

TRACKING CANCER IN LOUISIANA



MISSION >

SAVING LIVES WITH DATA

You can't fix a problem until you know what and where it is

The award-winning Louisiana Tumor Registry (LTR) is a statewide population-based registry that compiles information to help guide policies for cancer prevention, early detection, diagnosis, treatment, prognosis, and survivorship. LTR data help reduce the state's cancer burden and disparities, and improve the survival and quality of life for cancer patients, past, current and future. LTR data users include:

- Office of Public Health
- Cancer prevention programs
- Cancer researchers
- Physicians, medical practitioners
- Healthcare planning offices
- Public health community
- Cancer patients

LTR participates in the National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) program and the Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR). Due to LTR's exemplary and award-winning work, the CDC is also funding it to collect data in the following areas:

- Comparative effectiveness research (one of 10 registries doing so)
- Implementing the Caroline Pryce Walker Conquer Childhood Cancer Act (one of seven registries)
- Cancer recurrence and progression (one of five registries)
- Pre-cancerous lesions of the cervix (one of four registries)

LTR's work is critical to the state, as Louisiana has one of the highest cancer death rates in the U.S. - much of it preventable - while also bringing in millions of dollars in federal funding.

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ECONOMIC IMPACT >



LTR BRINGS IN ALMOST \$4M IN DIRECT FUNDING EACH YEAR

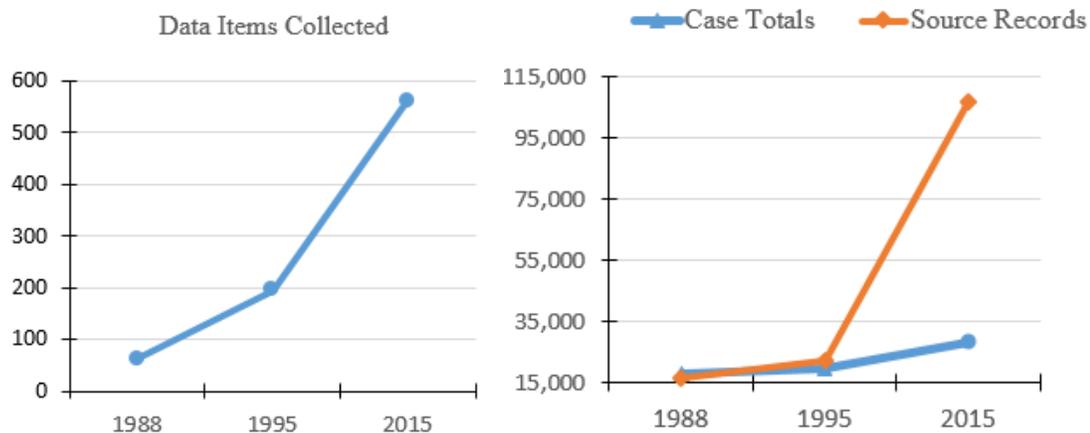
A state budget cut will mean less federal funds for LA

LTR is mainly funded by the CDC and the National Cancer Institute (NCI), which provides a 5-to-1 match to state funds, with the requirement that the state provide the basic infrastructure in a mandated cost-sharing arrangement. Cuts to LTR by the state will not only lessen the \$4 million in direct federal funding Louisiana receives, but will also negatively affect the other organizations that rely on LTR data to help obtain millions in outside funding, with the award-winning LTR having a widespread indirect economic impact across the state.

AWARDS & THREATS >

BUDGET CUTS THREATEN TOP LTR REGISTRY

Data requirements rise 8-fold with no funding increase; state wants more



Despite being one of the top U.S. cancer registries, LTR has not received a state general fund budget increase in 30 years, even as:

- Data items have increased from 63 to 542 standard questions: 1000+ on certain cancers.
- Information collection has grown from less than 200 facilities in 1988 to 500+ (hospitals, treatment centers, doctor's offices, pathology labs, nursing homes, hospices, 45 state cancer registries, and follow-up data from Medicare, Medicaid, LDH, SSA, the National Death Index, etc.), radically increasing the number of source records that must be examined.
- Annual cancer case counts have risen.

In addition, the LA state legislature recently mandated census-tract level cancer incidence data be published, a lengthy process to produce a reliable report that only one other state registry reports. (Why is it so difficult? One example: people who list a P.O. Box as an address must be tracked and linked to their specific residential address.)

Cuts not only threaten the basic data being

collected now, but would also impact the federal funds that require a match, indirect funding, as well as studies on the HPV vaccine, cervical cancer, prostate cancer, Body Mass Index (BMI), and a comorbidity/ hospital study - all of which impact Louisiana disproportionately, due to the state's low health ranking. Staff retention is also becoming an issue, as people can make more money with lower caseloads at other organizations.

LTR is one of the few bright spots in the state's health landscape. Its work is highlighted on a regular basis (published in 200+ peer-reviewed journals in 2015 alone). It is also one of the top registries in the country, winning:

- The Gold Certificate from the North American Association of Central Cancer Registries every year since 1997. In 2012, LTR alone received its 20th Anniversary Research Award.
- 1st place awards for the last 8 years from NCI's SEER program.
- Met all data standards of the CDC-NPCR program every year since 1998.