

Cancer Registry



Who?

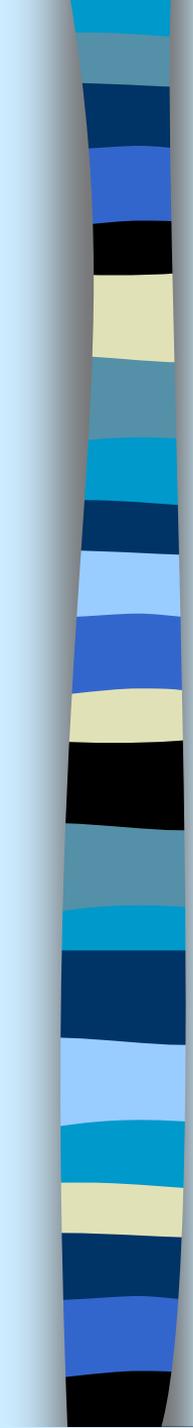
What?

When?

Where?

Why?

Louanne Currence, RHIT, CTR

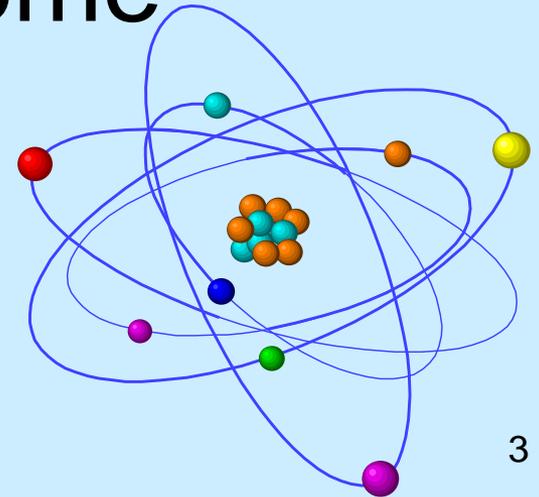


Patient Charles

- 64 y.o. man, complaining of constipation and occasional rectal bleeding
- At “Scopes-R-Us, total colonoscopy showed lesion at sigmoid
 - Biopsy showed adenocarcinoma, poorly differentiated
- Hemicolectomy at hospital showed T3N1M0 adenoca
- Chemo started at Dr Oncologist within month

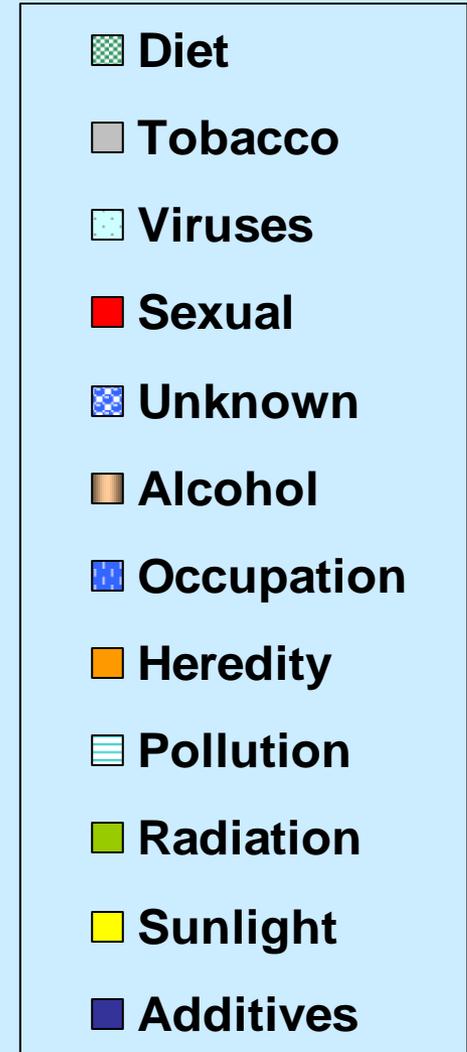
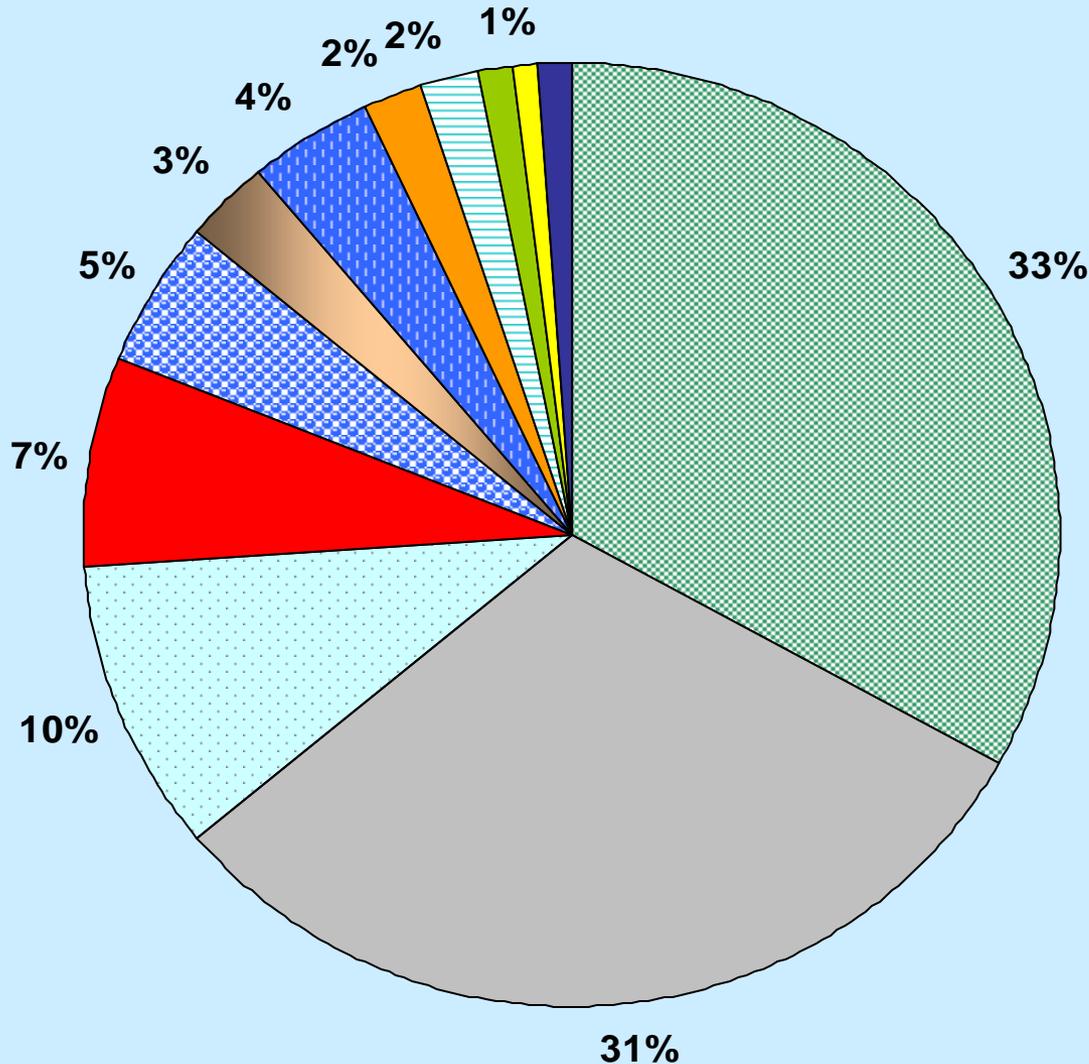
Cancer

The human body is comprised of more than 200 different types of cells, any one of which may become malignant.



