National Cancer Institute

Surveillance, Epidemiology, and End Results (SEER) Program

SEER Progress Report to the BSA

November 7, 2008

Brenda K. Edwards, Ph.D.
Surveillance Research Program, NCI
Sally Glaser, Ph.D.
Northern California Cancer Center
Dennis Deapen, Dr.P.H.
University of Southern California

Rationale for SEER

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

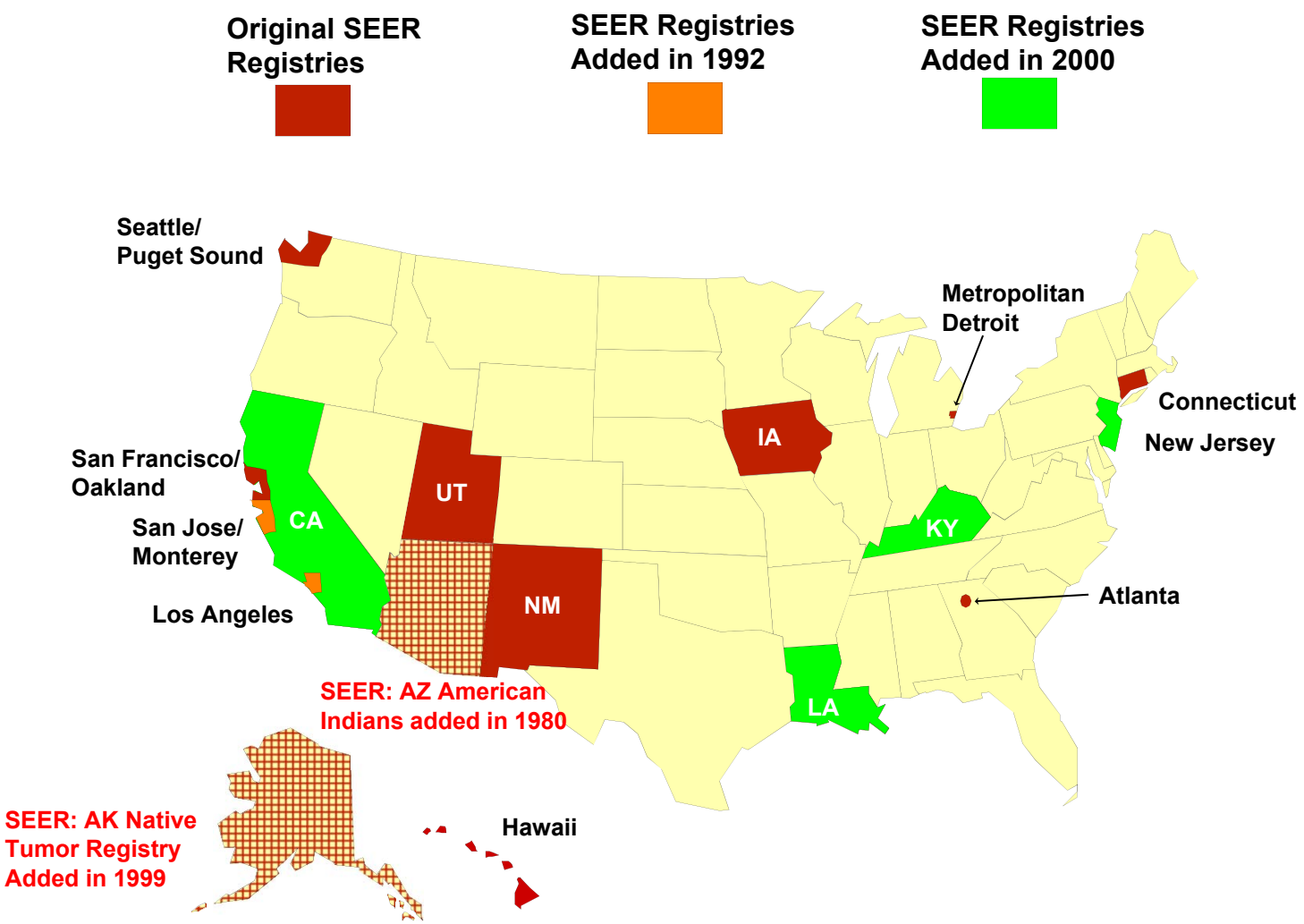
SEER is a mainstay of the National Cancer Program - it provides baseline measures of cancer rates essential to public health surveillance and focuses our research on the most important problems.

SEER: Measuring Our Nation's Progress Against Cancer

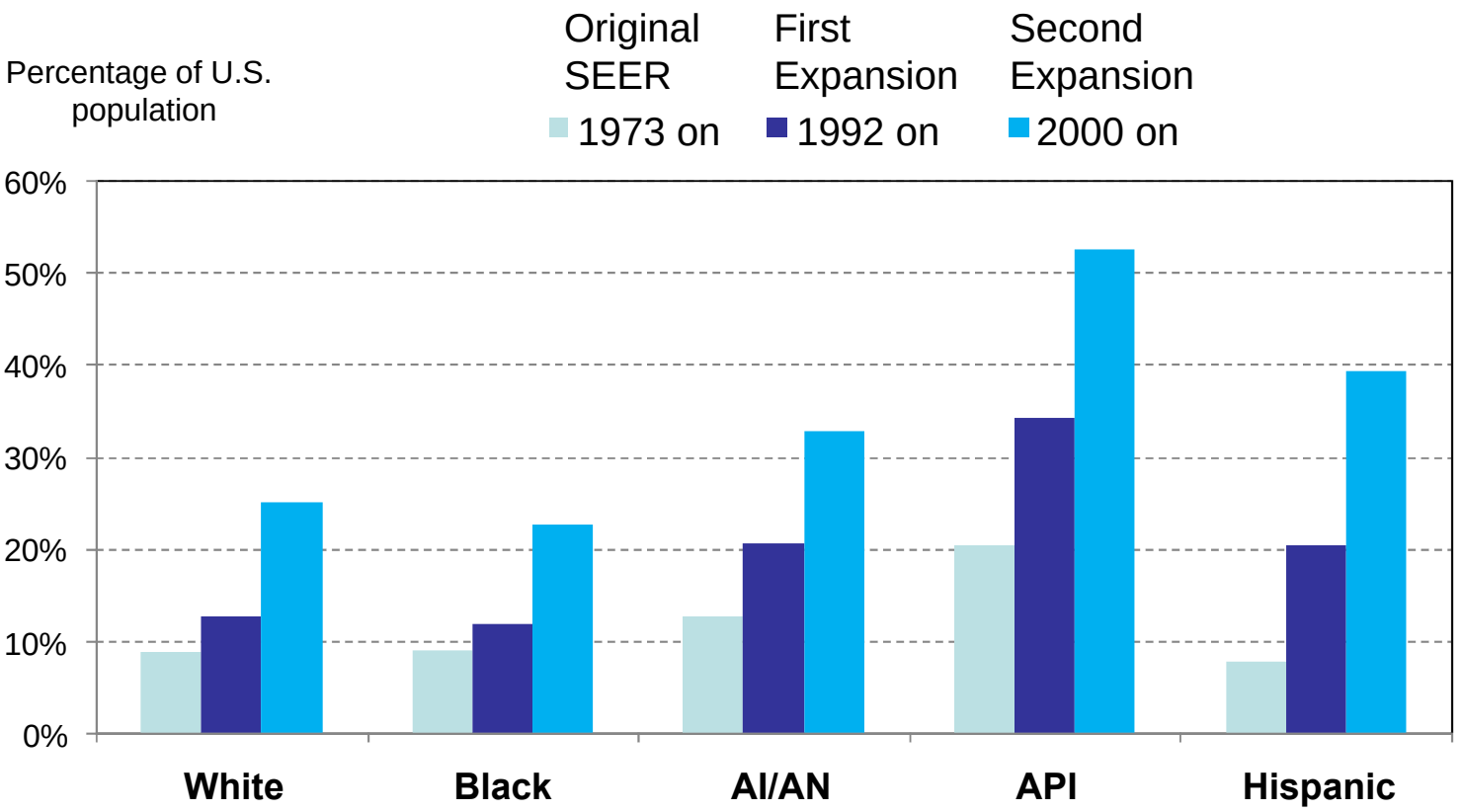
- Holds us all accountable for the public health impact of our science
- Foundational component of a national data system for cancer research and monitoring
- Unique resource that allows cancer to be a model for monitoring chronic disease(s)
- Provides essential data to inform the Nation's cancer health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


