

Louisiana Cancer Surveillance Moving to Higher Level

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DON'T FOCUS ON THE
PROBLEM
FOCUS ON THE
SOLUTION

problem
+
attitude = outcome

A top-down photograph of several people's hands stacked in a circle on a grey floor. The hands are of various skin tones and are reaching from the edges of the frame towards the center. The background is a plain, light-colored floor. The overall mood is one of unity and collaboration.

*"People
working
together
in a strong
community
with a shared goal,
and a common
purpose
can make the
impossible,
possible."*

– Tom Vilsack

Louisiana Tumor Registry (LTR)

- **Mission:**

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

- **Vision:**

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



Louisiana Tumor Registry (LTR)

- While working to achieve the mission - collect and report complete, high-quality, and timely population-based cancer data in Louisiana, we need to strategically and continuously build infrastructures for advancement and incoming challenges.
- **Urgent vs Important**
 - Urgent tasks require immediate attention
 - Important tasks contribute to our long-term mission, value, and goals.



Urgent vs. Important

1. Urgent/Important (necessity)

- Obtain complete, high quality and timely data
- Identify and resolve issues in cancer reporting
- Meet deadlines and deliverables

2. Not Urgent/Important (quality)

- Strategic planning
- Maintain a competent team
- Build infrastructures
- Promulgate Legislative rules meeting new needs
- Improve the efficiency of processing data
- Build partnerships
- Enhance uses of cancer registry data

Urgent and Important Tasks

- Complete, high quality, and timely data
 - Cancer control planning, interventions, and evaluations as well as policymaking.
 - Investigate suspicious cancer clusters in small communities.
 - Allocate health care resources.
 - Support cancer research

Incomplete and inaccurate data will lead to wrong decisions and actions on cancer control, public investigations, and policymaking.

- Increased requests to assess the cancer risk in small geographic areas using LTR data.
- LTR is required by legislative rules to publish cancer incidence counts and rates at the census tract level
- CDC's National Environmental Public Health Tracking is working to publish cancer data below the county level.
- NCI-SEER started the Zoom design project showing cancer data in small areas.

The complete case ascertainment never is so critical because missing a small number of cases may change the conclusion of risk assessments.

Louisiana officials say they will conduct 'comprehensive study' of cancer risks near Denka plant



Louisiana Legislative Rules

- All healthcare facilities and providers are required by law to report cancer cases to the Louisiana Tumor Registry (LTR).
- LTR will have to trace back to the health care facilities for any missing cases identified from any public health investigations and answer the public how the cases were missed.
- LTR makes every efforts to ensure complete case ascertainment, but cannot audit 100% of cases.



LTR's Efforts to Ensure Complete Data

- **E-path reporting (95% coverage):** Capture microscopically confirmed cases
- **E-radiology reporting (10 rad centers only):** Capture clinically diagnosed cases.
- **Statewide hospital inpatient discharge data (HIDD)**
 - Only cover 50% of the licensed hospitals
 - Pancreas, kidney, benign/borderline brain tumors
 - Cannot capture all clinically diagnosed cases
- **LTR casefinding audits**
 - Selected hospitals
 - 2-3 month of disease indexes
 - Cannot capture all missed cases



Complete Case Ascertainment

- LTR relies on hospital and regional abstractors to make efforts to ensure complete case ascertainment
 - Analytic and non-analytic
 - In-patient and out-patients
 - Microscopically confirmed and clinically diagnosed

Registry Casefinding and Disease Index Preparation:

Are You Capturing All Your Cancer Cases?

- IP/OP Admission/Discharge Documents
- Pathology/Cytology Pathology Reports
- Surgery Logs/Schedules
- Radiology
- Nuclear Medicine
- Radiation Therapy Logs
- Chemotherapy Outpatient Logs
- Emergency Room Records
- Autopsy Reports
- Pain Clinic Logs

- Use the most current ICD code casefinding list

<https://sph.lsuhscl.edu/louisiana-tumor-registry/cancer-reporting/hospital-reporting/resourceful-registrars/>

Why Is Important to Screen Out-patient Disease Index and Other Logs?

- It may be the only clue to detect cancer cases
 - Receive care at MD offices
 - Missed by other reporting hospitals
 - Did not receive treatment
 - Receive care at out-of-state hospitals and MD offices
- How can we deal with issues of understaffing with hospital cancer registries?
 - Help hospital administrators understand the legal obligation to report all cancer cases to LTR in compliance with the law.
 - Develop innovative approaches to achieve the completeness of cancer reporting with fewer resources.



