publications from the first CHANCE study is summarized below. This is the first study in any cancer site to find that distance disproportionately affects low-income patients. We hope this overview will give you some insight into why we ask what we do!

TRAVEL TIME TO DOCTOR MATTERS

In a study published in *Oral Oncology*, Dr. Andrew Olshan and colleagues demonstrated that travel time to provider affects the late diagnosis of squamous cell carcinoma of the head and neck (HNSCC) in North Carolina and that the travel burden disproportionately affects patients with lower income.

Travel has been shown to be a barrier to the early diagnosis of several other cancers. Patients with HNSCC may be especially susceptible to travel burden as diagnosis typically requires travel to an otolaryngologist or other physicians. Moreover, HNSCC frequently affects low income patients who may have additional difficulties in accessing care.

Head and Neck Squamous Cell Carcinoma: Overview

HNSCC is the sixth most common cancer worldwide and the fifth most common cancer in the United States, affecting approximately 40,000 new patients annually. HNSCC has a high mortality rate, with poorer survival than some other common cancers such as breast, cervical, and colorectal cancers. The stage of tumor at diagnosis helps predict survival in patients diagnosed with HNSCC. Patients with advanced tumor stage typically require aggressive surgery, chemotherapy, and radiation that can cause speech and swallowing difficulties and poor quality of life. While more than half of HNSCC is diagnosed at a late stage, early diagnosis may spare substantial morbidity and mortality.

Travel Burden Of Cancer Patients: Why It Matters

Access-to-healthcare services has been linked with late diagnosis of cancers including HNSCC. A delay in diagnosis may result in a cancer that has grown, be higher stage, and may be harder to treat. A key determinant of access may be the distance that a patient must travel to obtain a diagnosis. This distance may disproportionately affect HNSCC patients, who frequently have a low socioeconomic status and can lack resources for transportation. The disadvantaged patients may delay their presentation possibly due to difficulty reaching farther-away providers.

Key Study Findings

The study cohort comprised 808 HNSCC patients who were between 20 and 80 years of age at the time of their diagnosis and resided in a 46-county region in central North Carolina. The study used the individual measures obtained from the CHANCE. The research team found that low-income HNSCC patients with longer travel time to the provider were more likely to be diagnosed with advanced tumor stage than higher income patients.

Findings suggest that low socioeconomic status and limited resources for transportation may present barriers to patients seeking a timely diagnostic biopsy. This may lead to patients waiting until symptoms increase or until they require emergency care possibly due to difficulty with swallowing or airway compromise. Furthermore, patients with limited resources may lack access to screening for head and neck cancer through routine medical or dental visits.

This study is the first one in any cancer site to find that distance disproportionately affects low-income patients. Related knowledge gaps that still need to be filled including the influence of health literacy and medical insurance, and the ability to leave work to seek care.

At a Glance

- Longer travel time to provider among low-income HNSCC patients was associated with advanced tumor stage at diagnosis.
- Travel may be a barrier to early diagnosis of HNSCC for certain patients.
- This study is the first in any cancer site to find that distance disproportionately affects low-income patients.

RESOURCES

Head and Neck

Cancer Resources

American Cancer Society

1-800-ACS-2345

www.cancer.org

National Cancer Institute

1-800-4-CANCER

www.cancer.gov

We are on the web!

Visit our website for
more information

chance2.unc.edu



LINEBERGER
COMPREHENSIVE
CANCER CENTER



GILLINGS SCHOOL
OF GLOBAL
PUBLIC HEALTH



THE UNIVERSITY OF
TENNESSEE
HEALTH SCIENCE CENTER



Head and Neck Cancer Support Groups

Support groups can be a valuable place to talk through your cancer, experiences, and fears with others going through similar experiences. For some patients, the emotional support provided by a community who intimately understands the studies of cancer can be helpful. Members of a support group can provide strategies as to navigate the cancer journey or provide recommendations to communicate with health care professionals. The groups listed below are available in many areas across the U.S. While this list of resources is a good place to start, your social worker, therapist, treatment center or local faith groups may also be great avenues for support.

Support for People with Oral and Head and Neck Cancer, Inc. (SPOHNC)

SPOHNC is a nonprofit organization that works with health professionals and organizations to raise awareness and meet the needs of oral and head and neck cancer patients through its resources and publications. SPOHNC's Chapters and additional volunteers help to raise awareness through many events, which include oral cancer screenings, educational fairs, tasting events, and move to music classes. For more information, please visit spohnc.org.



The Oral Cancer Foundation (OCF)

OCF is a nonprofit national public service organization that offers education, research, advocacy, and patient support activities for oral cancer patients. OCF provides scientific and educational information for patients and caregivers and host fund raising, fun run events, awareness campaigns, and free oral cancer screenings events throughout the country. For more information, please visit oral-cancerfoundation.org.



Head and Neck Cancer Alliance (HNCA)

HNCA is a nonprofit organization that provides support to head and neck cancer patients and caregivers through the provision of educational information, activities to promote awareness, and resources for patients to engage and learn from one another. For more information, please visit headandneck.org.



The study is sponsored by The University of North Carolina at Chapel Hill Lineberger Comprehensive Cancer Center, where the research study is conducted. The study is also affiliated with the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill. This research was also funded by the University Cancer Research Fund of North Carolina and by the University of Tennessee Health Sciences Center in Memphis, TN. Investigators at Washington University and University of Tennessee Health Sciences Center are involved in the study planning.