National Center for Infectious Diseases
Arctic Investigations Program
MAYO CLINIC
BARBARA ANN KARMANOS CANCER INSTITUTE
FRED HUTCHINSON CANCER RESEARCH CENTER
Yale CANCER CENTER
UNIVERSITY of IOWA HOLDEN COMPREHENSIVE CANCER CENTER
STANFORD CANCER CENTER
The Cancer Institute of New Jersey
Bringing research to life.
UCSF University of California, San Francisco
HUNTSMAN CANCER INSTITUTE UNIVERSITY OF UTAH
City of Hope
KECK SCHOOL OF MEDICINE OF USC
UK HealthCare Markey Cancer Center
UNM HEALTH SCIENCES CENTER
EMORY WINSHIP CANCER INSTITUTE
Cancer Research Center of Hawai'i
UNIVERSITY OF HAWAI'I
Rollins School of Public Health
School of Public Health
LSU Health Sciences Center

Geographic Coverage



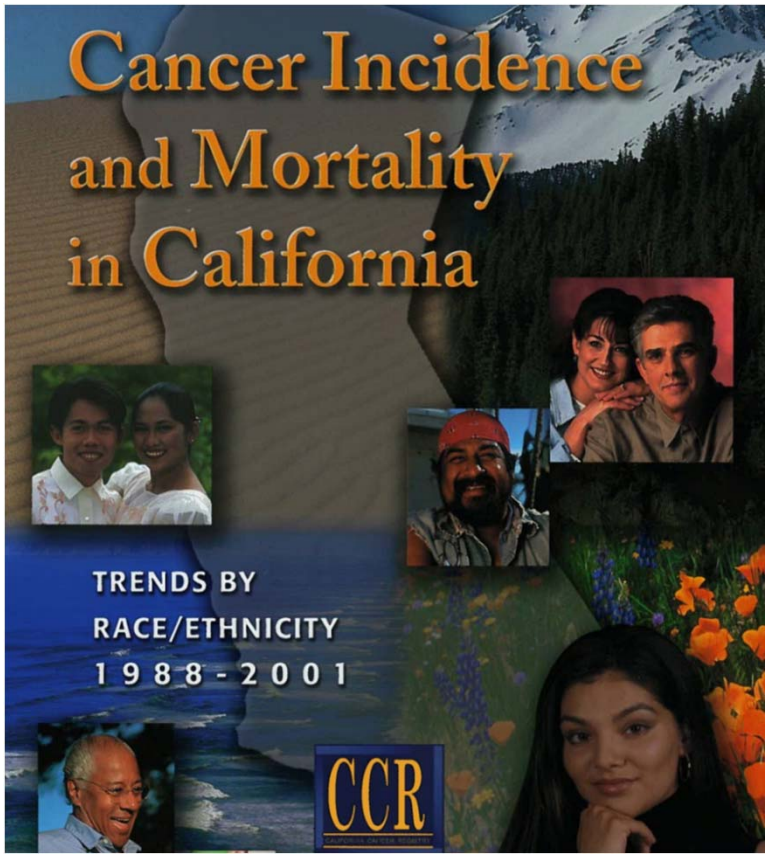
Population Coverage by Race/Ethnicity (2005 est.)



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

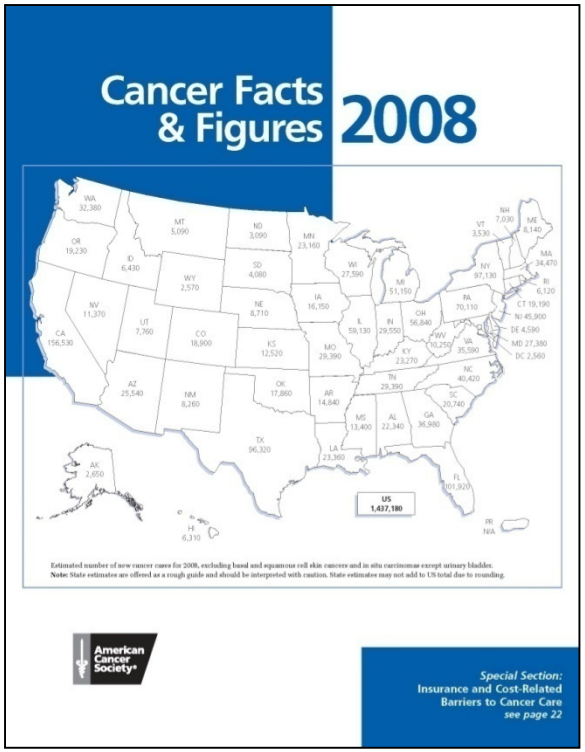
Health Disparities Findings

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

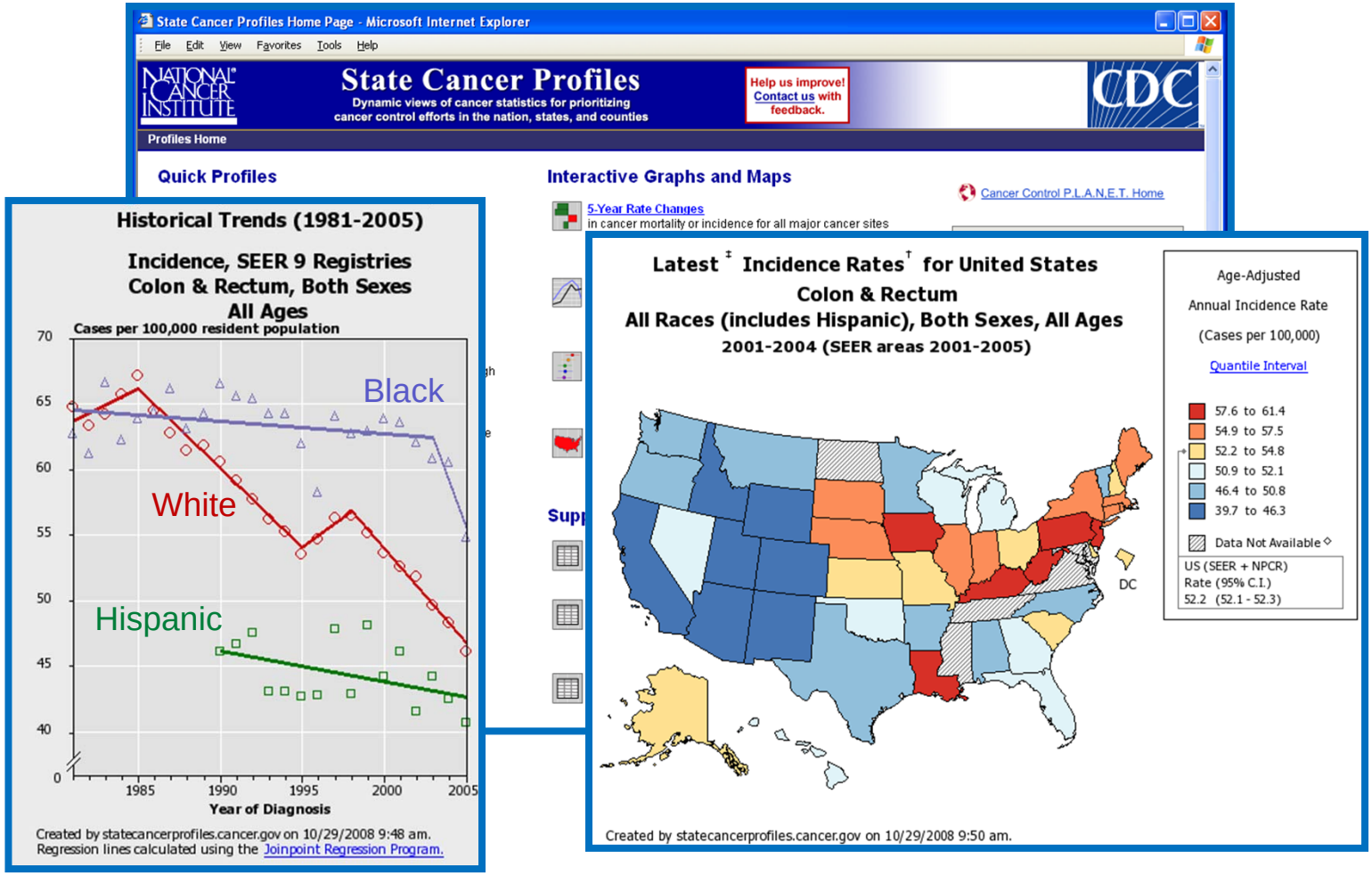


SEER is Widely Used

- 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:

