

# Cancer Surveillance Program Data as a Vital Tool for Public Health Practitioners

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## Objectives

To illustrate the breadth of data collected by cancer surveillance programs and how the data can be used in public health research and program development.

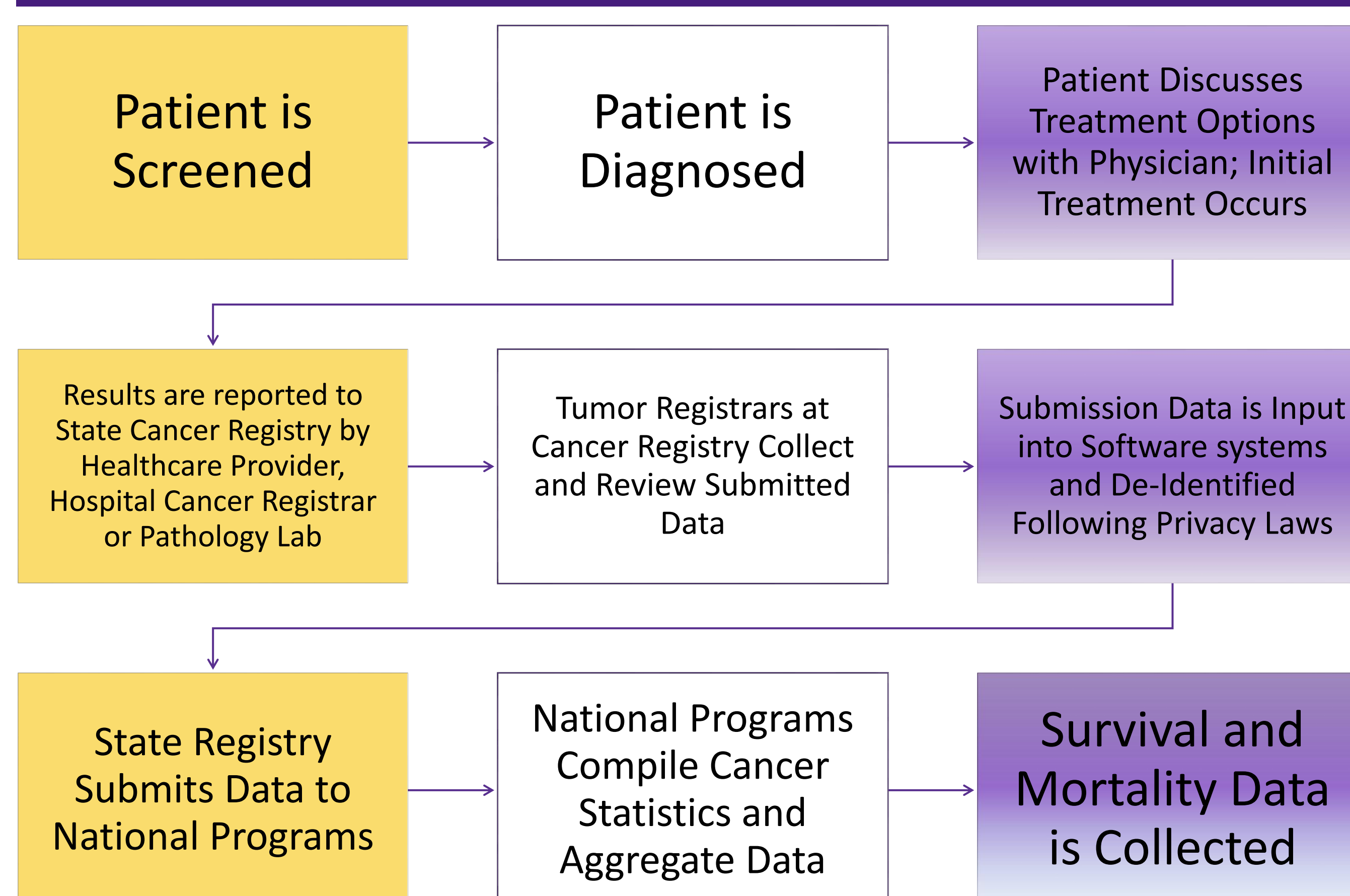
## Background

Surveillance, the systematic continuous collection, analysis, and interpretation of data,<sup>9</sup> is a core practice in nearly all aspects of public health. Cancer surveillance programs are essential to the advancement of cancer research. These programs provide researchers with vast amounts of data for calculating a multitude of statistics related to cancer incidence, mortality, and survival. Each state within the United States has a population-based cancer registry to which healthcare providers are required to report newly diagnosed cases of cancer. These registries compose a network who compile high-quality surveillance data on incident cases of cancer.<sup>3</sup>

