

Cancer Incidence in Louisiana by Census Tract, 2007-2016, Q & A

Q1: What is the Louisiana Tumor Registry (LTR) and what does it do?

A1: LTR is a statewide population-based cancer registry authorized by law to collect data on all reportable cancer cases occurring among Louisiana residents. A registry serves as an official count of a specific thing and its associated identifying information. For example, the Louisiana Vital Records Registry maintains records on births and deaths that occurred in Louisiana.

A cancer registry systematically collects data on reportable cancers, which includes patient demographics, cancer type, stage at diagnosis, and the first course of treatment, as well as survival. This information is used to answer questions such as: Are more or fewer people getting colorectal cancer from one reporting period to the next?

LTR's job is to collect high-quality, complete, and timely cancer data, which guides and supports cancer prevention and control activities, as well as many other cancer-related programs and research. Policymakers, state health departments, cancer control programs and other qualified health professionals decide if further action is warranted based on the LTR data.

LTR's excellence is attested by the National Cancer Institute (NCI), the Centers for Disease Control and Prevention (CDC), and the North American Association of Central Cancer Registries (NAACCR). LTR consistently achieves the benchmark of 98% case completeness set forth by NCI, and has received a first place award for data quality and completeness from NCI's Surveillance, Epidemiology, and End Results (SEER) program for the past ten consecutive years. LTR is considered to be one of the leading cancer registries in the nation.

For more detail on LTR, please visit: <https://sph.lsuhsu.edu/louisiana-tumor-registry/>

Q2: How is the Louisiana Tumor Registry (LTR) funded?

A2: LTR is funded by the National Cancer Institute (NCI), the Centers for Disease Control and Prevention (CDC), and the state of Louisiana.

Q3: Where does the Louisiana Tumor Registry (LTR) obtain cancer data?

A3: LTR collects cancer incidence data from all healthcare facilities and providers that diagnose and/or treat Louisiana cancer patients. By law, these facilities and providers must communicate all reportable cases to LTR. Through interstate data exchanges, LTR currently obtains data from 43 state cancer registries and the registries of the District of Columbia, 3 United States territories, and Bermuda on Louisiana residents diagnosed and/or treated out-of-state.

Q4: Why does it take so long for cancer registry information to be published?

A4: Timeliness of Louisiana Tumor Registry (LTR) data consistently exceeds the benchmark set by the National Cancer Institute (NCI)'s Surveillance, Epidemiology, and End Results (SEER) Program.

Cancer registry data is retrospective, and cancer cases cannot be collected until they occur and are reported – this takes months.

The following outlines the major steps conducted by LTR staff to complete one cancer case:

- Identify a reportable case from hundreds of sources.
- Review the medical record and extract pertinent information for up to 804 data items for each cancer.
- Verify all information to ensure accuracy.
- Consolidate information from multiple sources into a consolidated record for each reportable cancer case.

Once the above steps are complete, the following quality assurance activities are conducted every year to ensure identification of all cases and high data quality:

- Consolidate information from multiple sources by reviewing over 761,000 source records yearly and eliminate duplication for patients diagnosed and/or treated by multiple providers.
- Link with death certificates and statewide in-patient discharge data to capture missing cases.
- Link with the National Death Index, Social Security Administration, and the Centers for Medicare and Medicaid Services (Medicare only) to obtain follow-up information.
- Casefinding audits are conducted each year for selected hospitals to identify missed cases. Other quality assurance audits are also conducted.

Q5: Why has the Louisiana Tumor Registry (LTR) not published data at the census tract level before 2018?

A5: Previously, laws governing the actions of LTR prohibited the release of data below the parish level. In 2017, the Louisiana Legislature passed House Bill No. 483 (Act No. 373), authorizing LTR, for the first time ever, to publish cancer incidence counts and rates by census tract. LTR is not allowed, by the same law, to publish data that would disclose the identity of any person to whom the data was related, thus violating the requirements of the Health Insurance Portability and Accountability Act (HIPAA), which governs the use and disclosure of protected health information (45 CFR 164.514), as well as the rules of the United States Cancer Statistics (USCS) publications.

Q6: Why isn't the cancer incidence rate for every census tract in Louisiana reported?

A6: Louisiana Tumor Registry (LTR) can only report cancer incidence rates for individual census tracts that meet the publication criteria. Federal Health Insurance Portability and Accountability Act (HIPAA) law prohibits publication of health information by geographic

area when the underlying population is 20,000 or less. The United States Cancer Statistics (USCS) publication standards for generating reliable cancer incidence rates requires case counts of 16 or more. However, all census tracts in Louisiana were included when calculating the state rate.

Q7: What is a census tract? How do I know which census tract I live in?

A7: Census tracts are small, relatively permanent statistical subdivisions of a parish. Census tracts generally have a population size between 1,200 and 8,000 people.

To identify the census tract in which you live, please follow the instructions in the report on page vi and use the links to the census tract reference maps on page vii.

Q8: Why do you report cancer incidence by census tract but not zip code?