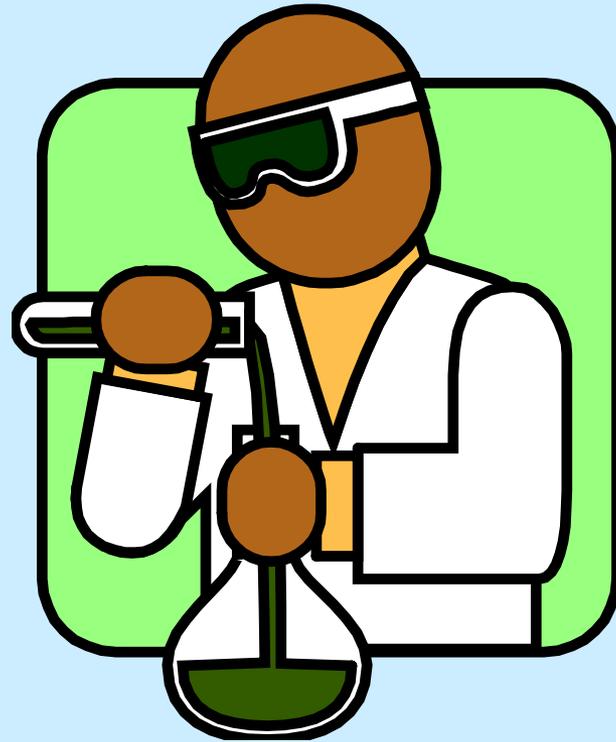
Cancer Risk Factors

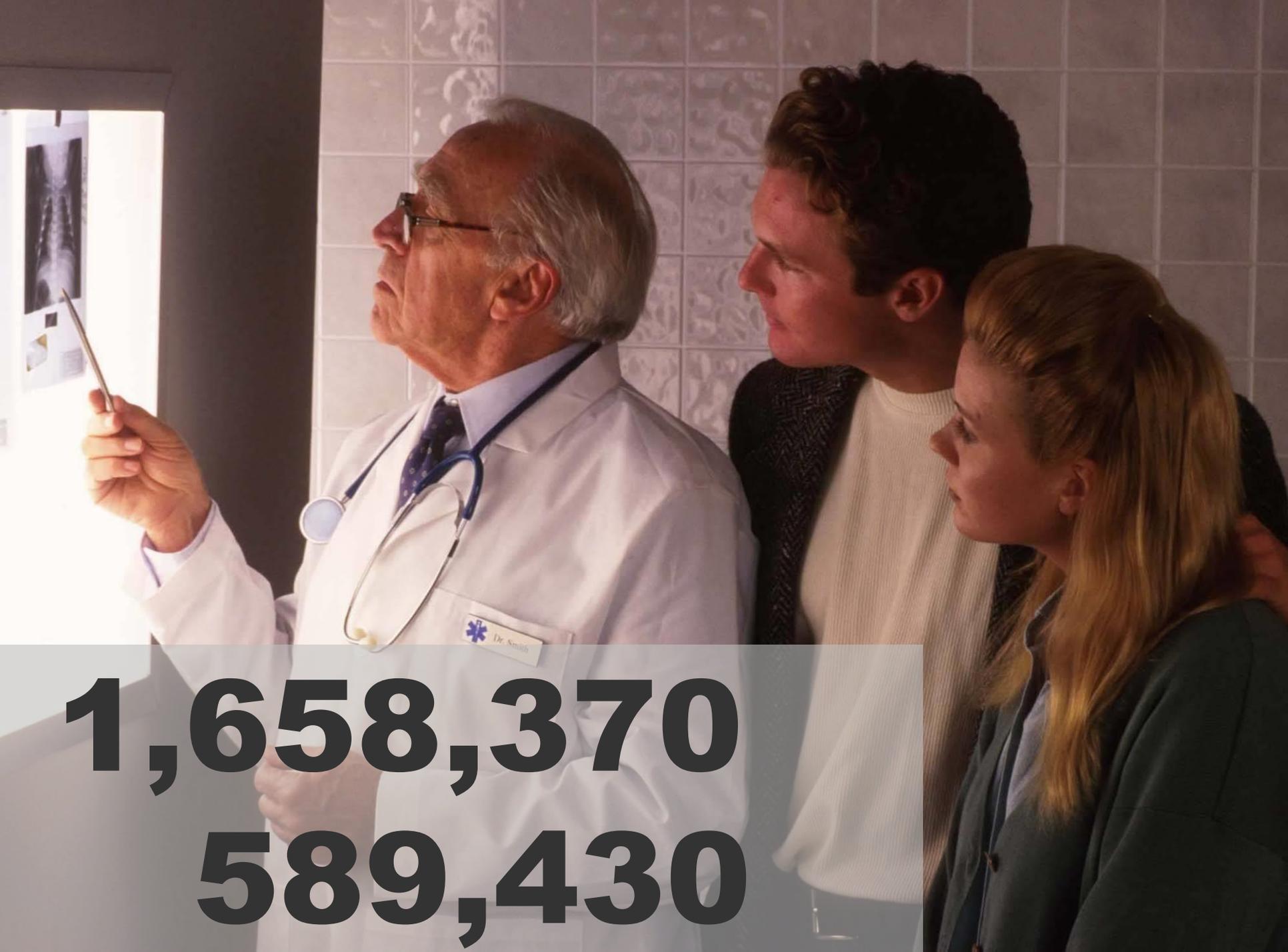
Everyone's Guide to
Cancer Therapy, 4th ed.



Why?

- Incidence
- Follow-up
- Education
- Research





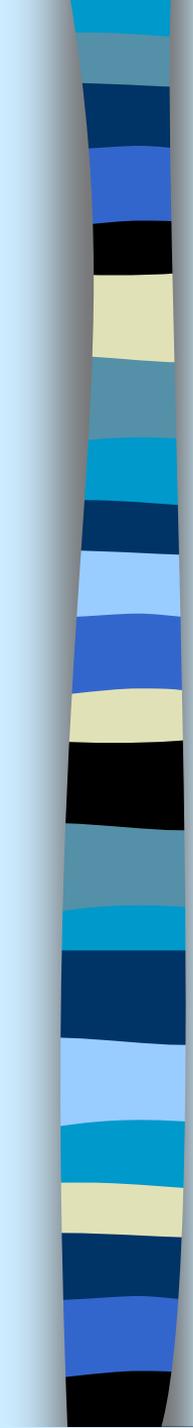
1,658,370

589,430

COSTS OF CANCER

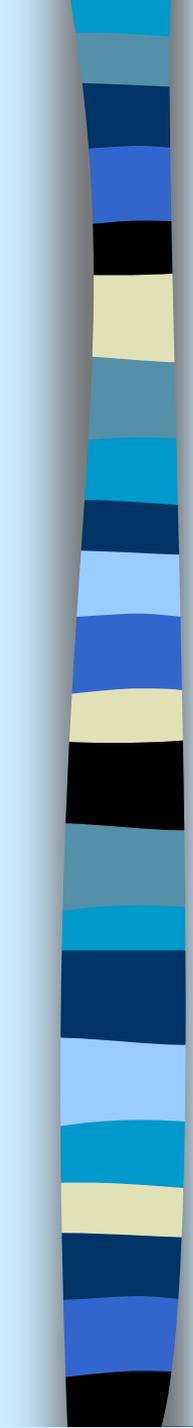
- \$89.0 billion (treatment)
- \$18.2 billion (indirect morbidity)
- \$112.0 billion (indirect mortality)





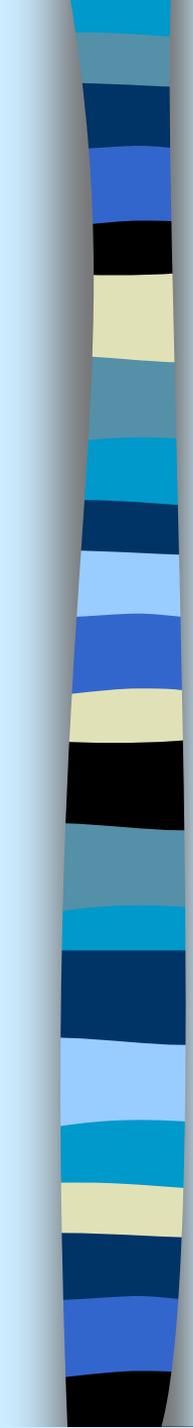
Who?