Cancer registry data is often misunderstood due to its highly complex composition. Data collected by cancer registries are numerous. Factors such as demographics, cancer morphology, stage at diagnosis, and treatment information are typically collected.<sup>4</sup> One factor not collected that is important to point out is causal data. Therefore, it is impossible to make causal associations utilizing cancer registry data alone.

While it is evident in the vast returns within database searches (6,590 peer-reviewed articles with "SEER Registry and 134,170 peer-reviewed articles with "cancer registry" between 2000 and 2022) that cancer registry data is used thoroughly within research globally, it is important to understand how cancer registries work, the guidelines registries must follow, and what data are collected. Further, it is important to clarify ways that data from cancer registries can be used in multiple area of public health.

## Cancer Registry Data Collection Process<sup>2</sup>



## Louisiana Tumor Registry

Louisiana Revised Statute 40:1105.1 established the framework for the creation of the Louisiana Tumor Registry (LTR).<sup>5</sup> RS 40:1105.1 requires that all healthcare facilities in the state report any newly diagnosed case of cancer to LTR.<sup>5</sup> Louisiana Administrative Code Title 45, part five lays out the rules that govern the operations of the LTR, data collected, and confidentiality regarding the data.<sup>5</sup>

Cancer registration began in New Orleans in 1947, with statewide coverage was achieved 1988.<sup>7</sup> In 2001, LTR was selected to join the Surveillance, Epidemiology, and End Results program.<sup>7</sup> LTR has a long history of achievements and awards including Gold Certificates from the NAACCR since 1997, meeting the standards of the NPCR since 1998, met or exceeded data quality goals in the SEER Data Quality Profile with a first-place award annually since 2009, among others.<sup>8</sup>

LTR data are made available to the public through the annual Cancer in Louisiana monograph, the interactive data visualization on the website, cancer one-pagers, special publications, and through special request.<sup>6</sup> LTR collects more than 500 data points from more than 716,000 source records annually.<sup>6</sup> Data must meet case count minimum standards to be released in order to protect confidentiality and rate strength.

## Data Collected by Cancer Registries

**Vast amounts of data are collected by cancer registries annually. This complex data collection helps to build a comprehensive database from which statistics such as cancer incidence, mortality, and survival can be compiled.**

- Age
- Gender
- Race/Ethnicity
- Geographic/Location Data
- Other Demographic Data
- Primary Cancer Site
- Morphology
- Stage at Diagnosis
- First Course of Treatment

