

Lessons from Cancer Surveillance relevant to improving Epilepsy Surveillance

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Mindset: Turning *Knowledge* Into *Action*

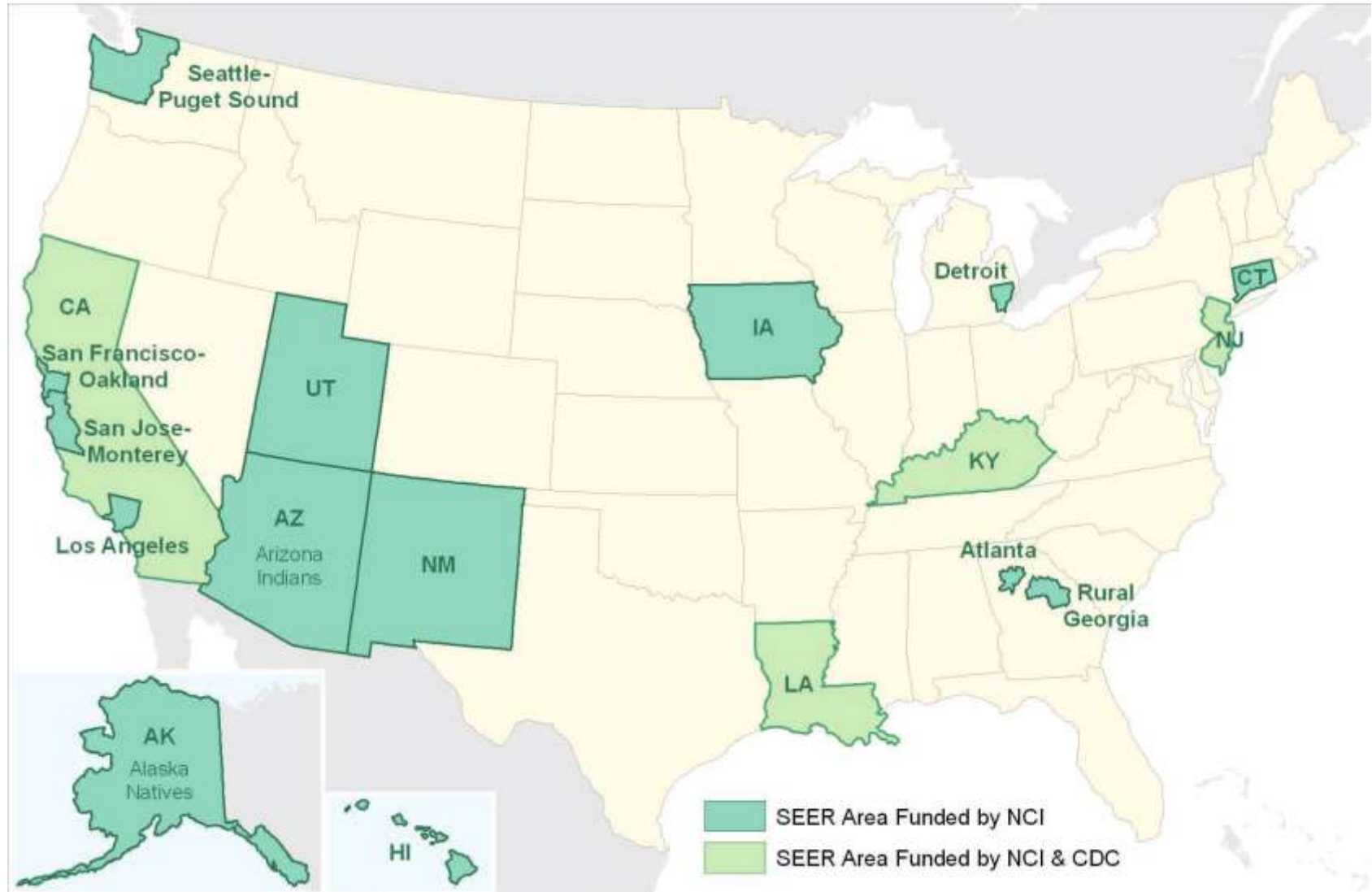
- Collect, analyze and publicize data on all incident cancers in a region
- Respond to community requests for data on cancer occurrence
- Provide data for legislative advocacy
- Achieve Cancer Control

- Determining the effectiveness of cancer control efforts:
 - Primary prevention (e.g. SunSmart programs)
 - Changing patterns of incidence over time, and in various groups (race/ethnic, SES, etc)
 - Secondary prevention (screening)
 - Rate of ‘late stage’ disease – earlier stage disease represents successful screening
 - Tertiary prevention (efficacy of care)
 - Changing mortality rates over time, or in various groups (race/ethnic, SES, etc)

Cancer Surveillance National Integration

- Cancer Registries linked to research institutes throughout the U.S. are the basis of cancer prevention and control
 - *Surveillance Epidemiology and End Results (SEER)*: NCI-funded, 15 State/Regional Registries, 26% of the U.S. population (individual records, de-identified)
 - *National Program of Cancer Registries (NPCR)*: CDC-funded, 45 State, 96% of the U.S. population (limited rate data)
 - *National Association of Central Cancer Registries (NAACR)*: Volunteer integration of US-wide data

SEER population coverage



Achieving *epilepsy* control with surveillance activities

3 Challenges
And
3 Recommendations

Key challenge: data integration and standards

- Formalize centralized data items and coding
- Revisit and revise regularly
- Provide data collection/standardization training
- Provide ‘analytic dataset’ clearinghouse and portal
- Include investigators and public comment at all stages
- Provide clear documentation

Key challenge: national integration

- Local “registry” collaboration methods:
 - Centralized processing centers
 - Combination of funded and volunteer efforts:
 - www.naaccr.org
 - Set standards
 - Organize scientific meetings
 - Community liaison and translation

Key challenge: electronic record use

- “Automatic” surveillance opportunity
- Informatics infrastructure for integrating widely differing data structures (including proprietary data systems)
- How do we deal with records that aren’t already in an electronic format, or are not ever likely to be?