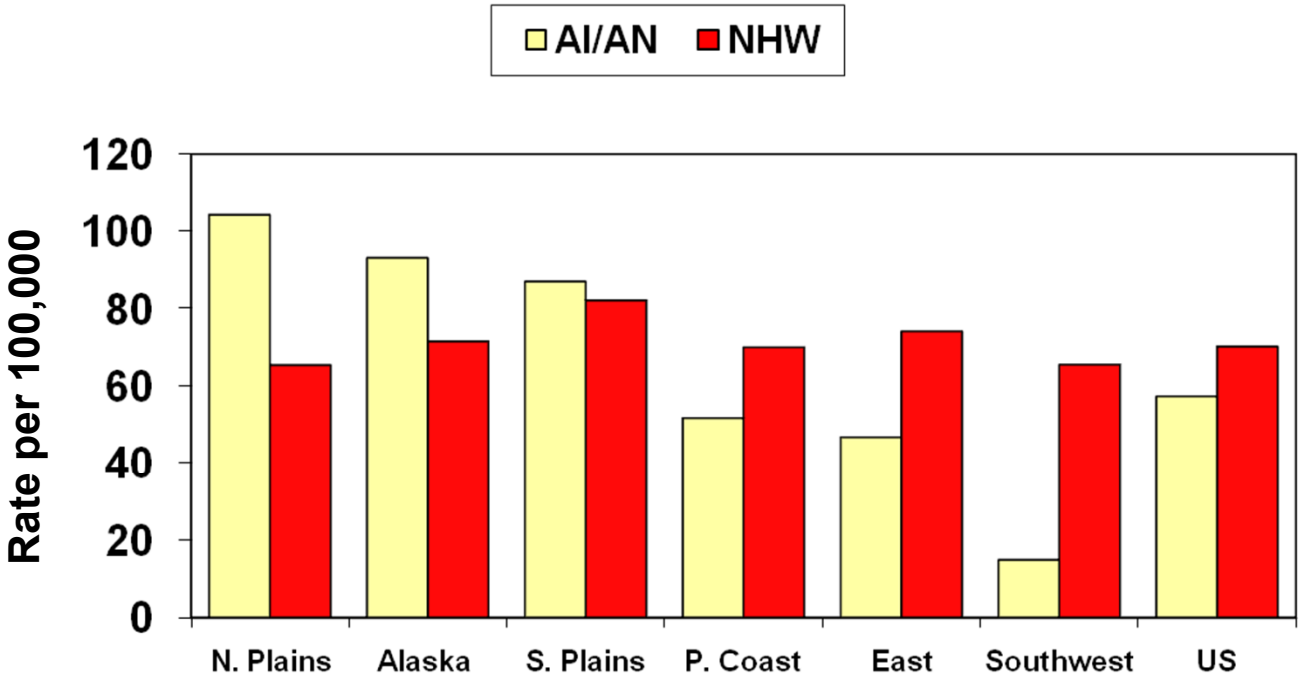
- American Cancer Society
- American College of Surgeons Commission on Cancer
- Centers for Disease Control and Prevention's National Program of Cancer Registries
- International Association for Research on Cancer
- International Association of Cancer Registries
- National Cancer Registrars Association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

