Surveillance, Epidemiology, and End Results (SEER) Program

SEER Progress Report to the BSA

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Rationale for SEER

- 1971 National Cancer Act:
  - SEER established in 1973
- Surveillance (Incidence, Survival, Mortality)
  - and more
- Improving quality of cancer care

SEER is a mainstay of the National Cancer Program - it provides baseline measures of cancer rates essential to public health surveillance and focuses our research on the most important problems.
SEER: Measuring Our Nation’s Progress Against Cancer

- Holds us all accountable for the public health impact of our science
- Foundational component of a national data system for cancer research and monitoring
- Unique resource that allows cancer to be a model for monitoring chronic disease(s)
- Provides essential data to inform the Nation’s cancer health policy and practice
Geographic Coverage

Original SEER Registries
- UT
- NM
- Hawaii
- IA
- Seattle/Puget Sound

SEER Registries Added in 1992
- Connecticut

SEER Registries Added in 1999
- SEER: AK Native Tumor Registry

SEER Registries Added in 2000
- SEER: AZ American Indians added in 1980
Population Coverage by Race/Ethnicity (2005 est.)

Percentage of U.S. population

Original SEER
- 1973 on

First Expansion
- 1992 on

Second Expansion
- 2000 on

Race/Ethnicity
- White
- Black
- AI/AN
- API
- Hispanic

AI/AN: American Indian and Alaska Native
API: Asian and Pacific Islander
Health Disparities Findings

- People from low income populations are often diagnosed at later stages with less favorable outcomes.
- Need for better cancer prevention and early detection programs.
SEER is Widely Used

- ACS annual Facts & Figures publication
- SEER-Medicare linkage
- Patterns of Care/Quality of Care studies
- International Partners
- State Cancer Profiles
State Cancer Profiles

http://statecancerprofiles.cancer.gov/
SEER is Widely Cited

Publications: By the summer of 2008, there were 5,248 entries in the SEER online bibliography.

Citations:
- Basic research: 66,879
- Clinical oncology: 56,448
- General medical research: 49,941
- Public health: 29,340
- Internal/general medicine: 27,285

- Web of Science Citations for SEER 1981-2004
Surveillance Partners

The organizations include:

- American Cancer Society
- American College of Surgeons Commission on Cancer
- Centers for Disease Control and Prevention’s National Program of Cancer Registries
- International Association for Research on Cancer
- International Association of Cancer Registries
- National Cancer Registrars Association
- North American Association of Central Cancer Registries
- World Health Organization
Timely Release of New Information

AI/AN and NHW incidence rates, lung cancer, both sexes, by region, 1999-2004

AI/AN: American Indian and Alaska Native
NHW: Non-Hispanic White
Estimated Number of Cancer Survivors in the U.S. From 1971 to 2008

Year

Number


0 2,000,000 4,000,000 6,000,000 8,000,000 10,000,000 12,000,000

12.3 million
# Projections of US cancer prevalence by phases of care, 2005-2020

## Table 1. Projections of the US Cancer Prevalence by Phases of Care

<table>
<thead>
<tr>
<th>Year</th>
<th>Population</th>
<th>Cancer Prevalence (Number of people)</th>
<th>% increase 2000-2020</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All ages</td>
<td>65+ years</td>
<td>Total</td>
</tr>
<tr>
<td>2,005</td>
<td>295,507,134</td>
<td>36,695,904</td>
<td>10,797,060</td>
</tr>
<tr>
<td>2,010</td>
<td>308,935,581</td>
<td>40,243,713</td>
<td>12,639,522</td>
</tr>
<tr>
<td>2,015</td>
<td>322,365,787</td>
<td>46,790,727</td>
<td>14,666,942</td>
</tr>
<tr>
<td>2,020</td>
<td>335,804,546</td>
<td>54,631,891</td>
<td>16,891,169</td>
</tr>
</tbody>
</table>

- **Population**: All ages, 65+ years
- **Cancer Prevalence (Number of people)**: Total, Initial, Monitoring, Last-year of life
- **% increase 2000-2020**: 14%, 49%, 56%, 35%, 57%, 48%
Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2005 by Site (N = 11.1 M)

- Female Breast: 24%
- Prostate: 20%
- Colorectal: 10%
- Gynecologic: 9%
- Hematologic (HD,NHL,Leukemia, ALL, Myeloma): 8%
- Urinary Tract (Bladder, Kidney, Renal Pelvis): 7%
- Melanoma: 7%
- Thyroid: 4%
- Other: 11%
• Public-use data
  • Over 2000 data use agreements per year

• SEER-Medicare
  • Over 500 data requests, 325 publications, 61 grants

• SEER Surveillance Studies
  • Over 260 publications
  • Background for grants, K07s
Landmark Studies - Examples