- Who establishes the registry?
- Who wants the data?
- Who can become a registrar?



Authority?

- MO Cancer Registry created 1972
 - Approximately 12 volunteer hospitals
 - Statute 192.650 RSMO enacted 1984
 - Revised 192.50-192.657 Aug 1999
- Federal (Cancer Registries Amendment Act of 1999, Public Law 102-515)
 - Fund central registries in all states

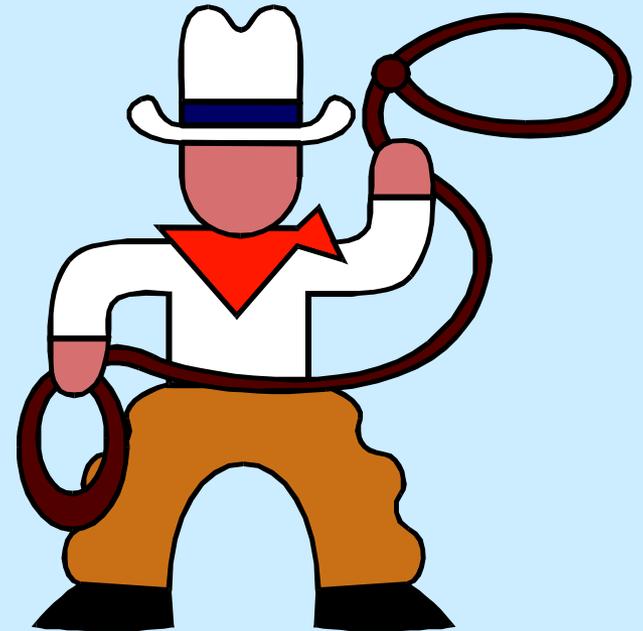


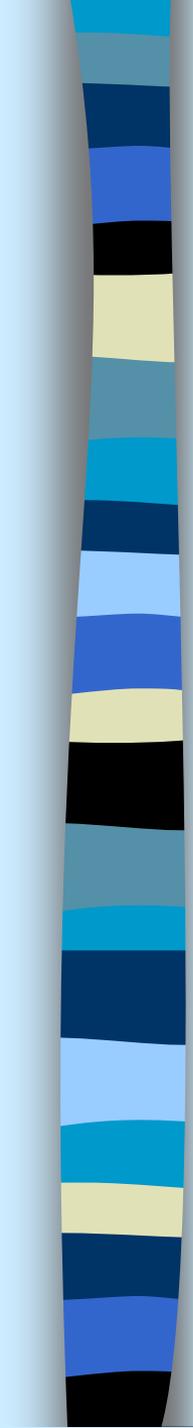
Patient Confidentiality

- Legislative mandates
- Research requires Human Subjects Review Committee (IRB)
- Written guidelines/Confidentiality pledge
- Firewall

What?

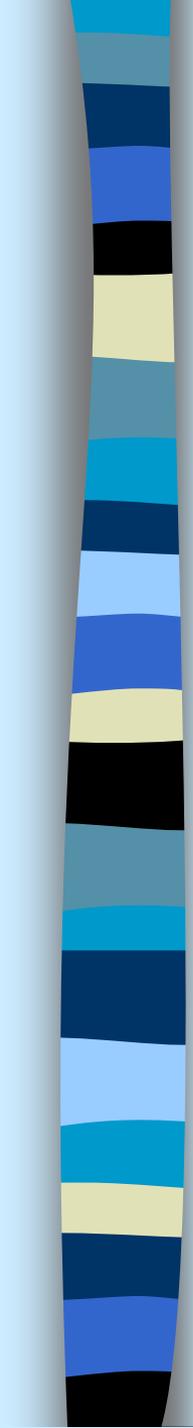
- What is gathered?
 - Demographics
 - Diagnosis
 - Workup, staging
 - Treatment





Patient Identification

- Accession #
- Sequence #
- MR#
- SS#
- Name
- Addresses
- Telephone
- Place/Date Birth
- Age at Diagnosis
- Race 1-5
- Spanish Origin
- Sex
- Primary Payer
- Comorbidities
- Physicians

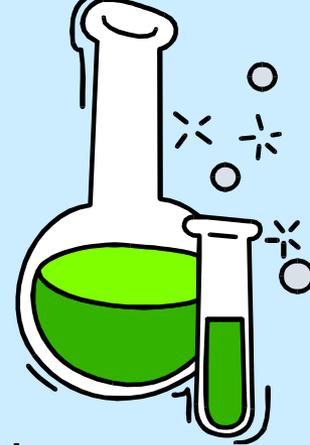


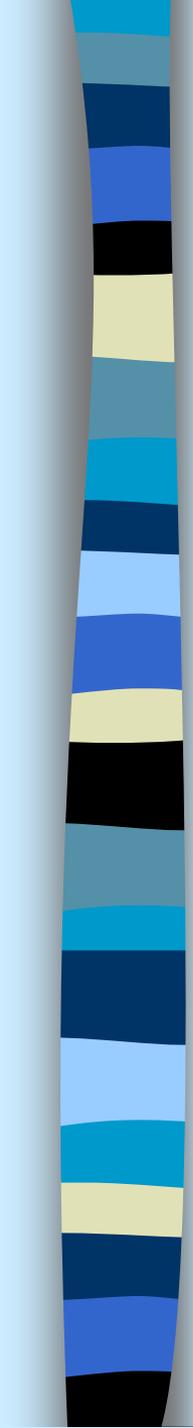
Cancer Identification

- Class of Case
- Facility From & To
- Dates
- Primary Site
- Laterality
- Histology
- Diagnostic Confirmation

FCOT

- Surg Dx/Stage
Procedure (bx, bypass)
- Surgery
 - Primary Site, Reg LN, Other
 - Surgical Approach
 - Surgical Margins
- Radiation
 - Where, Site, Amount, Fractions, Start & Finish
 - Reason No Tx
 - Surg/RT and/or Surg/Systemic Sequence
- Systemic
 - Chemotherapy
 - Hormone Therapy
 - Immunotherapy
 - Transplant/Endo Procedures
 - Other
 - Palliative