## National Cancer Registry Programs in the US

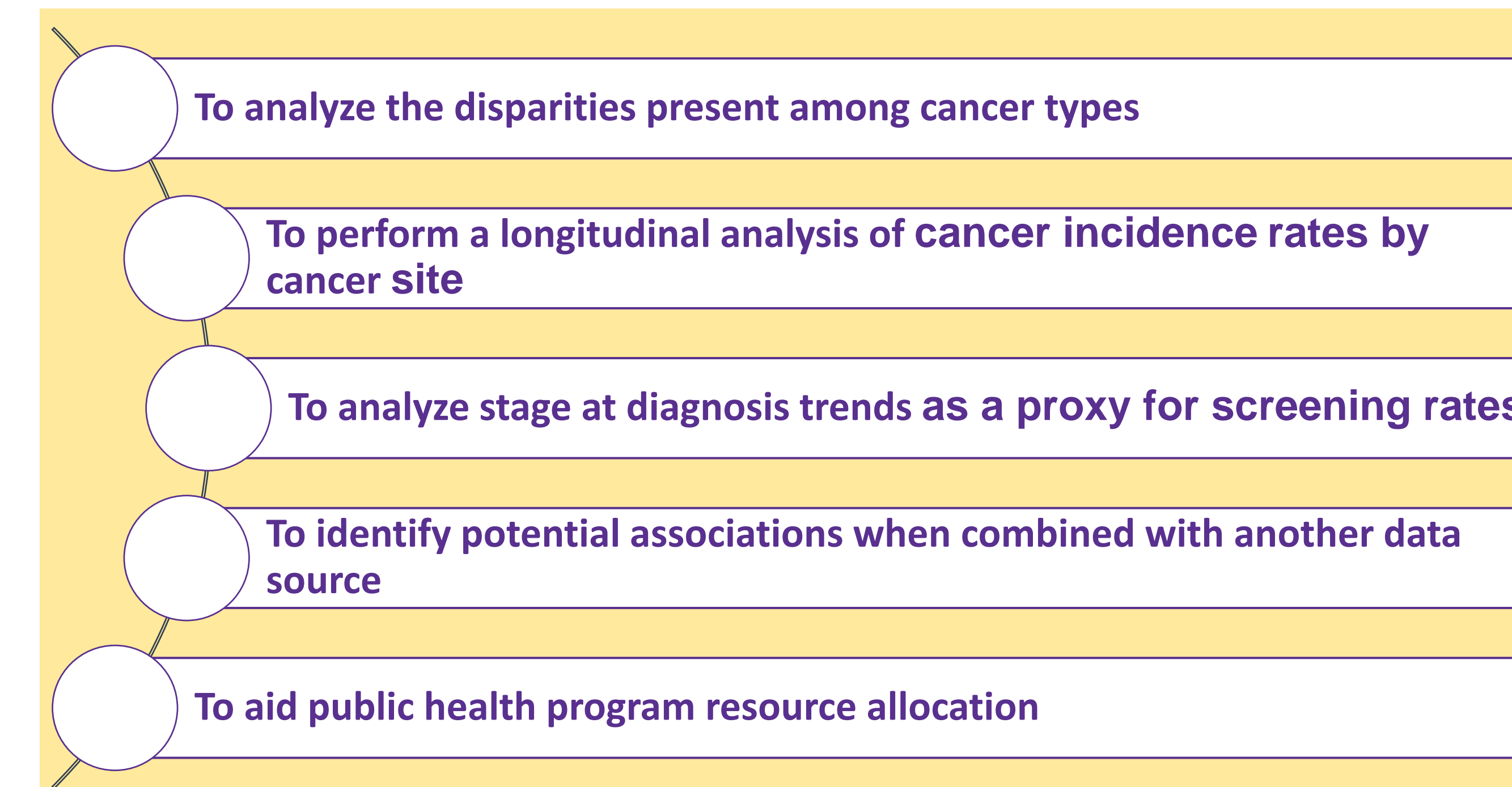
### CDC: NPCR

- Since 1992
- Supports central registries in 46 states, DC, Puerto Rico, US Pacific Island Territories, and the US Virgin Islands
- Represents approximately 96% of the US population