- **Surveillance Studies**
  - Endometrial cancer and estrogen
  - Breast cancer incidence decline
  - Environmental tobacco—Surgeon General’s Report
  - Rare Cancers
  - Health Disparities

- **Cancer Etiology**
  - NSAIDS and cancer prevention
  - AIDS-related cancers
  - Genetic susceptibility studies

- **Cancer Outcomes**
  - Patterns of Care—PCOS
SEER Database Features

• Population basis
  – Everyone is included, group is well-defined
  – Findings are generalizable

• Representativeness
  – Cancer burden not equally distributed by
    • age, sex, race/ethnicity, social class, geography
  – SEER samples population to include these groups

• Time
  – Trends in incidence, treatment patterns
  – Survival
Understanding Cancer Burden

- Public health monitoring
- Size that provides capacity to evaluate
  - Rare cancers
  - Cancer heterogeneity (tumor, patient)
- Research scope broadened through leveraging
  - Linkage to a range of other population-based data sources
Monitoring the Impact of Cancer

- Important for ongoing surveillance
  - All sites, common or rare
  - All populations, by age, sex, race, geography
- Identifying unusual patterns
  - Rapid changes in incidence
    - Relevance to etiology
    - Relevance to public health
      - Planning
      - Evaluating the impact of public health interventions
Figure 1. Yearly incidence rates for Kaposi sarcoma and non-Hodgkin lymphoma from 1973 to 1998

Clarke, AIDS 2001
The Decrease in Breast-Cancer Incidence in 2003 in the United States

Ages 50-69

Release of WHI ↓ results 7/2002

Ravdin et al, NEJM 2007
Size of SEER: Rare Cancers, Cancer Heterogeneity

- The four most common cancers comprise approximately 50% of the cancer burden
- However, >50 other cancers exist
  - Lead to considerable morbidity and mortality
- Beyond primary cancer sites, ~300 anatomic subsites and ~500 histologic subtypes
- SEER database = resource with adequate numbers to evaluate this detail
### Neuroendocrine/carcinoid Tumors: A Growing Problem

#### Annual percent change in incidence rates by anatomic subsite, 1973-2005

<table>
<thead>
<tr>
<th>Anatomic subsite</th>
<th>Annual % change</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Esophagus</td>
<td>0.94</td>
<td>0.19</td>
</tr>
<tr>
<td>Stomach</td>
<td>6.85</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Small Bowel</td>
<td>3.57</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Appendix</td>
<td>0.66</td>
<td>0.27</td>
</tr>
<tr>
<td>Colon</td>
<td>4.03</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Rectum</td>
<td>8.28</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Anus</td>
<td>~</td>
<td>~</td>
</tr>
<tr>
<td>Liver and biliary</td>
<td>~</td>
<td>~</td>
</tr>
<tr>
<td>Pancreas</td>
<td>2.38</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Unknown Primary</td>
<td>3.49</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td><strong>All Sites Combined</strong></td>
<td><strong>4.39</strong></td>
<td><strong>&lt;0.05</strong></td>
</tr>
</tbody>
</table>
Tumor Heterogeneity: Lymphoma

Figure 3. Incidence of lymphoid neoplasms by subtype and race, 12 SEER registries, 1992-2001. *All incidence rates are age adjusted to the 2000 United States population. Abbreviations are explained in Table 1.

Morton et al, Blood 2006
Differences across Groups

- Cancer burden differs across racial/ethnic groups
- Increasing diversity in US
  - ~30% population = Asian or Latino
Research on Disparities: Effect of Immigration Status

- Cancer patterns differ between immigrants and persons in country of origin
- Immigrant populations in the US are increasing rapidly
  - In California, comprising
    - ~80% of Asians
    - ~60% of Latinos
- SEER data is being used to create a resource to study cancer incidence trends in specific Asian and Latino immigrant groups
Leveraging by Linkage

- Research breadth facilitated by linking SEER’s core data to other population-based data sources:
  - Medicare
  - AIDS registries
  - Transplant registries
  - Census data and geospatial data for characterizing social and built environment

- Combined datasets expand SEER research opportunities
SEER-Medicare

- Data resource created by linking patients from SEER with their Medicare claims
- Medicare claims provide longitudinal perspective on health care from eligibility to death
  - Before, during and after cancer diagnosis
- Resource=2.4 million persons with cancer
- One of only population-based resources for studying quality of cancer care
  - Evidence-based decisions
Research Topics Using the SEER-Medicare Data

- Treatment/Outcomes
- Research Methods
- Health Disparities
- Health Care Systems
- Screening/Surveillance
- Economics of Cancer
- Survivorship/End of life
Androgen Deprivation Therapy (ADT) primarily recommended for advanced prostate cancer