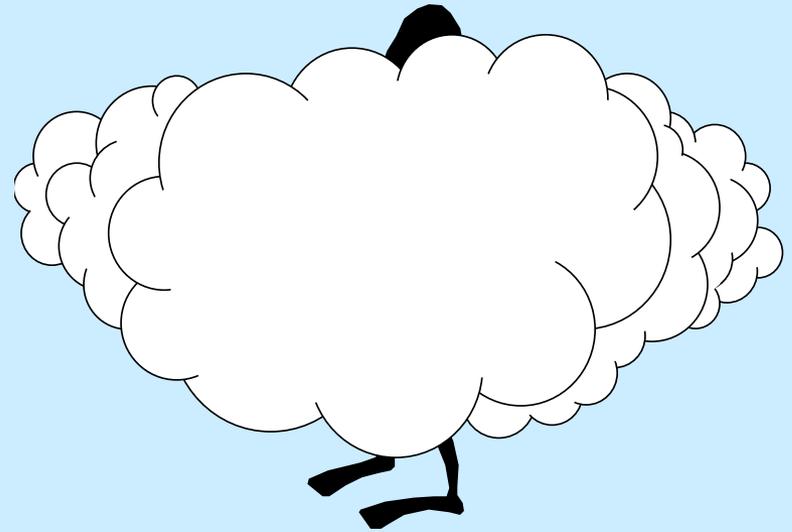


Charlie's Treatment

- Biopsy date
- Hemicolectomy date, surgery, reg LN
- Chemo at doc's office

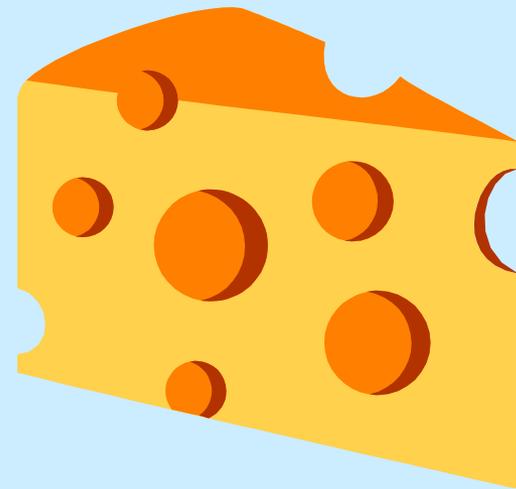
Meaningful Data is the Key

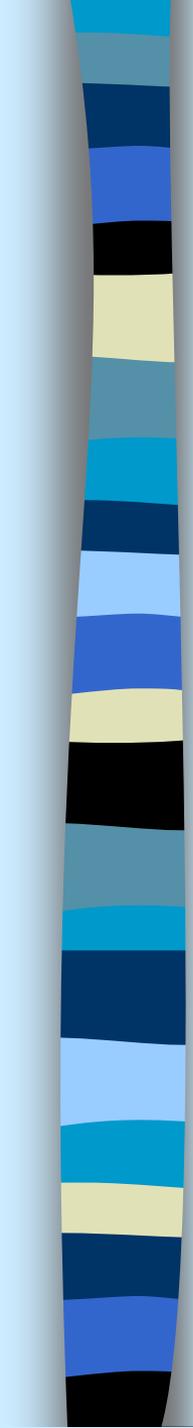
- Standardization
- Pertinent
- Reasonable
- Accurate



Standard Setters

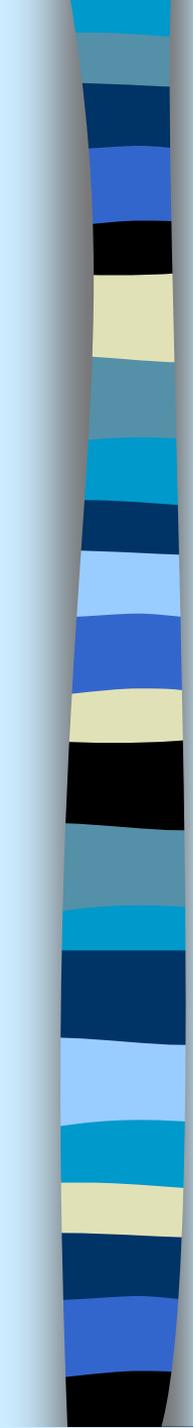
- NPCR
- NAACCR
 - Central registries
- SEER
 - NCI funding
- COC
 - Hospitals





When?

- Many time tables for registry:
 - Abstract 4-6 months after dx
 - Follow-up yearly*
 - Annual report yearly
 - PCEs, other studies prn
 - Cancer Comm meetings quarterly*
 - Tumor Conferences*



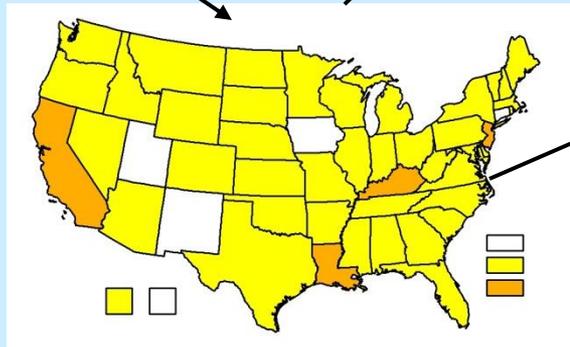
Where?

- Reports
- American Cancer Society
- Journal articles
- Cancer in North America
- National Cancer Data Base
- Data Requests



**Where
Data
Goes**

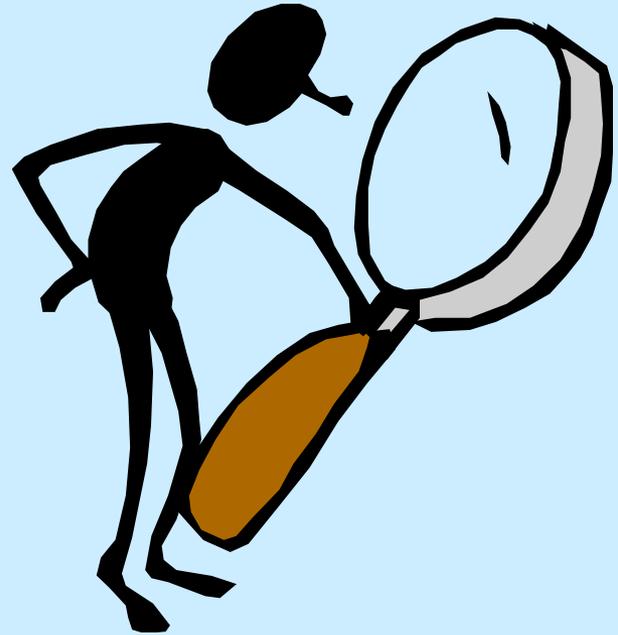
**National
Program
Cancer
Registries**



**International
Association
Cancer
Registries**

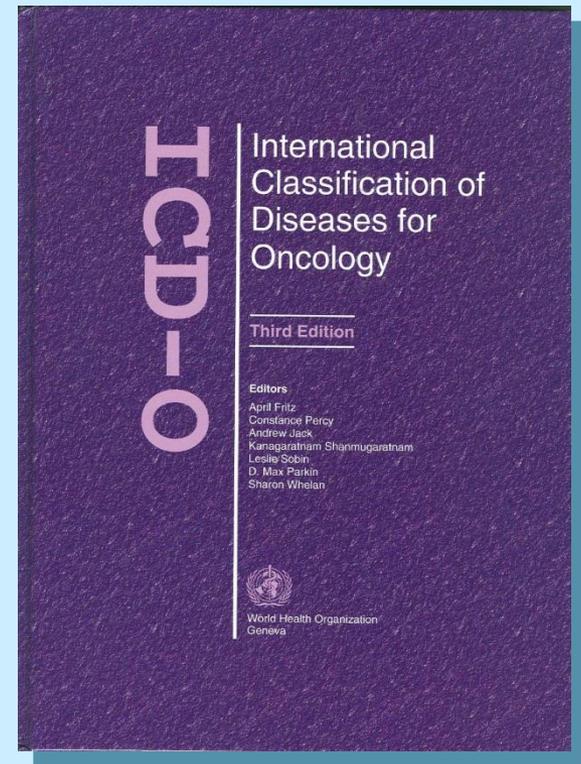
Casefinding

- Reportable Lists
 - COC Standards
 - State Rules
 - by Agreement
- Exclusions
- Suspense File



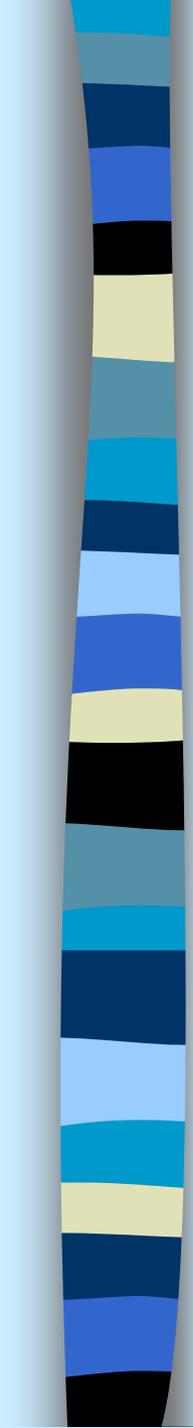
Coding

- ICD-O-3 in 2000
- Site coding
- Morphology coding
 - 4-digit histology code
 - 1-digit behavior code
 - 1-digit grade code



