

The role of central cancer registries in the investigation of unusual patterns of cancer

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Overview

- Cancer surveillance overview
- Investigating potential cancer clusters
- How registries will be able to apply the updated guidelines
- Incorporating genomic data into cancer surveillance

Cancer Surveillance in the US

- National system of central (state) cancer registries
 - Collect incidence data, population-based, not a sample
 - Primary Role: Identify burden and trends of cancer, support cancer control programs
 - Secondary Role: Generate hypotheses about cancer risk and etiology
 - Goal: Guide policy decisions to reduce the burden of cancer
- NAACCR (North American Association of Central Cancer Registries)
 - Non-profit, collaborative organization that supports central cancer registries, governmental agencies, other orgs
 - Develop national data collection standards
 - Evaluate and Certify registry data based on data quality
 - Support scientifically rigorous and relevant analysis of cancer data

Cancer registry activities—local & national

- Generate annual cancer rates/trends
 - County and sub-county, visualize data on a map
- Provide data for cancer control and research
- Respond to community concerns
 - Evaluate O/E rates by geography, coordinate with environmental health, geospatial analysis
- NAACCR Committee work
 - Workgroups address data collection and analysis issues

Investigations of potential cancer clusters

- Methodologic limitations
- Increase found but cause unknown
 - Could be unrelated/random
 - Could be real but cause unidentified
- Unintended consequences
- Known health hazards
 - Should be addressed proactively
 - Not wait for study results

Annals of Internal Medicine

ESTABLISHED IN 1927 BY THE AMERICAN COLLEGE OF PHYSICIANS

From: Mapping It Out: Using Atlases To Detect Patterns in Health Care, Disease, and Mortality

Ann Intern Med. 2000;133(2):161-162. doi:10.7326/0003-4819-133-2-200007160-00102

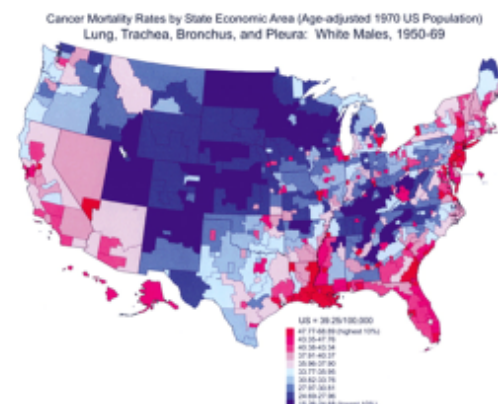


Figure Legend:

Cancer Mortality Rates by State Economic Area (Age-adjusted 1970 US Population). Lung, Trachea, Bronchus, and Pleura: White Males, 1950-69.

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CDC/ATSDR Guidelines

- Registries apply guidelines when responding to cancer concerns
- Recent updates addressing proactive & continuous monitoring
 - Registries support movement in this direction
 - NAACCR has history of involvement in research supporting proactive support & cluster detection
- Registries may need additional support
 - Lack of methods & data required
 - Current level of funding/resources make it difficult to incorporate

Incorporating genomic & biomarker information

- Demographics, tumor, treatment
 - Derived from clinical records
 - Primary purpose to generate cancer statistics
 - No genetic information standardly collected
- NAACCR WG assessing feasibility of genomic data collection
- [Genomics - CodeX - Confluence \(hl7.org\)](https://hl7.org/genomics-code-x/confluence/)
 - Translate isolated pdf test reports to standardized, transferable format
 - Clinical care and research

Incorporating genomic & biomarker information

- VPR-CLS (Virtual Pooled Cancer Registry Cancer Linkage System)
 - NAACCR secure on-line service designed to:
 - Efficiently connect researchers performing minimal risk linkage studies with multiple central cancer registries;
 - Perform standardized linkages with cohort files
 - Linking potentially nimbler than collecting/storing in registry
 - Currently limited in capacity
- Potential partnerships

QUESTIONS?

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On-line cancer data:

<https://www.naaccr.org/interactive-data-on-line/>