A8: The reason that Act No. 373 requires the use of census tracts rather than zip codes is that zip codes do not have distinct geographic boundaries. Designed by the United States Postal Service for use in mail delivery, zip codes represent carrier routes made up of individual addresses. A true representation of zip codes may separate out individual housing units, and releasing zip code data may risk disclosing personally identifiable information. In addition, census tracts are more consistent and exist even where mail service does not.

Q9: Why isn't the cancer I want to know about listed? How were these cancers selected?

A9: If the cancer type you are interested in is not included in the report, this means that no census tracts met the publication criteria for that cancer type. All cancer types that met the publication criteria were included in the report.

Q10: Are cancer incidence rates higher in the industrial corridor?

A10: The industrial corridor consists of Ascension, East Baton Rouge, Iberville, St. Charles, St. James, St. John the Baptist, and West Baton Rouge parishes. Industrial corridor census tract cancer incidence rates vary when compared to the overall Louisiana rate, with some tracts exhibiting higher rates, some with rates similar to that of Louisiana, and some lower.

Q11: Does "Cancer Alley" exist?

A11: Given the data items routinely collected by the Louisiana Tumor Registry (LTR), this question cannot be answered. LTR collects data on cancer diagnosis, treatment and survival according to the national data standards and data dictionary of central cancer registries, but does not collect information on individual risk factor exposures, such as tobacco, obesity, poor diet, family history of cancer, physical inactivity, or exposure to environmental pollutants (i.e. years of exposure, exposure level, etc.).

Assessing an individual's exposure to the above factors and their association with cancer would involve well-designed research studies. Given the limited number of studies

investigating whether residents in the industrial corridor have an increased cancer risk, the existence of “Cancer Alley” has not been proven thus far.

Q12: Can cancer registry reports be used to evaluate a link between emissions and cancer?

A12: Louisiana Tumor Registry (LTR), as well as other state population-based cancer registries in the United States, collect standard data items on reportable cancers. However, registries do not collect information on exposures or emissions. Cancer is a general term for over 100 different diseases with causes or links such as smoking, viruses, alcohol use, heredity, obesity, and radiation, as well as many industrial exposures. Many cancers do not yet have causes identified. Cancer also has a long latency period from exposure to cancer risk factors to the development of cancer. For example, people who smoke generally do not develop cancer until 20 to 40 years after. Many things can happen to a person across those decades including people moving from place to place. Nationally, cancer registries collect cancer cases based on the address at the time of diagnosis. Someone diagnosed with cancer could have moved from an area of high exposure, but the registry would only have the address at diagnosis and would not be able to make that connection. This could make the cancer rates lower in an area of high exposure. If LTR data shows a higher incidence rate in an area, the Office of Public Health will determine whether to proceed with a more in-depth investigation of a suspected “cancer cluster,” which is defined as a greater than expected number of cancer cases among a group of people in a defined geographic area over time:

<https://www.cancer.gov/about-cancer/causes-prevention/risk/substances/cancer-clusters-fact-sheet>).

However, for reasons listed above, it is very difficult to link a cluster to a particular cause. So in short, cancer rates alone neither prove a link between cancer and an industrial emission nor disprove such a link.

Q13: Why did you combine 10 years of data in this report?

A13: To comply with Health Insurance Portability and Accountability Act (HIPAA) and the United States Cancer Statistics (USCS) publication standards, we combined multiple years of data together to increase the number of census tracts meeting the publication requirements (population count > 20,000 and number of cancer cases ≥ 16). If we used only one year of data, no census tracts would have met the publication criteria.

In this report, cancer incidence data from 2007 through 2016 are included. Cases diagnosed after 2016 are not included because the most recent, complete cancer incidence data in Louisiana is from diagnosis year 2016, which is consistent with other state cancer registries in the U.S.

Q14: Why did you use a different population data source in this year’s census tract report?

A14: In our 2018 and 2019 reports, we utilized the 2010 Census population data. The year 2010 fell in the middle of the diagnosis years that were included in our two previous reports, so using population counts from the 2010 Census was appropriate assuming a steady

population growth over those years. However, in this year's report, as we add diagnosis years that are further away from 2010, the use of the 2010 population as the population count for these later diagnosis years could overestimate the cancer incidence rate. Therefore, we decided to utilize population data from Woods & Poole Economics, Inc., which estimates the population count for each individual year at the census tract level. The estimates of population count by Woods & Poole were made based on the 2000 Census and 2010 Census for intercensal years (2001-2009) and 2010 Census for postcensal years (2011-2019). For more details on the methodology utilized by Woods & Poole, please see Appendix B of *Cancer Incidence in Louisiana by Census Tract, 2007-2016*. Prior to making this decision, we consulted with experts from the National Cancer Institute and conducted an analysis to ensure that these population estimates would result in reliable incidence rates.

Q15: What does invasive mean with regard to a cancer diagnosis?

A15: An invasive cancer is a cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues. Only invasive cancer cases are included in the report to be consistent with cancer surveillance publications. The only exception is bladder cancer for which both in situ and invasive cancers are included due to the difficulty in distinguishing in situ and invasive cancers of the bladder.