International Agency for Research on Cancer

Centre International de Recherche sur le Cancer

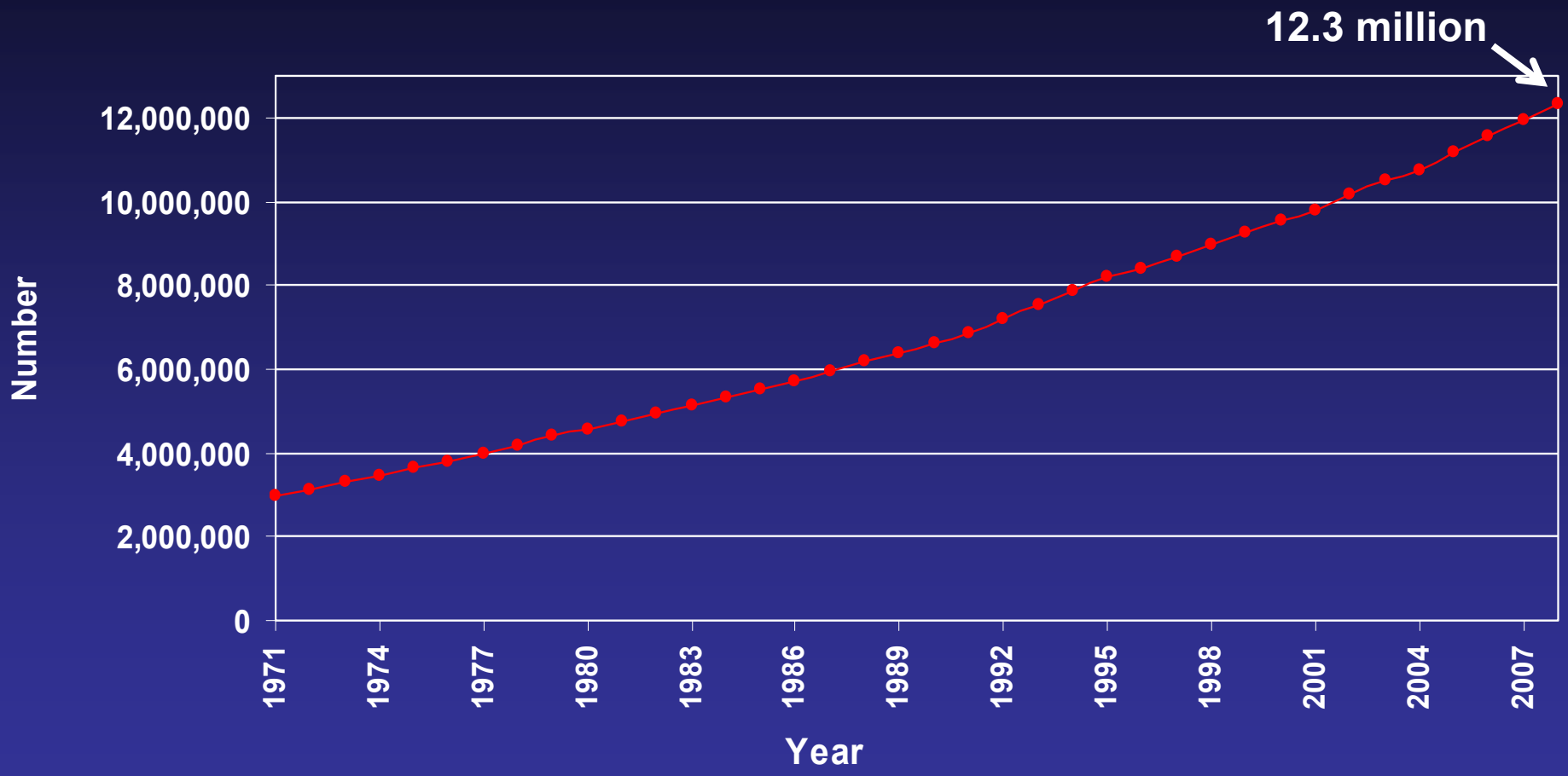
Timely Release of New Information

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

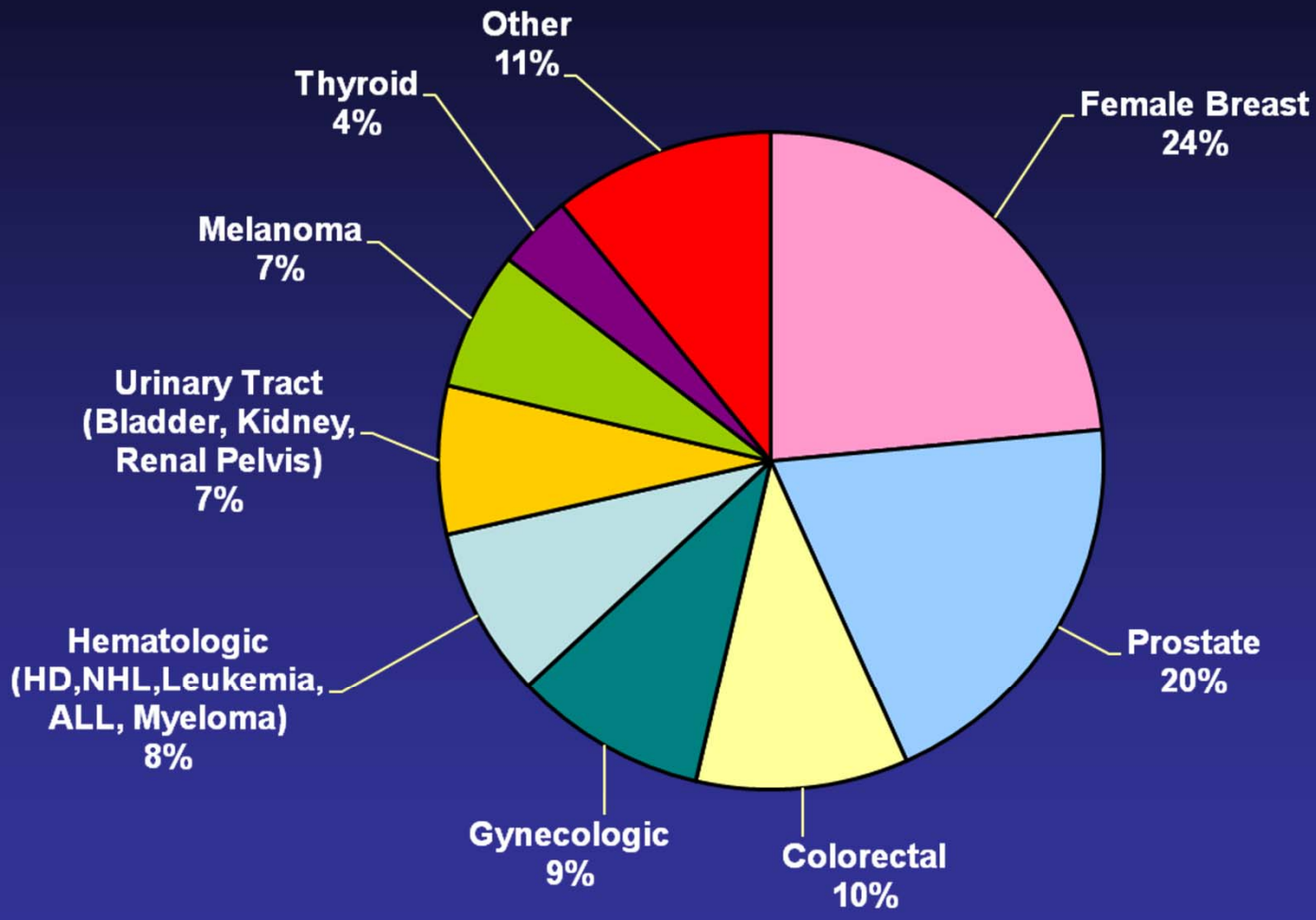


Projections of US cancer prevalence by phases of care, 2005-2020

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

Year	Population		Cancer Prevalence (Number of people)			
	All ages	65+ years	Total	Initial	Monitoring	Last-year of life
2,005	295,507,134	36,695,904	10,797,060	986,602	10,537,886	259,175
2,010	308,935,581	40,243,713	12,639,522	1,088,428	12,343,550	295,971
2,015	322,365,787	46,790,727	14,666,942	1,205,722	14,330,122	336,820
2,020	335,804,546	54,631,891	16,891,169	1,331,655	16,508,821	382,348
% 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)

