

## Special Studies

Comprehensive and innovative use of central cancer registry data and infrastructure for cancer control and research has always been a high priority for the LTR. The registry has actively participated in research studies in collaboration with investigators from the Louisiana State University Health Sciences Centers, the NCI, the CDC, other cancer registries, and universities.

The following are the funded studies in which the LTR currently participates that involve additional data collection. All studies received IRB approval.

- Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers and Social Stress (RESPOND)
  - The RESPOND Study is a multi-site study funded by the NCI which seeks to identify the reasons behind the disproportionately higher risk of prostate cancer and death from the disease in African American (AA) men. The overall goal of the study is to establish a prospective cohort of AA men with prostate cancer to uncover etiologic and prognostic genetic and non-genetic risk factors related to disease aggressiveness that underline prostate cancer health disparities in incidence and mortality for AA men. The LTR is currently recruiting patients for this study and expects to enroll over 1,000 men.
- Exercise and Colon Cancer Treatment (EXACT) Trial
  - The EXACT Trial is funded by the National Cancer Institute and is taking place at Pennington Biomedical Research Center (PBRC). The purpose of the study is to learn about the benefits of physical activity in people who have finished their medical treatments for colon cancer. The LTR is assisting with recruitment by identifying eligible patients within the registry database and contacting those patients in order to find patients who are interested in participating in the study.
- Generating Critical Patient-Centered Information for Decision Making in Localized Prostate Cancer
  - This study is a five-year project funded by the Patient-Centered Outcome Research Institute (PCORI) and AHRQ to follow up with patients enrolled into the CEASAR study longitudinally and collect patient-reported outcome data through 3-year and 5-year patient surveys.
- SEER Patterns of Care (PoC) Studies
  - The SEER PoC studies are conducted every year to comply with the Congressional Directive to the NCI under Public Law 100-607 to "assess the incorporation of state-of-the-art cancer treatment into clinical practice and the extent to which cancer patients receive such treatment."
- Early Case Capture (ECC) of Pediatric and Young Adult Cancers
  - In 2008, the US Congress signed into law the Caroline Pryce Walker Conquer Childhood Cancer Act. Through it, the ECC project was initiated to increase the availability of timely pediatric cancer data for the surveillance, clinical, and research communities with the goal of developing a repository of childhood cancer that is representative of the US population.

- Cervical intraepithelial neoplasia (CIN III)
  - With the introduction of the HPV vaccine, baseline information on precancerous cervical lesions is required in order to assess the impact of the vaccine on the disease burden. The baseline estimate of the incidence of these lesions, based on this investigation, will be vital in subsequent studies of the efficacy of population-based HPV vaccination efforts to reduce the incidence of cervical cancer and precancerous lesions.
- Young Breast Cancer Survivors
  - The Young Breast Cancer Survivors Study is funded by the CDC and will include about 100 residents of New Orleans and Baton Rouge who were under the age of 45 at the time of their breast cancer diagnosis, as well as 50 family members and 25 service providers for the young cases. For more information about the program and resources available to young breast cancer survivors, please visit [www.survivedat.org](http://www.survivedat.org).
- SEER Rapid Response Surveillance Studies (RRSS)
  - These are short-term studies evaluating a wide range of topics, including surveillance methods, treatment outcomes, screening practices, health behaviors, and potential improvements in registry operations. These studies may serve as the basis for larger research initiatives funded by other organizations. We apply and participate in SEER RRSS every year.
- SEER-Linked Virtual Tissue Repository (VTR)
  - The objectives of the VTR project are to assess the ability of the SEER registries, including the LTR, to serve as a resource for biospecimen research, locate cases with biospecimens in pathology laboratories and determine the requirements to retrieve those biospecimens, provide custom annotation of specified data items, and to capture information on costs for identifying each available biospecimen and performing custom annotation on each biospecimen.

The LTR also participates in the following linkage studies:

- Linkage Study for the Forteo Post-Approved Osteosarcoma Surveillance
  - The purpose of this study is to link the LTR data with the Forteo Patient Registry data for an estimation of the incidence of osteosarcoma in patients who received Forteo treatment.
- American Cancer Society Cancer Prevention Study II
  - This study examines the impact of environmental and lifestyle factors on cancer etiology in a large group of American men and women.
- American Cancer Society Cancer Prevention Study III
  - This linkage will allow researchers to identify incident cancers within the cohort and obtain diagnostic and prognostic information necessary to conduct epidemiologic analyses related to cancer.
- NCI-American Association of Retired People (AARP) Diet and Health Study
  - This prospective study aims to elucidate the impact of diet and lifestyle factors on the likelihood of developing or dying from cancer.