Sample: Poor diff
adenocarcinoma,
sigmoid colon

C187, 8140/33

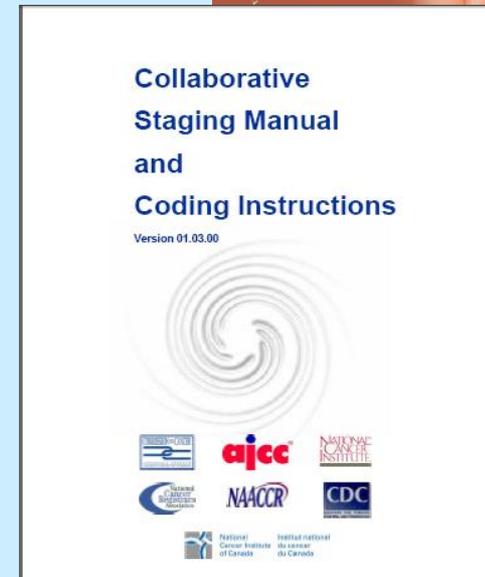
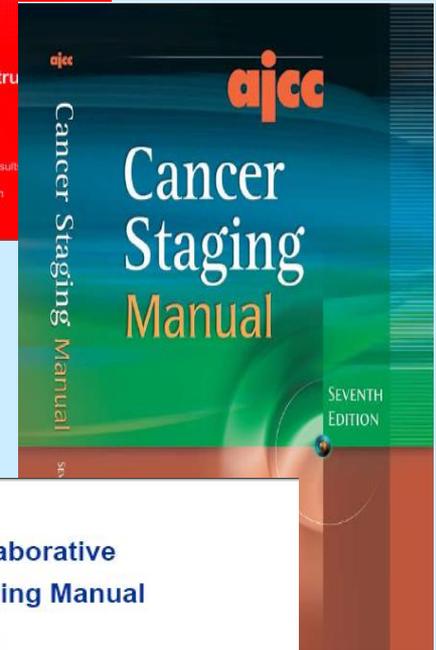
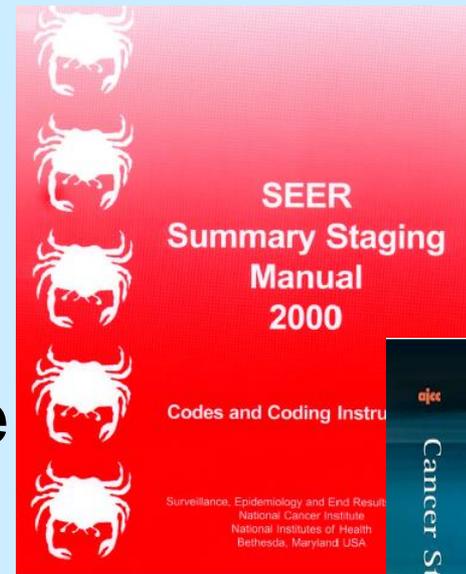


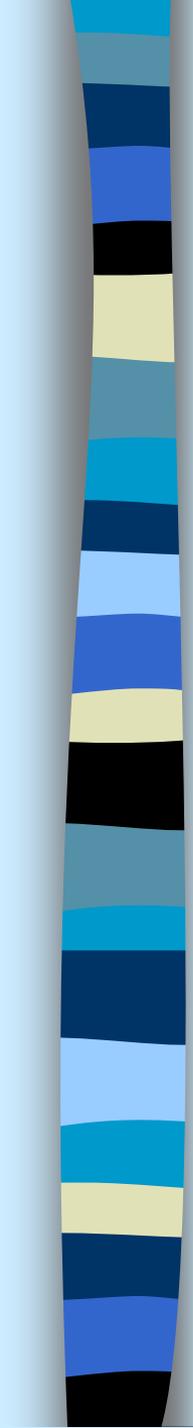
Other Coding Guidelines – SEER Rules

- Multiple Primaries/Histology (MP/H)
 - When are multiple tumors counted as > 1 ?
 - What is best histology for any tumor?
- Hematopoietic Database and Coding Rules
 - Coding leukemia, lymphoma, and other heme diseases

Staging

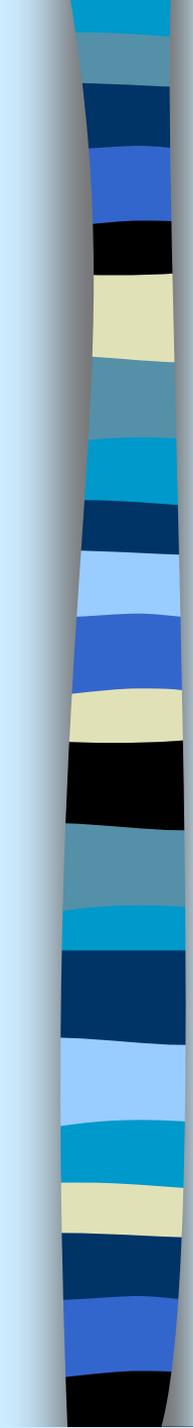
- Determine appropriate treatment
- Predict prognosis
- Provide means of comparison
 - ~ General Summary/SEER
 - ~ AJCC (TNM)
 - ~ Collaborative Stage (D/C cases diagnosed 2016)





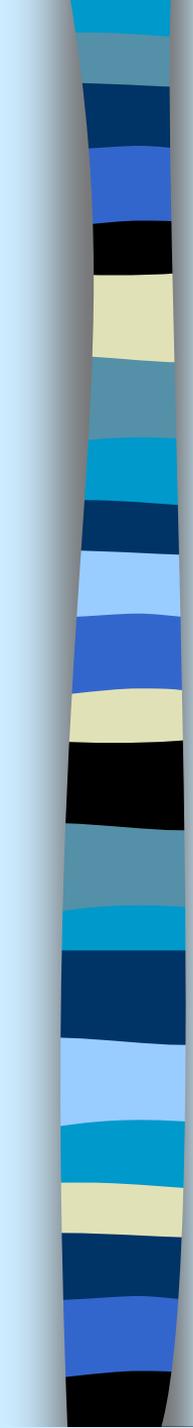
Abstracting

- Facility Oncology Registry Data Standards (FORDS)
 - Definitions
 - Files
- Commission on Cancer: Cancer Program Standards



Follow-Up

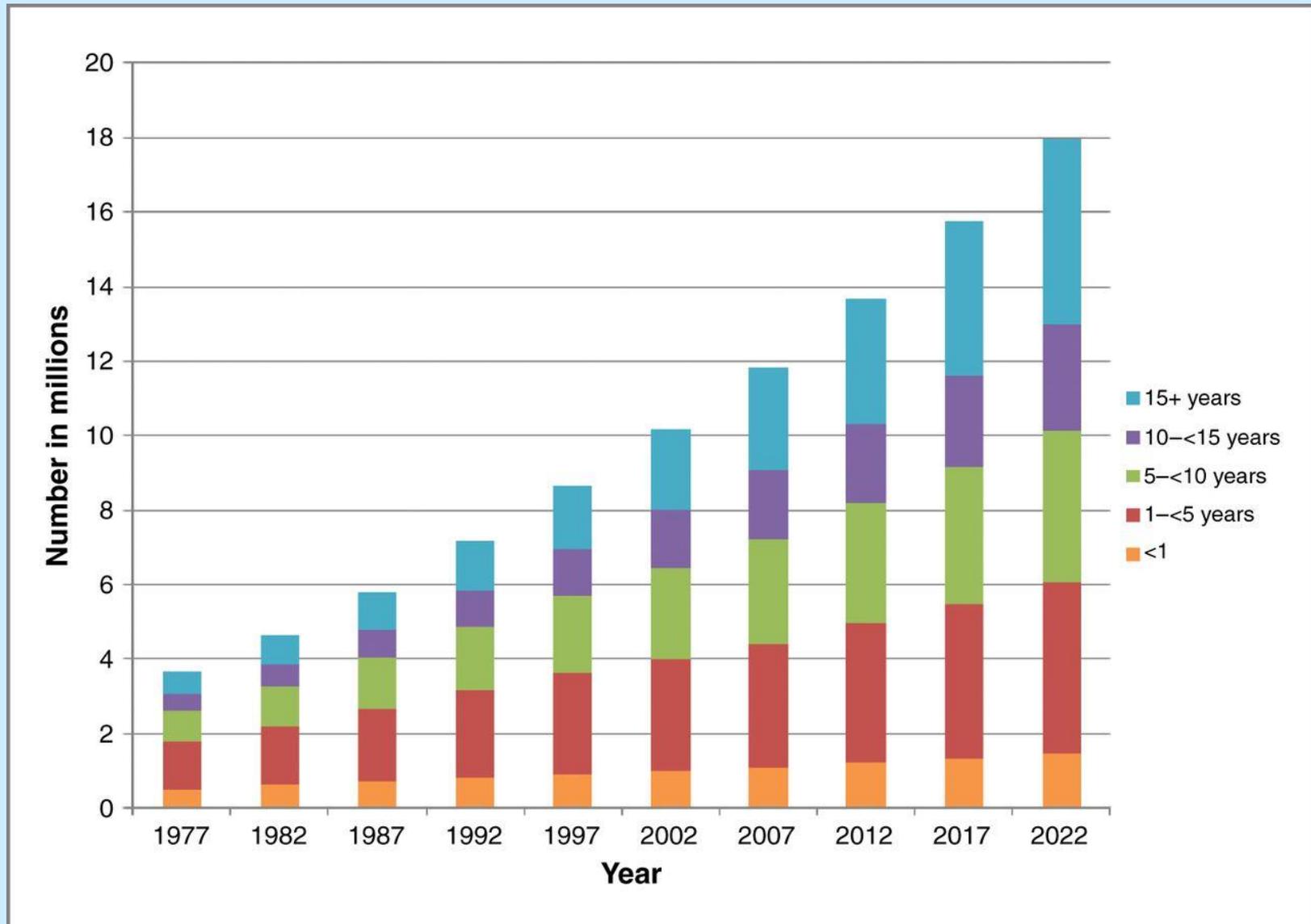
- Required for COC accreditation
 - Yearly
 - 90% analytic patients dx in past 5 years
 - 80% analytic patients in entire registry
- Central registries moving toward



