Louisiana Tumor Registry: Mission, Progress, and Opportunities

Xiao-Cheng Wu, MD, MPH
Director, Louisiana Tumor Registry
Professor, Epidemiology & Population Health Program
School of Public Health, LSU Health New Orleans

Louisiana Cancer Board Meeting September 25, 2025

1

Outline

- LTR Mission and Vision
- Legislative Mandate
- History and Achievements
- LTR Structure and Funding Sources
- Current Priorities, Challenges, and Opportunities
- Q&A

What is the Louisiana Tumor Registry (LTR)?

LTR is legally authorized to undertake the ongoing and systematic collection, storage, and management of essential population-based cancer data. It serves as a vital resource for cancer surveillance, research, prevention, and control.

MISSION

LTR Mission:



To collect and report complete, high-quality, and timely populationbased cancer data in Louisiana to support cancer research, control, and prevention.



LTR Vision:



To reduce suffering and death from cancer using information collected by the Louisiana Tumor Registry.

3

Legislative Mandate of the Louisiana Tumor Registry (LTR)

- State Law: Designated as Louisiana's official, population-based cancer registry.
- Authorized Role: Access identifiable cancer patient information from all hospitals, pathology laboratories, radiation centers, physicians, nursing homes, coroners, and other licensed healthcare facilities and providers.
- Scope of Work: Collect, manage, and analyze all reportable cancer cases statewide.
- Public Health Purpose: Provide data for cancer surveillance, guide cancer prevention and control, inform policy decisions, and support research.

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LTR History and Achievements

- Established in the Early 1980s: Created by legislative mandate as Louisiana's official, population-based cancer registry.
- National Participation: part of the NCI-SEER and the CDC-NPCR Programs.
- National Recognition for high quality, completeness, and timeliness:
 - o **NCI-SEER:** 1st place award, every year for the past 15 years.
 - o NAACCR: Gold certification every year since the 1990s
 - o CDC-NPCR: Registry of Excellence/Distinction
- Cancer Control Resource: Support statewide cancer control planning, target interventions, and program evaluation.

5

LTR History and Achievements (Cont.)

- Research Infrastructure: Provide data, linkages, and biospecimens to advance diverse research.
- **Policy Impact**: Inform healthcare policy, resource allocation, and legislative decisions.
- Scientific Contributions: Supply high-quality data for peer-reviewed publications, surveillance reports, visualization tools, and cancer research.



LTR Structure and Funding Sources

- **Housed at:** LSU Health New Orleans
- Statewide Network:
 - LTR central office + in-house region
 - Regions 2/5: Mary Bird Perkins Cancer Center
 - **Regions 4/6:** Acadian Medical Research Foundation
 - **Regions 7/8:** University of Louisiana in Monroe
- Funding support for routine operations:
 - **State** (34%): Data collection from hospitals
 - CDC-NPCR (19%): Quality assurance, data dissemination, and cancer control programs.
 - NCI-SEER (47%): Non-hospital settings, advanced case consolidation and edit, patient follow-up, and infrastructures for research
- **Grant and contracts:** Additional competitive funding for special research studies

7

LTR Challenges

- Manual data collections: LTR and its regional staff manually collect data from hundreds of hospitals and non-hospital settings, except for ~30 hospitals that operate their own cancer registries.
- Limited remote access to EMRs: LTR and its regional staff have limited remote access to medical records, making data collection more difficult and time-consuming.
- Workforce shortage: National and statewide shortage of oncology data specialists (ODS)/certified tumor registrars (CTR).
- Rising Complexity: Growing demands for more detailed, clinically relevant data and new coding systems (64 data items in 1987 and over 800 per cancer case today).
- Level funding: Increased data items, more source records, rising ODS salaries, and leveled or reduced funds.

LTR Priorities and Opportunities

- **Maintain Excellence:** Sustain high-quality, complete, and timely cancer data to achieve SEER, NPCR, and NAACCR requirements.
- **Expand Remote Access to EHRs:** Increase secure remote access to medical records at hospitals and providers' offices.
- Develop innovative approaches:
 - Automatically code data from electronic pathology reports
 - Extract data not captured in the LTR database by linking to medical records.



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LTR Priorities and Opportunities (Cont.)

- Enhanced Visualization and Repository Access:
 - Enhance visualization tools
 - Streamline the Virtual Tissue Repository (VTR) program, enabling more efficient research and deeper insights.
- Support Cancer Control and Clinical Trial Networks: Strengthen collaborations to inform prevention, resource use, and research translation.