Solvable

- Development of manual and automatic electronic record archiving
- Importance of determining minimum datasets.

Recommendations: address and location data

- Standardization of address collection and geocoding processes:
 - Determining appropriate population denominator estimate sources for incidence rates
 - Exposure estimates for studies of causation
 - Conducting follow-up and survivorship studies

Recommendations: follow-up

- Centralized patient follow-up for cohort studies.
(Long term follow-up Center)
 - Cohort studies provide the most useful data on causation
 - Without surveillance and follow-up data, selection and participation biases reduce scientific integrity
 - National Death Index linkage and Medicare linkage

Recommendations: rapid research

- Rapid response surveillance studies:
 - Funded through surveillance support (for SEER, through NCI)
 - Rapidly peer reviewed by surveillance community
 - Respond to events as they happen (e.g. collecting discarded tissue; including a new medical record system as it goes online)
 - Gather momentum for improving surveillance

http://statecancerprofiles.cancer.gov/

State Cancer Profiles Home Page

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Profiles Home

State Cancer Profiles
 Dynamic views of cancer statistics for prioritizing cancer control efforts in the nation, states, and counties

Help us improve!
 Contact us with feedback.



Quick Profiles

Area:

Cancer:

Graphs and Maps

5-Year Rate Changes
 in cancer mortality or incidence for all major cancer sites by user selectable criteria
[learn more...](#)

Historical Trends
 compare trends in cancer mortality and incidence by user selectable criteria
[learn more...](#)

Comparative Data Display (Micromaps)
 explore relationships across geography of mortality, incidence, demographics, or risk factors
[learn more...](#)

Interactive Maps
 for states or for counties in a state - mortality and incidence maps
[learn more...](#)

[Cancer Control P.L.A.N.E.T. Home](#)

Comparison Tables

Rate/Trend Comparisons
 set higher priority for cancer control when rates are high or rising
[learn more...](#)

- [Prioritize cancer sites](#) for a specific state or county
- [Prioritize states or counties](#) for a specific cancer site

Death Rates
 for states or for counties in a state
[learn more...](#)

Incidence Rates
 for states with high quality cancer registries
[learn more...](#)

Prevalence Projections (Breast Cancer only)
 for counts, percents and age-adjusted percents

Support Data

Screening and Risk Factors
 prevalence percents by state from behavioral surveys
[learn more...](#)

Demographic Data
 showing census data for counties and states - expanded data now available
[learn more...](#)

New Releases

[2008 Screening and Risk Factors](#)

[2006 USCS Incidence Data](#)

2006 SEER Incidence Data (also released in the [Cancer Statistics Review](#))

[2006 Mortality Data](#)

[Breast Cancer Prevalence Projections](#)

[Download State Cancer Profiles brochure \(PDF\)](#)

[Revision History \(Updated: 3/10/2010\)](#)

[Release Schedule](#)

Help & About

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Note: This Web site is best viewed in

http://seer.cancer.gov/

SEER Web Site

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Surveillance Epidemiology and End Results

providing information on cancer statistics to help reduce the burden of this disease on the U.S. population

Welcome to the Surveillance, Epidemiology and End Results (SEER) Program, a premier source for cancer statistics in the United States. We collect information on incidence, prevalence and survival from specific geographic areas representing 26 percent of the US population and compile reports on all of these plus cancer mortality for the entire country. Our site is intended for anyone interested in US cancer statistics or cancer surveillance methods.

Current Data & Statistics

- [Cancer Statistics Review, 1975-2006](#) (April 15, 2009)
- [SEER Data, 1973-2006](#) (April 15, 2009)
- [Annual Report to the Nation, 1975-2006](#) (December 7, 2009)

Information on [Finding Cancer Statistics](#)



Publication Search

Search the SEER Bibliography to find links to PubMed and abstracts.

[Search SEER Bibliography](#)

Quick Statistics

Fact Sheets

Get printouts of the latest cancer statistics for major cancer types.

Select a cancer type from the list:

Fast Stats

Build your own tables and graphs of key SEER and US cancer statistics.

Select how to view your statistics:

Research Areas

- [Rapid Response Surveillance Studies](#)
- [Residual Tissue Repository Program](#)
- [SEER-Medicare Linked Database](#)
- [Historical Landmark Studies](#)
- [National Longitudinal Mortality Study](#)

SEER Highlights

- [Hematopoietic Database version 1.4](#) (March 11, 2010)
- [SEER*Stat software version 6.6.1](#) (March 9, 2010)
- [US Population Data for 1969-2007](#) (Nov 20, 2009)



Job Opportunities

Positions available within the Surveillance Research Program

Questions?

- Please e-mail....

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