Survival

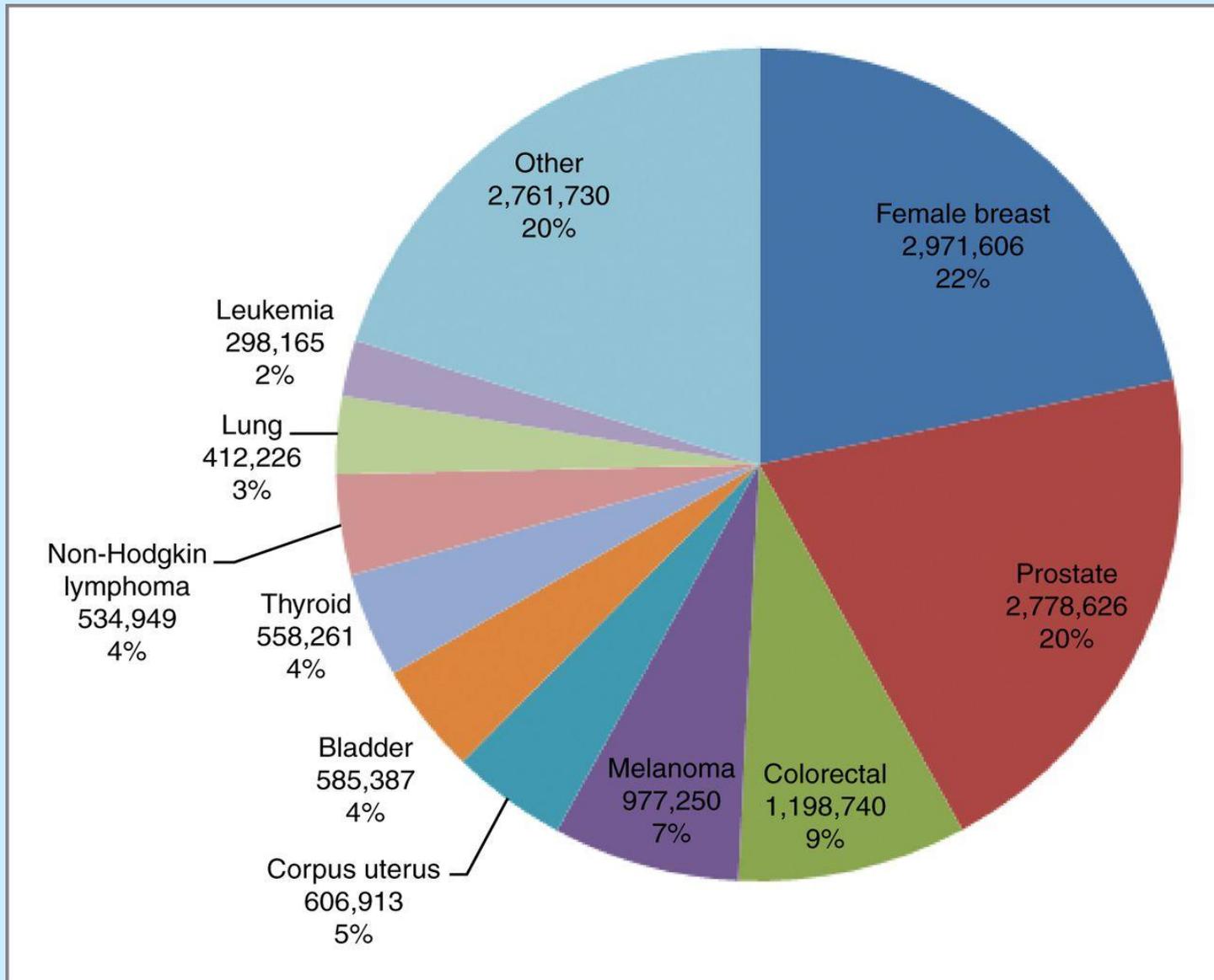
- 1/6 people older than 65 are survivors
- 64% adults can expect 5-year survival
- 79% children can expect 5-year, 75% 10-year survival

Estimated and projected number of cancer survivors in the United States from 1977 to 2022 by years since diagnosis.



de Moor J S et al. Cancer Epidemiol Biomarkers Prev
2013;22:561-570

Estimated number of cancer survivors in the United States as of January 1, 2012 by cancer site.



Charlie's Survival?

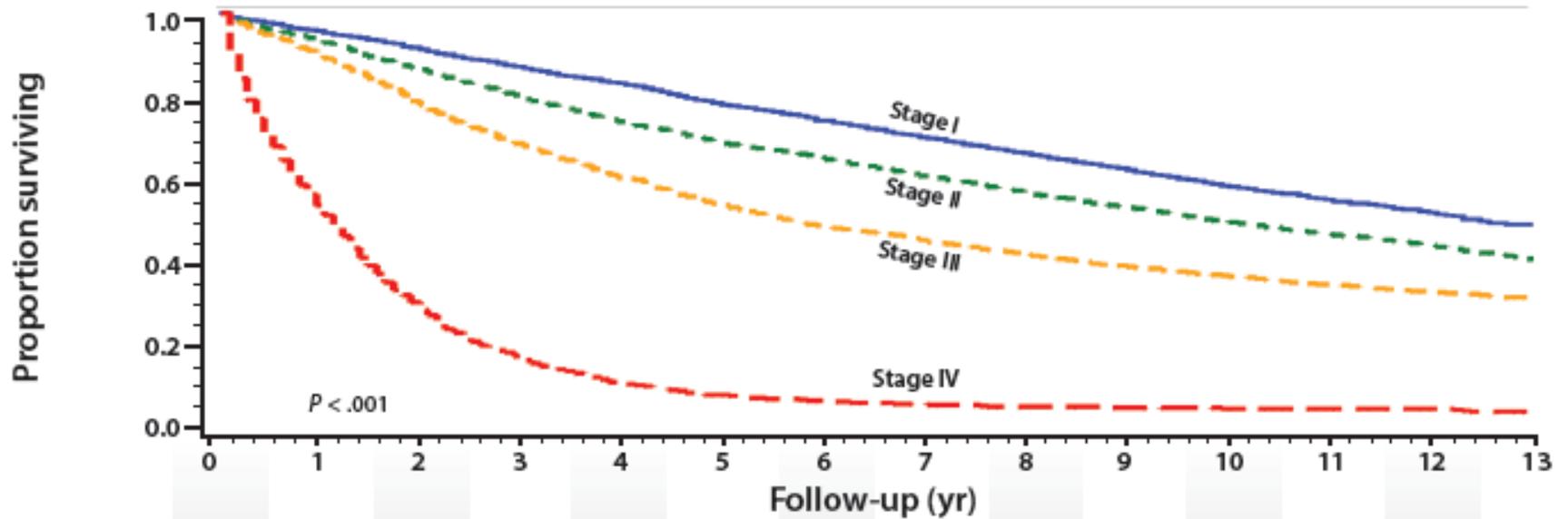
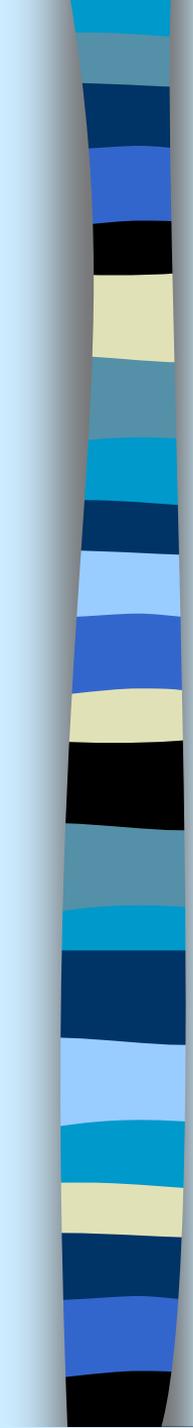