SEER-Medicare data assessed:

- Long-term risk of adverse events:
  - Fracture- 19% ADT users vs 12% ADT non-users (NEJM, 2005)
  - Cardiovascular events- 19% ADT users vs 15% ADT non-users (Cancer, 2007)

- Use of ADT for localized prostate cancer
  - From 1991 to 1999, ADT use increased from 4% to 31% (Cancer, 2005)
  - Yet, no survival benefit of ADT over expectant management (JAMA, 2008)
Public and Research Access to SEER Data

- Interactive public portal to SEER data seer.cancer.gov
- Software packages which increase ease of analysis of SEER data while reducing error
- Theoretical statistics research for high-level analyses
- Linked tumor tissue/SEER demographic and clinical data to support molecular science
Public and Research Access to SEER Data: Interactive Portal

**Fast Stats**

**Statistics Stratified by Cancer Site**

- **Data Type**: Choose Data Type
- **Statistic Type**: Choose Statistic
- **Year Range**: Choose Year Range
- **Race/Ethnicity**: Choose Race/Ethnicity
- **Sex**: Choose Sex
- **Age Range**: Choose Age
- **Output**: Graph, Table
Public and Research Access to SEER Data: SEER*Stat

- Frequencies & rates
- Frequencies & distributions
- Crude rates (non-adjusted)
- Trends (percent change, annual percent change)
- Age-adjusted rates
- Incidence-based mortality rates
- Rate ratios for significance testing

- Survival statistics
- Observed survival
- Relative survival
- Cause-specific survival
- Conditional survival
- Actuarial and Kaplan-Meier methods
- Period method
- Limited-duration prevalence
- Multiple primary standardized incidence ratios
SEER Incidence, Delay Adjusted Incidence and US Death Rates
Melanoma of the Skin, White, by Sex

Male

- Rate per 100,000
- APC = 8.9°
- APC = 7.2°
- APC = 0.2
- Year of Diagnosis/Death

Female

- Rate per 100,000
- APC = 3.6°
- APC = 3.2°
- APC = -0.4°
- Year of Diagnosis/Death

JoinPoint - Trend Analysis
DevCan - Lifetime Risk

Years, Lifetime Risk of Cancer Given Cancer Free At 2005 By Race/Ethnicity
Diagnosed with Cancer +30 yrs
Percent ( 95% C.I. )

- 0.76 ( 0.75, 0.77 )
- 1.60 ( 1.59, 1.61 )
- 3.96 ( 3.95, 3.98 )
- 9.53 ( 9.50, 9.56 )
- 19.67 ( 19.62, 19.73 )
- 30.65 ( 30.56, 30.73 )
- 35.46 ( 35.36, 35.56 )
- ( - , - )
- ( - , - )
SEER Data on the Grid

Link SEER with other data

Biomedical Research Data

Data visualization and discovery tools

caGrid

BRFSS

Gapminder

Community Health Status Indicators

many eyes
Collect → Inform → Seize opportunity

Detailed Population-based Survival Data → NCI Progress Review Group/ Lance Armstrong Foundation Report finds survival improvement lags among adolescents and young adults (AYA) → SEER AYA HOPE Study
Translating Data into Opportunity: AYA HOPE Study
Information Technology - Electronic Data Collection

- E-path - tools to capture patient data
  - Efficient
  - Privacy-friendly
  - High speed – today’s diagnoses tomorrow
  - Creates research opportunities
    - e.g., population-based full text, clinically and demographically-characterized pathology records for 35 years for Los Angeles
  - >175 laboratories installed
Clinical Trials Support

• E-path populated with clinical trial eligibility criteria can send early automated alert to PI of potential patients
Information Technology - Electronic Data Collection

In development…

• E-path+
  - Additional clinical, demographic and treatment data

• Automated Cancer Extraction Software (ACE)
  - Outpatient setting
  - Finds missed cases
  - Captures outpatient treatment, co-morbidities
Survival Calculator

• When someone calls 1-800-4CANCER and asks about the prognosis of a family member who was newly diagnosed, where should the information come from?

• How can oncologists get a better understanding of how the chance of dying of cancer and of other causes compete against each other in assessing a patient's prognosis?
Population Cancer Pharmacogenomics Research

• Identify specific epidemiologic, clinical, and genomic profiles that could enhance response to therapy and minimize toxicity

• SEER Lymphoma Pharmacogenomics Pilot Study
  – A prognostic cohort study to examine the association of pharmacogenomic markers and response and/or toxicity of treatment for NHL

• Other opportunities for post-marketing surveillance?
Your Feedback

- How might SEER best be leveraged as a resource for the National Cancer Program?
- What additional data can SEER provide?
- What additional services can SEER provide to researchers, clinicians and the public?