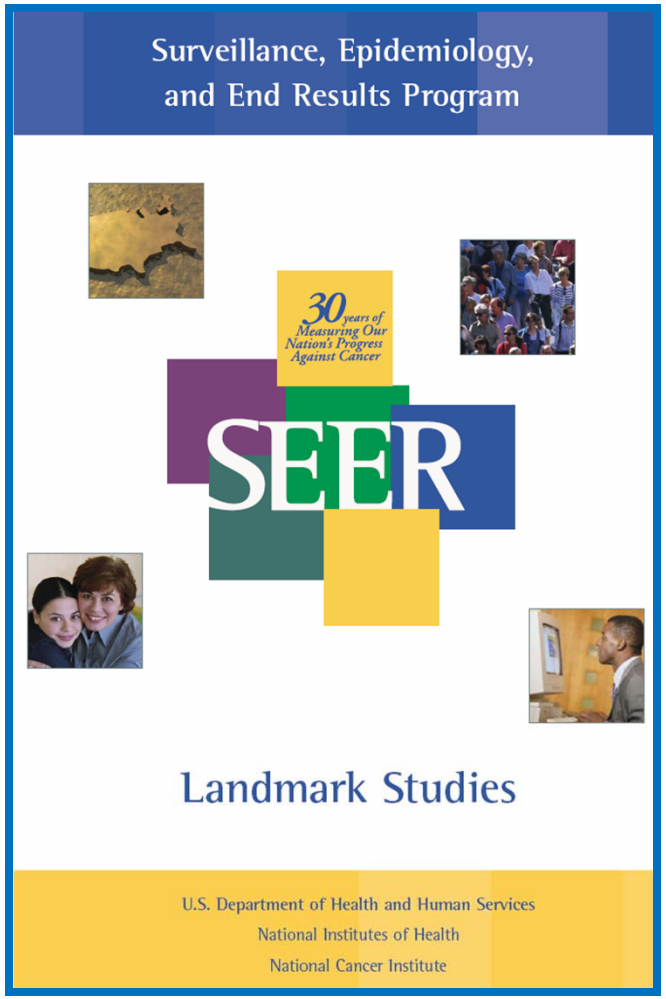


SEER Data Usage - Examples

- 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

Cancers and AIDS Epidemic

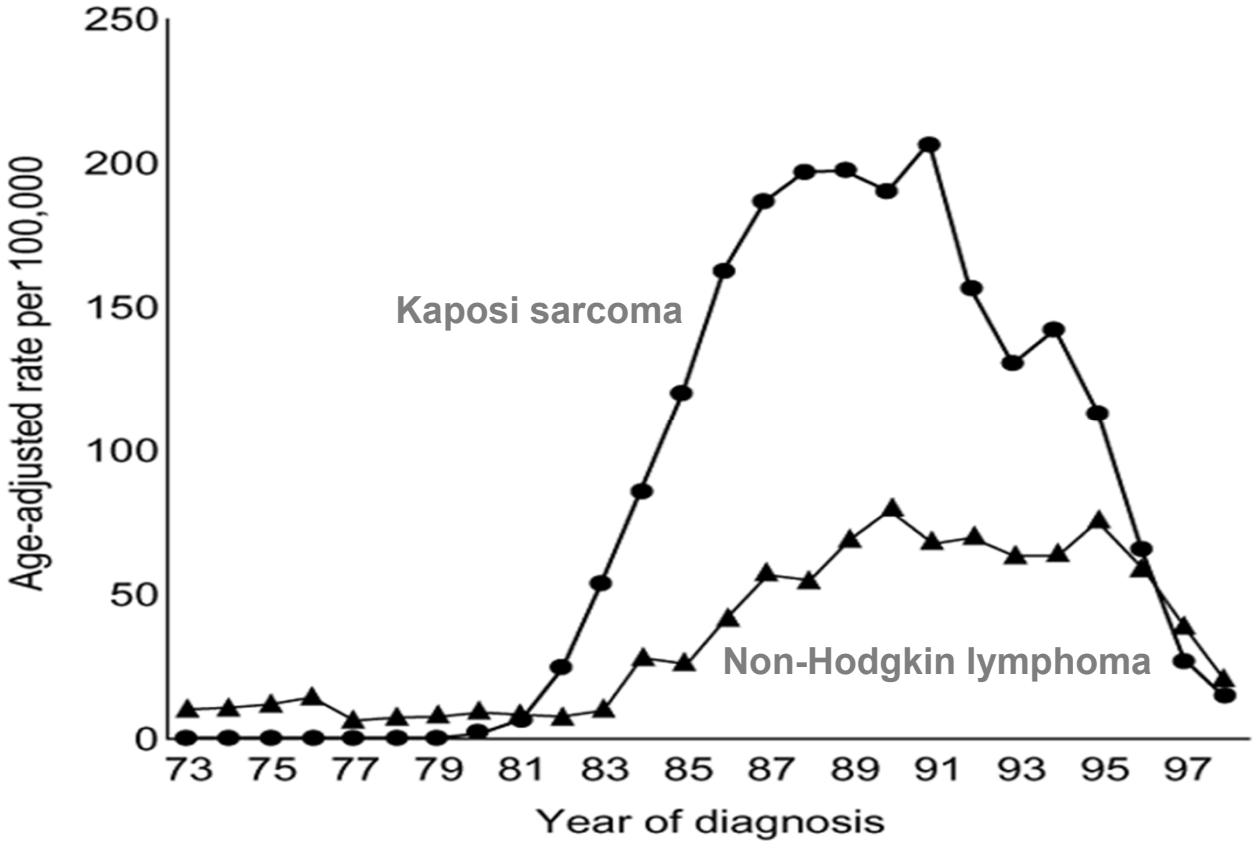


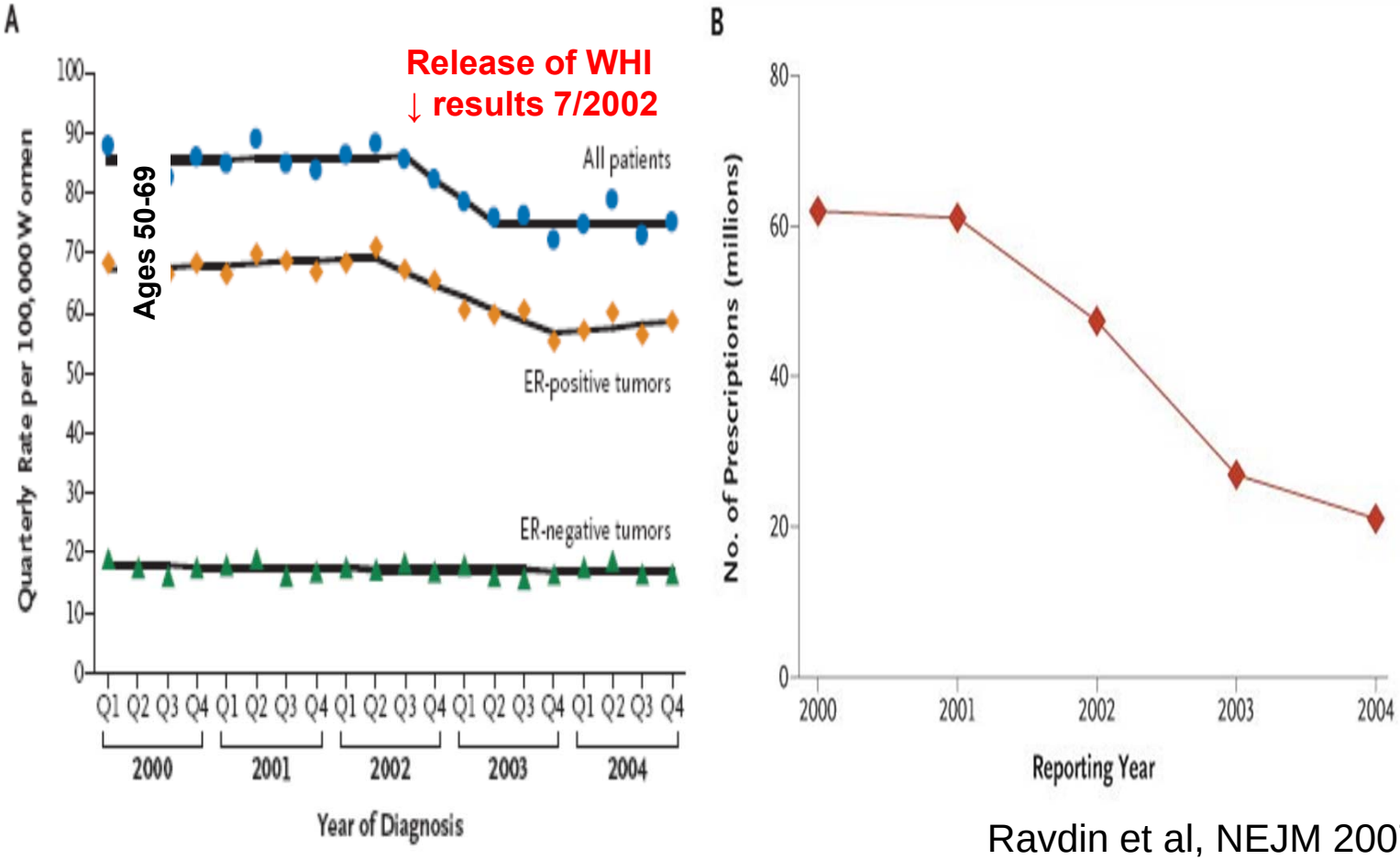
Figure 1. Yearly incidence rates for Kaposi sarcoma and non-Hodgkin lymphoma from 1973 to 1998

Clarke, AIDS 2001

The NEW ENGLAND JOURNAL of MEDICINE

SPECIAL REPORT

The Decrease in Breast-Cancer Incidence in 2003 in the United States



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

Anatomic subsite	Annual % change	p-value
Esophagus	0.94	0.19
Stomach	**6.85**	**<0.05**
Small Bowel	**3.57**	**<0.05**
Appendix	0.66	0.27
Colon	**4.03**	**<0.05**
Rectum	**8.28**	**<0.05**
Anus	~	~
Liver and biliary	~	~
Pancreas	**2.38**	**<0.05**
Unknown Primary	**3.49**	**<0.05**
All Sites Combined	**4.39**	**<0.05**