Figure: Kaplan-Meier Curve Displaying Overall Survival of Colorectal Cancer by Stage Among Men 60–75 Years of Age Diagnosed in 1998–2000.

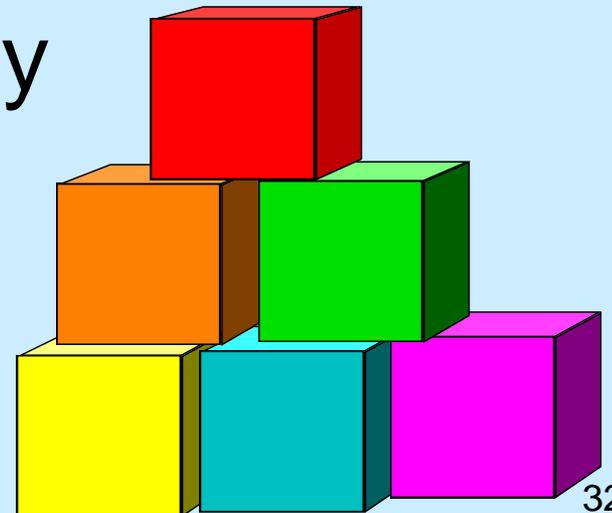


COC Standards

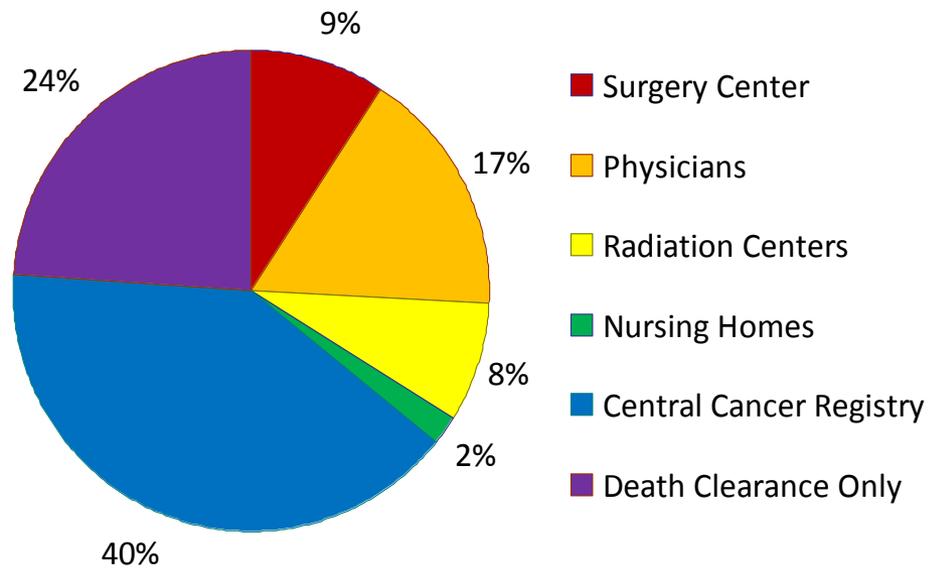
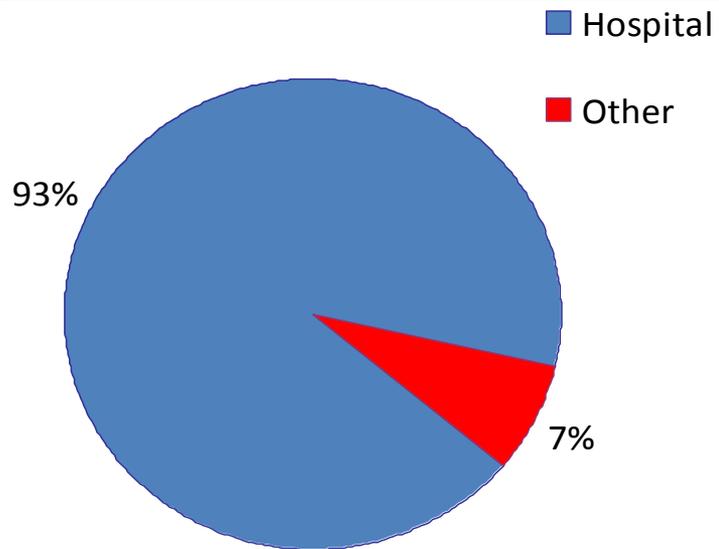
- Voluntary program to accredit programs
- Areas of concentration
 - Eligibility Requirements
 - Program Management
 - Clinical Services
 - Continuum of Care Services
 - Outcomes
 - Data Quality

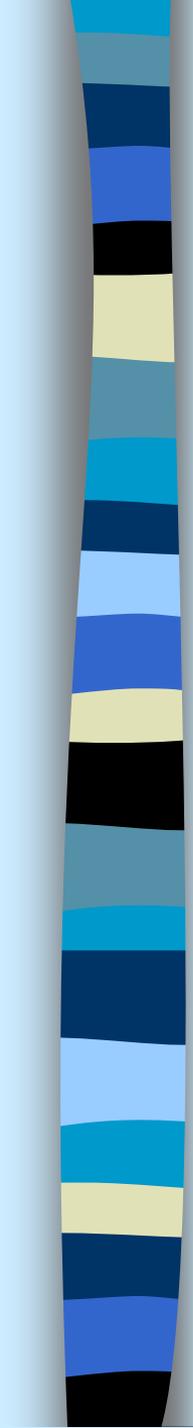
Central Registry

- Population-based
- Case ascertainment
- Case consolidation
- Death Clearance Only



Cases to MCR



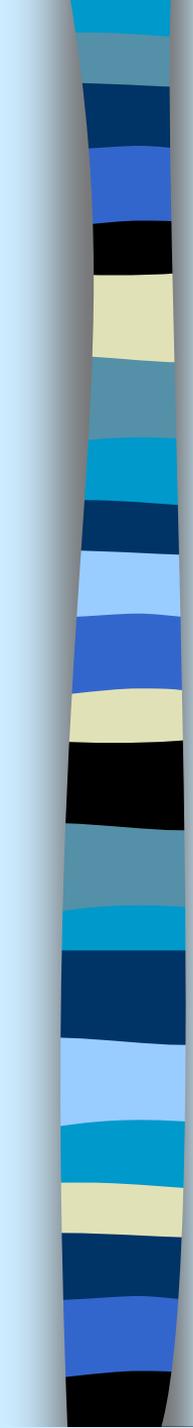


Data Processing

- Patient Linkage
 - New vs. Existing Patient
- Data Items Compared
 - Name (First, Last)
 - Date of Birth
 - Social Security Number
 - Sex
 - Other