LTR's Efforts to Ensure High Quality Data

- **Electronic editing:** Run electronic SEER, NPCR, NAACCR, and in-house editing programs used to identify and correct coding errors.
- **Manually editing:** Manually review All NAACCR abstracts to identify and correct errors based on attached source records.
- **Re-abstracting audit:** Identify abstracting and coding issues
 - Selected hospitals, cancer sites, and small numbers of cases.
 - Cannot identify all issues.
- **Re-code audit:** Identify inconsistencies between coded values and texts
 - Selected hospitals, cancer sites, and small numbers of cases
 - Cannot identify all issues

Accuracy Rates Varied by Hospital Registries

- LTR re-abstraction audit (2015 diagnosis year) showed a large variation in the accuracy rate by hospitals

Data Type	Accuracy Rate
Demographics	69.3% - 74.7%
Tumor characteristics	76.0% - 95.5%
CS staging	70.6% - 91.3%
SSFs	63.3% - 85.0%
Treatment	68.0% - 90.9%

- Re-abstraction audits are needed at the hospital level to identify and resolve abstracting and coding issues. LTR can provide needed education and training.

LTR's Efforts to Ensure Timely Data

- Established the timely data reporting policy and reporting calendars

<https://sph.lsuhsu.edu/louisiana-tumor-registry/cancer-reporting/hospital-reporting/>

- Closely monitor the timely reporting by facility and region
- 15-month data resubmission: Obtain complete treatment data while meeting the 6-month timeline for timely reporting.
- LTR will notify hospitals if the timely data submission is not feasible such as the delay in submitting 2018 diagnosed cases.
- Hospitals need to notify LTR central or regional offices if delaying data submissions are not preventable.

Important Tasks – Strategic Planning

- **Challenges for cancer surveillance**
 - More timely data
 - More complete data
 - More clinical relevant data such as SSDI to support the precision medicine
 - Complete 1st course and subsequent treatment data
 - Long-term outcome measures such as recurrence
 - Comorbid conditions
 - Support biospecimen research

To effectively respond to these challenges, we must have well-thought strategic planning.

Building Infrastructures

- Continue to implement electronic reporting
 - E-path reporting, including ADT and e-path forwarding
 - E-radiology reporting
 - Electronic health information exchange (EHIE)

- Obtain data via linkages with
 - Genomic Health Incfor Oncotype Dx
 - Statewide STD/HIV data
 - Claims and pharmacy data

Enhance Uses of LTR Infrastructures

- Rapid case ascertainment thru e-reporting to support research
 - Successfully support research studies, such as CEASAR, MY-Health, osteosarcoma, breast cancer young survival studies.
- Virtual pool registry (VPR) to support studies requesting data from multiple registries.
- Participate in the NCI-SEER initiations to develop tools for automation (natural language process/machine learning) to reduce manual abstraction and improve consistency and accuracy.

Building Infrastructures

- Establish the virtual tissue repository (VTR) to support biospecimen research
 - Use path reports to select eligible cases
 - Annotate biospecimen samples with registry data
 - Only release de-identified biospecimen samples to IRB approved research
- Examples
 - SEER-Linked VTR study: breast and pancreatic cancers
 - TNBC study: the association of obesity with unfavorable immunological biomarkers and differences in molecular and expression of immunological biomarkers between white and black women

Building Partnerships to Enhance Uses of LTR Data

- Louisiana Cancer Prevention and Control Programs, including the Louisiana Breast & Cervical Cancer Health Program and Louisiana Colorectal Cancer Roundtable
- LSUHSC Stanley S. Scott Cancer Center
- Gulf South Minority-Based NCI Community Oncology Research Program
- Louisiana Public Health Institute's REACHnet
- Taking Aim at Cancer in Louisiana (TACL)

Building Partnership to Enhance Uses of LTR Data

- Louisiana Department of Health
 - Section of Environmental Epidemiology and Toxicology
 - Environmental Public Health Tracking Program
 - Statewide STD/HIV program
 - Statewide HIDD
 - Statewide Immunization Program
 - Vital records office



Efforts to Increase Uses of LTR Data

- “Cancer Incidence in Louisiana by Census Tract ” reports
 - Advanced uses of LTR data
- Geospatial cancer data and mapping to display geographic patterns
 - Identify areas with a high proportion of late-stage CRC cancers for the Colorectal Cancer Roundtable.
 - Design sub-county zones for cancer surveillance reporting
- Data Visualization: Query LTR data on incidence, prevalence, stage, and survival online.
- In 2017, 724 journal papers using LTR data and 24 papers by LTR authors
- Respond to hundreds of data requests

Is it a group of people,
or a **team**?

What makes
the difference?



Work Together: We Can Make Impossible Possible!

Together ...



... We Can