Tumor Heterogeneity: Lymphoma

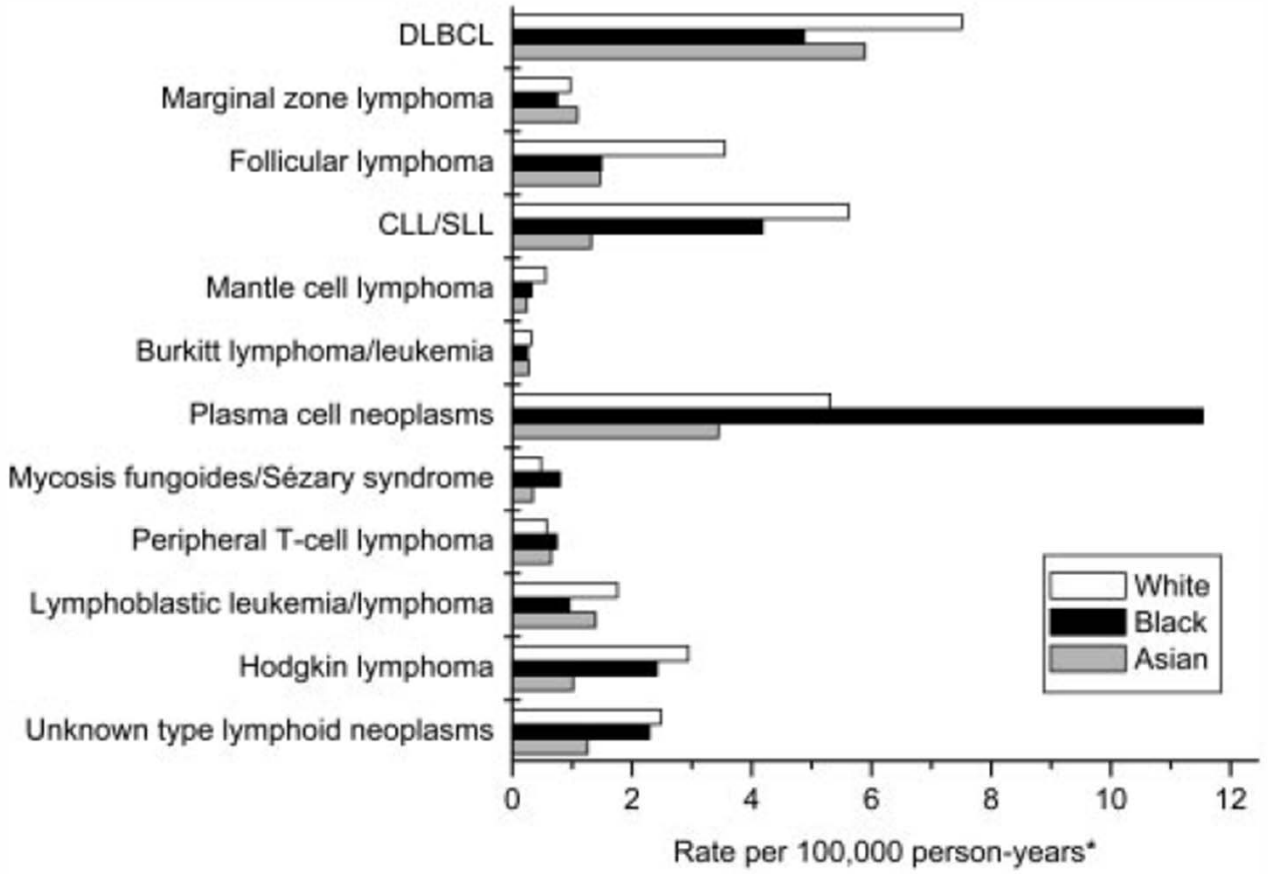
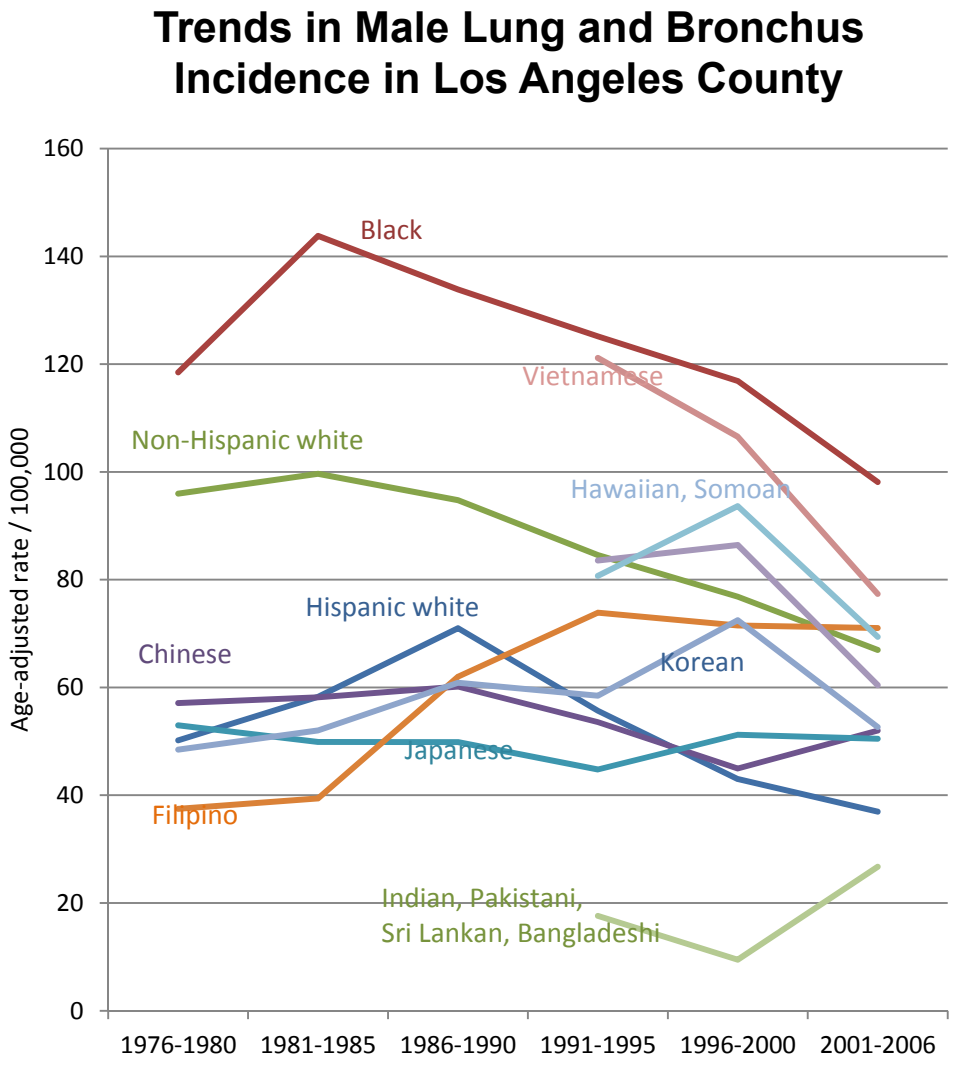


Figure 3. Incidence of lymphoid neoplasms by subtype and race, 12 SEER registries, 1992-2001. *All incidence rates are age adjusted to the 2000 United States population. Abbreviations are explained in Table 1.