### NCI: SEER

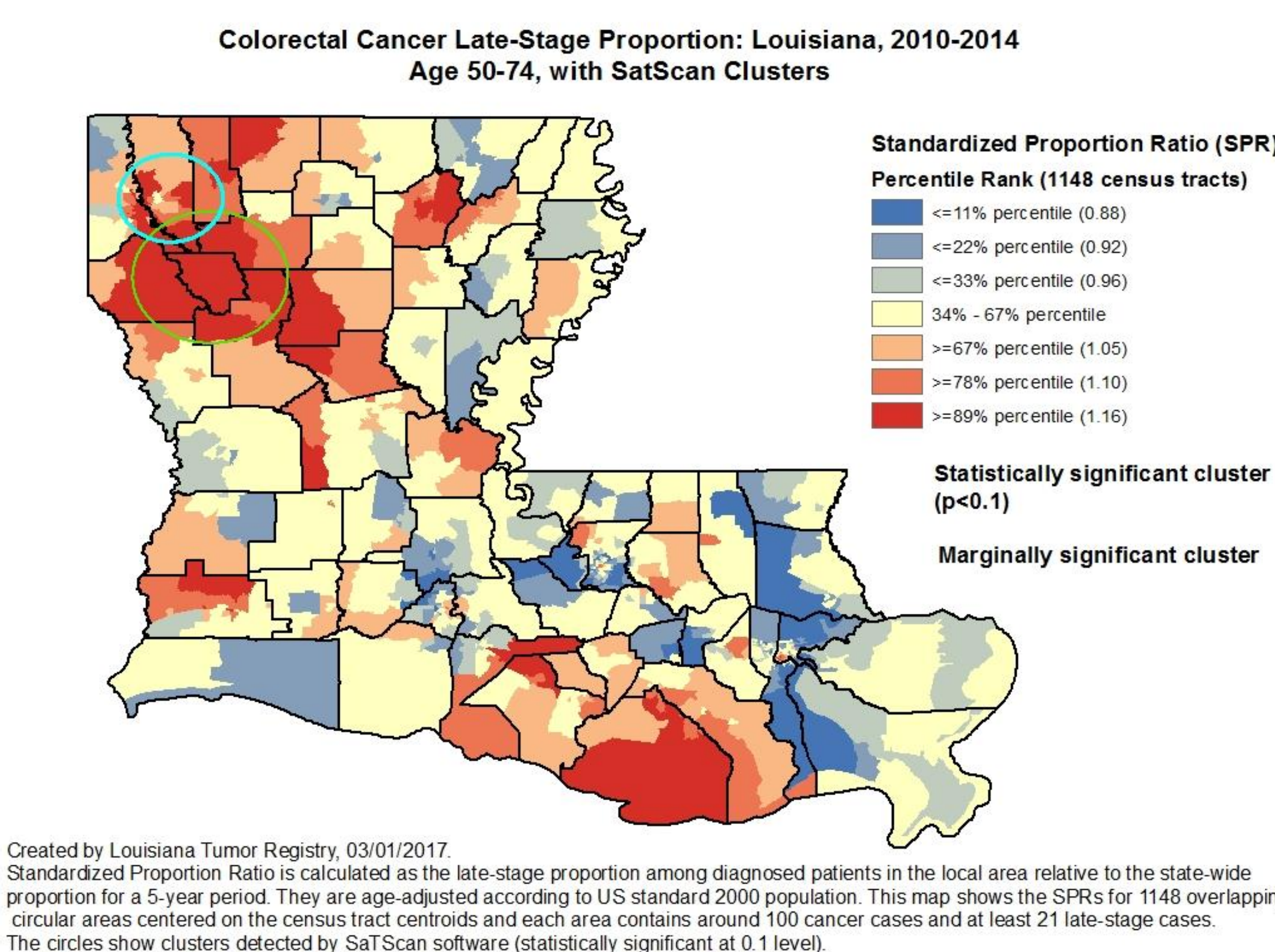
- Since 1971
- Network of 18 Core registries and 10 Research Support Registries
- Represent approximately 48% of the US population
- Includes 3 registries of Indigenous populations

## How Cancer Registry Data Can Be Used



## Example of Using Cancer Registry Data

Cancer registry data was utilized through this geospatial pilot project by the LTR to identify areas where colorectal cancer screening rates are low. Through a SatScan cluster analysis, late-stage proportion was analyzed to identify hotspots where late-stage proportion was higher than the state average. With this information, colorectal cancer screening programs could focus resource allocation to these areas in need (ex. provider education, allocating screening resources).



## Sources

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- <sup>3</sup>White, M. C., Babcock, F., Hayes, N. S., Mariotto, A. B., Wong, F. L., Kohler, B. A., & Weir, H. K. (2017). The history and use of Cancer Registry data by Public Health Cancer Control Programs in the United States. *Cancer*, 123, 4969-4976. <https://doi.org/10.1002/cncr.30905>
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- <sup>8</sup>Louisiana Tumor Registry. (2016, August 10). *Achievements*. Louisiana State University Health New Orleans School of Public Health. Retrieved March 23, 2022, from <https://sph.lsuhscc.edu/louisiana-tumor-registry/about-the-registry/achievements/>
- <sup>9</sup>Porta, M. S. (2014). *A dictionary of epidemiology*. Oxford University Press.