- Black Women’s Health Study
  - The goal of this study is to identify and evaluate causes and preventions of cancers and other serious illnesses among African-American women.
- Southern Community Cohort Study
  - This NCI-funded study addresses many questions about the root causes of disparities in the incidence of chronic diseases, including cancer, to help prevent and reduce the burden of cancer among all populations.
- SEER Medicare Linkage Project
  - This linkage of NCI-SEER data with data from the Centers for Medicare and Medicaid Services creates a unique population-based source of information that can be used for studies on patterns of care for cancer patients aged 65 years and older.
- Cancer Incidence Study of Shell Manufacturing Employees in Louisiana
  - The purpose of this study is to determine the cancer incidence of employees at two Shell facilities by comparing their cancer risk with that of the South Louisiana general population.
- Gulf Long-Term Follow-Up Study (GuLF STUDY)
  - This linkage of LTR data with data collected in the GuLF STUDY will examine the relationship between oil spill-related exposures and cancer outcomes.
- NAACCR Virtual Pooled Registry (VPR)
  - The purpose of VPR is to assist researchers who want to link cohorts with multiple cancer registries. Patient data is not aggregated and remains behind each registry’s firewall for the initial linkage. A single cohort file is securely exchanged and simultaneously linked with multiple cancer registries using a standardized protocol and linkage software.

The LTR previously participated in these funded studies:

- Case Investigation of Cervical Cancer (CICC)
  - The purpose of this CDC-funded study is to understand why women continue to get cervical cancer despite the availability of prevention and early detection. Survey and medical chart abstraction data from women diagnosed with invasive cervical cancer will be collected to identify potential missed opportunities for proven public health interventions and determine the barriers and facilitators to screening.
- HPV Typing Project
  - In 2007, the LTR in conjunction with the CDC’s Division of Cancer Prevention and Control participated in a project to estimate the type distribution of human papillomavirus (HPV) in six cancer sites: cervical, anal, vulvar, vaginal, penile, and oral. In 2017, a repeat of this initiative was conducted to assess whether the HPV vaccine effected the HPV type distribution in these select cancers.
- Comparative Effectiveness Analysis of Surgery and Radiation (CEASAR)
  - The CEASAR Study is a three-year project funded by the Agency for Healthcare Research and Quality (AHRQ). Its purpose is to learn about the effectiveness of

contemporary surgical and radiation techniques for localized prostate cancer in terms of patient-reported outcomes via baseline, 6-month, and 12-month surveys, including side effects and complications of treatment.

- Patient Centered Outcomes Research (PCOR)
  - As part of the CDC's expanding data collection infrastructure, through its NPCR, the PCOR project collects longitudinal follow-up information for cancer cases of the colon, rectum, and breast (male and female) diagnosed in 2011. Follow-up includes assessment of vital status, disease recurrence, disease progression, and additional types of treatment.
- North Carolina-Louisiana Prostate Cancer Project (PCaP)
  - Prostate cancer patients from North Carolina and Louisiana were enrolled in the PCaP study, funded by the Department of Defense, to develop both effective therapies for advanced prostate cancer and techniques to distinguish between indolent and aggressive disease.
- Quality of Life in Prostate Cancer Project (QPCAP)
  - QPCaP evaluates the hypothesis that racial differences in long-term quality of life for prostate cancer survivors are the results of racial differences in pre-diagnosis health-related behaviors, socioeconomic status, and healthcare-seeking behaviors and beliefs.
- Adolescent and Young Adult Health Outcome and Patient Experience (AYA HOPE) Study
  - Compared with younger and older cancer patients, adolescents and young adults (ages 15 to 39 years old) with cancer have seen little or no improvement in cancer survival for decades. This research sought to identify factors that contribute to the poorer survival in adolescents and young adults.
- CDC Breast and Prostate Cancer Data Quality and Patterns of Care Study
  - This study involved researchers from the CDC and seven states to examine patterns of first-course treatment received by prostate cancer and female breast cancer patients.
- Measuring Your Health (MY-Health) Study
  - The MY-Health Study is funded by the National Institutes of Health at four research centers around the country to learn about the experiences of individuals in different communities who have been diagnosed with and treated for cancer, to determine the best questions that healthcare providers and researchers should ask to better understand the physical and emotional experiences of cancer patients, and to improve our understanding of the quality of life after a cancer diagnosis.
- African-American Cancer Epidemiology Study (AACES)
  - The AACES, funded by the National Cancer Institute through a grant to the Duke Cancer Institute, seeks to better understand the causes of ovarian cancer in African-American women.
- Comparative Effectiveness Research (CER)
  - In response to the need for data to support comparative effectiveness, or patient-centered outcomes, research, the Agency for Healthcare Research and Quality and

the CDC's NPCR developed this special data collection enhancement project for breast, colon, and rectal cancers as well as chronic myeloid leukemia cases diagnosed in 2011. They also established sustainable procedures to gather more information on all cancer cases, including co-morbidities, height, weight, smoking status, detailed staging, census tract-level socioeconomic status variables, and recurrence.

- Patient-Centered Outcome Study (PCOR)
  - After collecting data for the CDC-funded CER project, the LTR was awarded additional funds by the CDC to collect data on cancer recurrence and progression 5 years after diagnosis, as well as data on subsequent treatment, for the cases included in the original CER project. Because population-based cancer registries do not collect data on cancer recurrence and progression, successful collection of this information by LTR and other participating registries has provided useful data, in addition to opening opportunities for registries to enhance their ability to collect this data more efficiently.

Please visit our website for a list of [LTR Journal Publications](#).