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

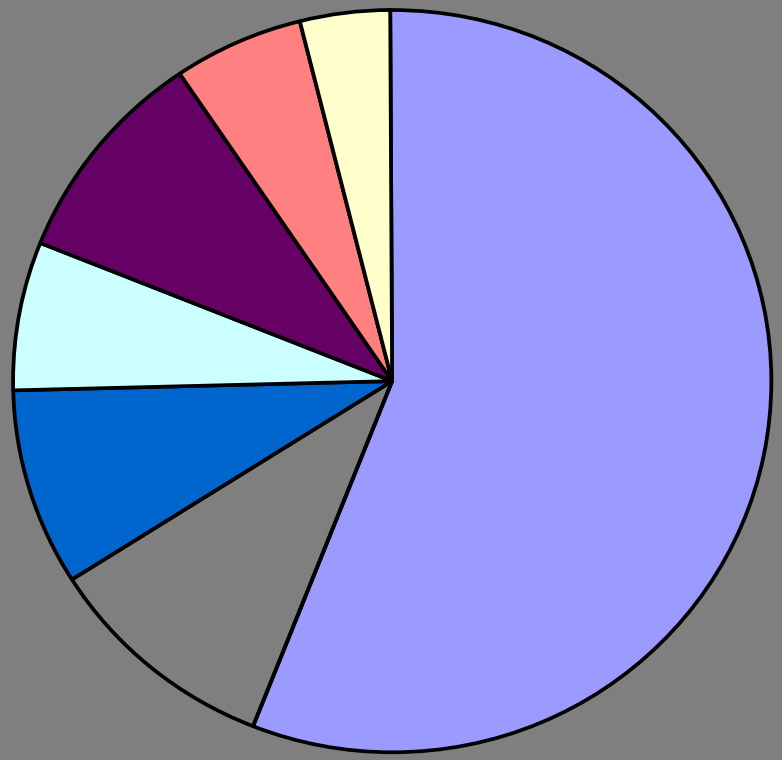
Leveraging by Linkage

- 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

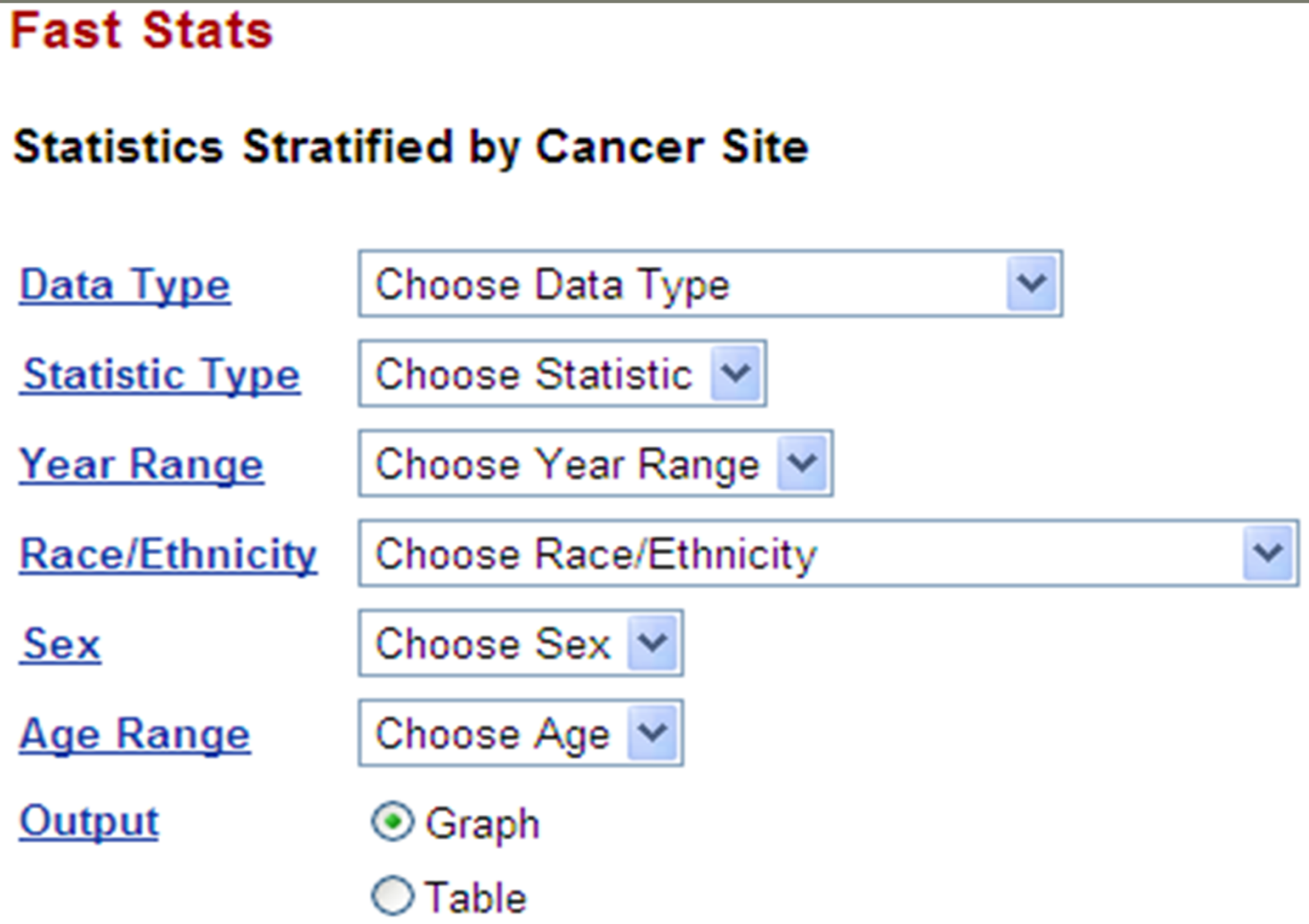
SEER-Medicare: ADT and Prostate Cancer

- 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



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

Public and Research Access to SEER Data: Statistical Modeling

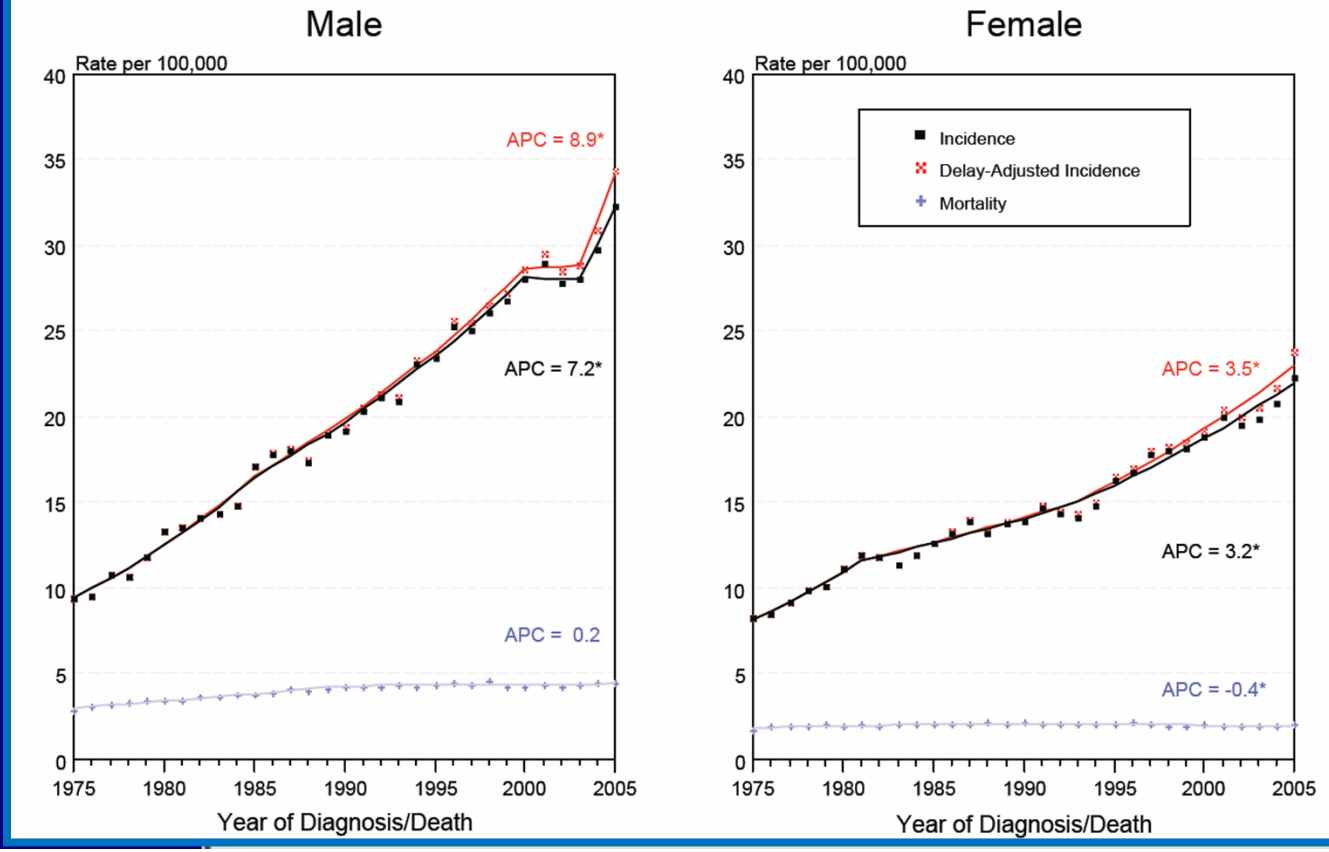
Statistical Methods and Software for Population-based Cancer Statistics

Incidence → Delay Model

JoinPoint - Trend Analysis

DevCan - Lifetime Risk

SEER Incidence, Delay Adjusted Incidence and US Death Rates[a]
Melanoma of the Skin, White, by Sex



Years, Lifetime Risk of
cer 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)
-	(- , -)
-	(- , -)

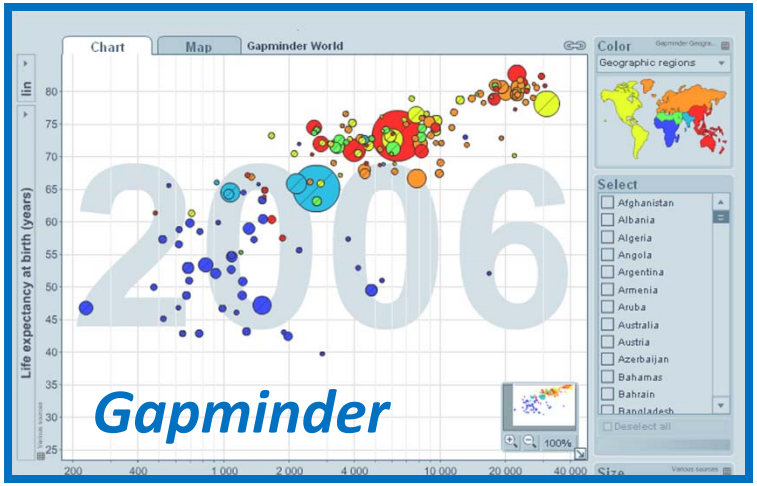
SEER Data on the Grid

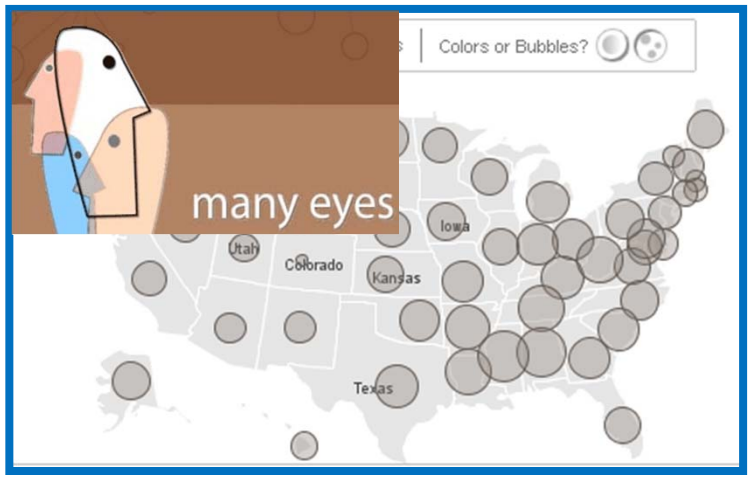
BRFSS

Community Health Status Indicators

Biomedical Research Data

caGrid





Link SEER with other data

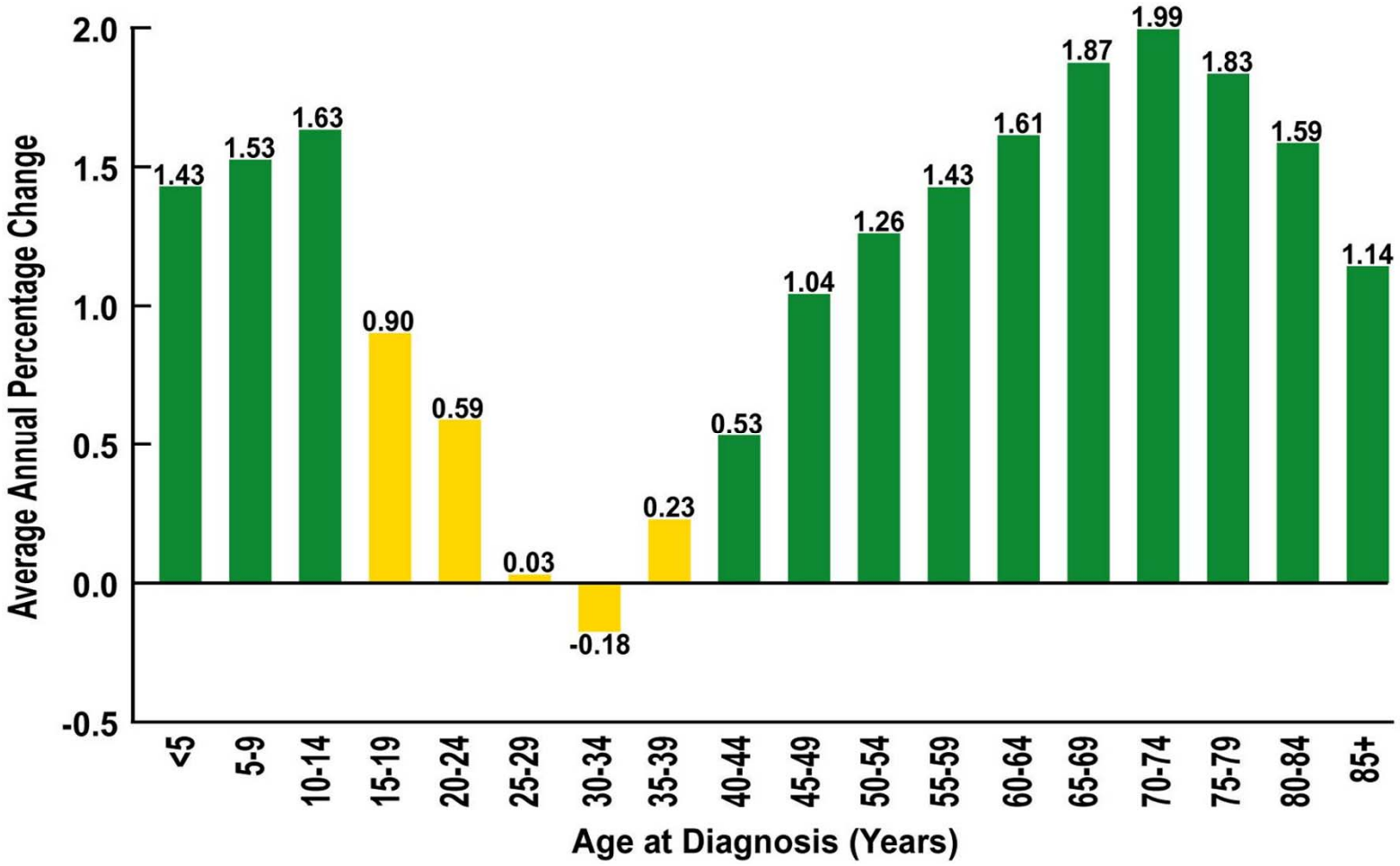
Data visualization and discovery tools

Translating Data into Opportunity

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

Survival Improvement Gap: ***Improvement in 5-Year Relative Survival, Invasive Cancer, 1975 – 1997***



Translating Data into Opportunity: AYA HOPE Study

AYA HOPE

Adolescent and Young Adult Health Outcomes and Patient Experience Survey

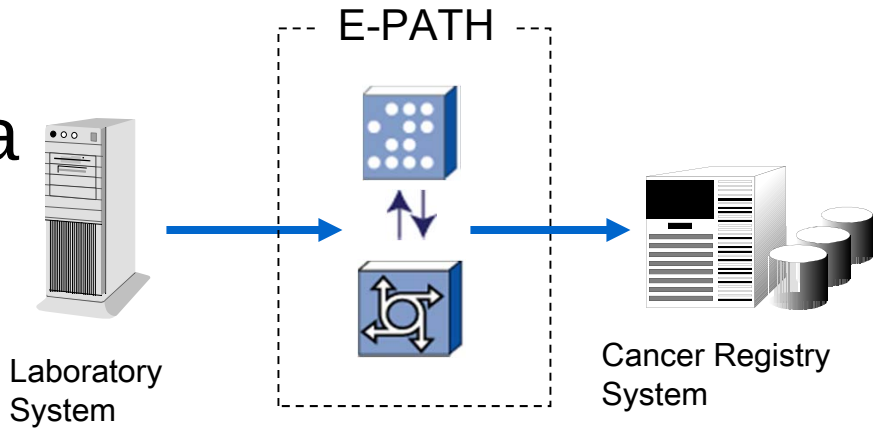
National Cancer Institute

U.S. Department of Health and Human Services
National Institutes of Health

LIVESTRONG
LANCE ARMSTRONG FOUNDATION

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



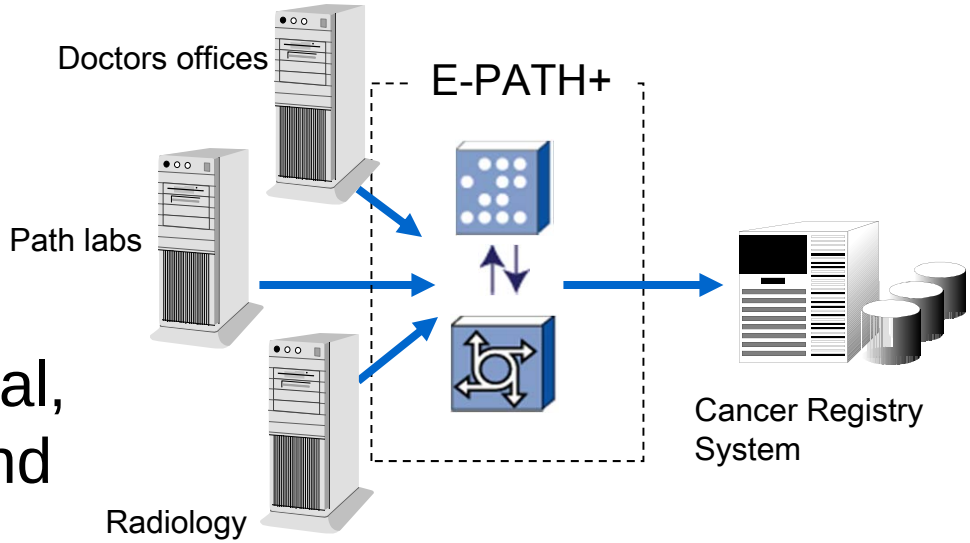
SEER Moving Forward: Emerging Opportunities

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

SEER Moving Forward: Emerging Opportunities

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 patients 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?