Sample Patient Linkage

LAST	FIRST	DOB	SEX
DUCK	DONALD	19550101	M
DUCK	DONALDO	19550308	M
DUCK	DONNA	19821202	F
DUCK	D. EDWARD	19550308	M

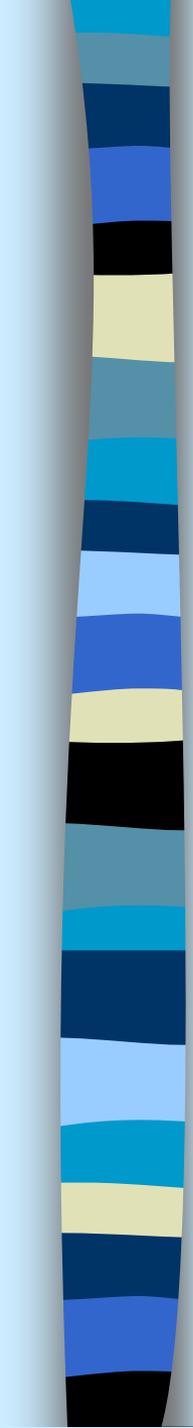


Data Processing

- Tumor Linkage
 - New vs. Existing Tumor
- Data Items Compared
 - Site
 - Histology
 - Laterality
 - Hospital Number
 - Sequence Number

Sample Tumor Linkage

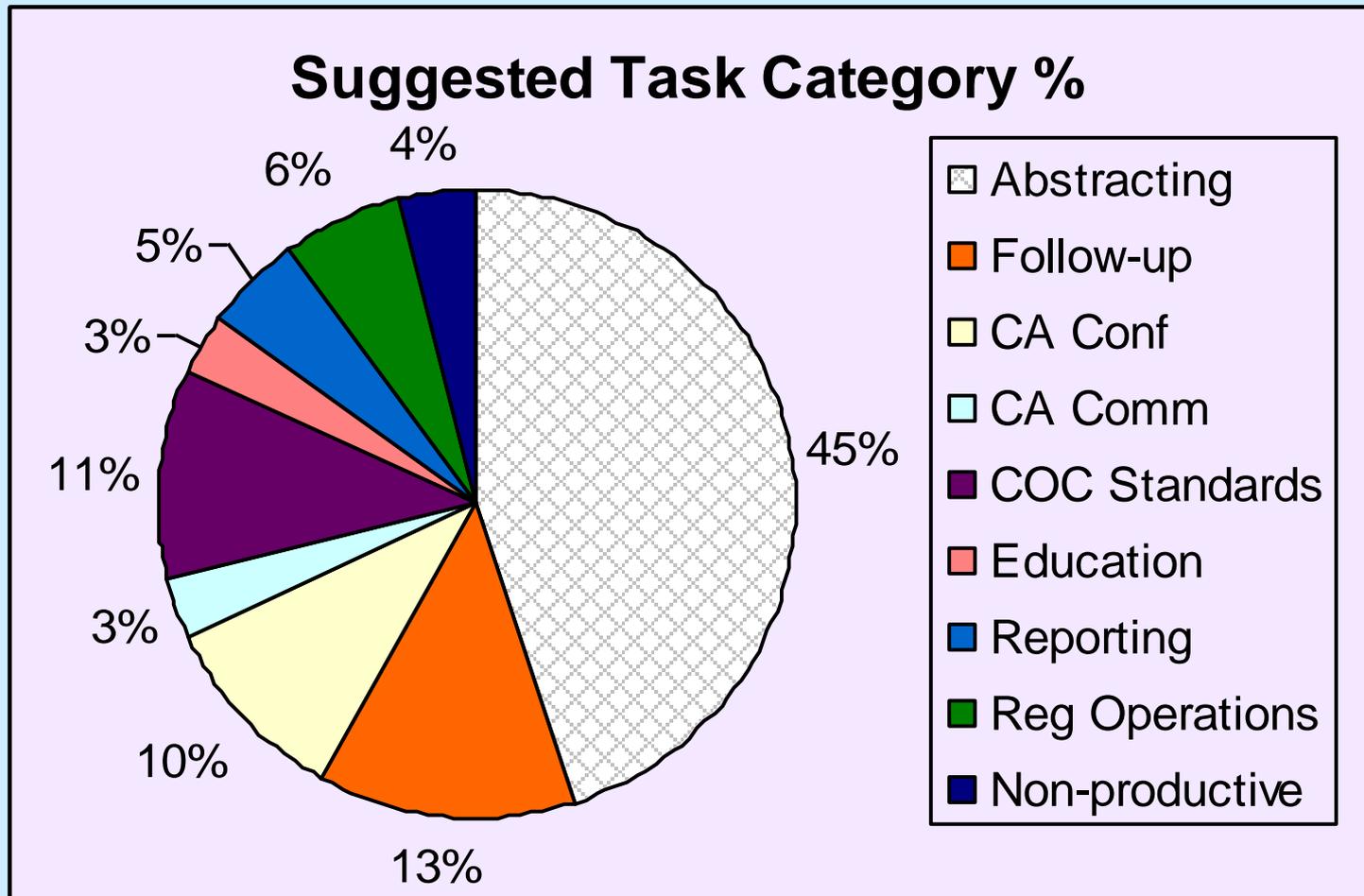
Name	Site	Histology	Diagnosis Date	Class case
Duck, D	C189	8140/3	20050101	21
Duck, D	C184	8480/3	20050114	14
Duck, D	C220	8140/3	20050101	32



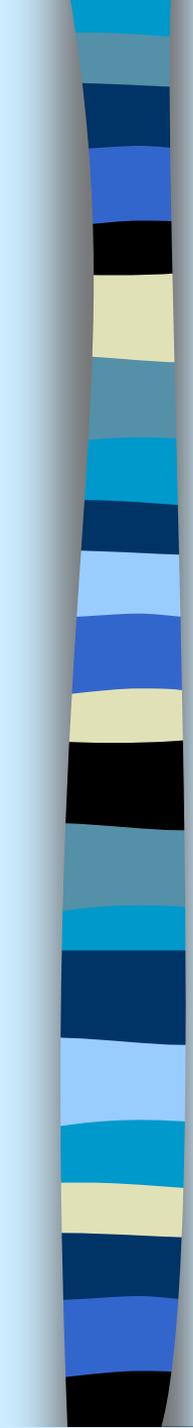
Hospital vs Central Registries

- Single facility
- Hosp patients only
- Improve care
- FU, survival
- Service-oriented
- Self-evaluation by CA Comm
- Multi-facility
- All residents of area
- CA prevent/control
- Incidence/survival rates
- Research-oriented
- Population-based surveillance

How do hospital registrars spend time?



Source: JRM Vol 34, #3 – Kootenai Med Center Staffing Article



Registry Statistics

- Hospital

- Incidence
- Qualitative
- Survival

- Central Registry

- Incidence
- Prevalence
- Survival



About Quality Programs

ACS NSQIP

ACS NSQIP Pediatric

Bariatrics

Breast Disease

Cancer

Cancer Programs

Accredited Cancer Programs

Commission on Cancer

National Cancer Data Base

American Joint Committee on Cancer

Cancer Liaison Program

Stereotactic Breast Biopsy Accreditation Program

CoC News

Contact Us

Surgeon Specific Registry

Cancer



The American College of Surgeons Cancer Programs benefit an array of health care professionals, patients, and facilities through standard-setting, accreditation, and educational activities. Representing leaders in cancer care and aiming to improve cancer patient care, our nationally recognized programs—the Commission on Cancer, the National Accreditation Program for Breast Centers, the National Cancer Data Base, the American Joint Committee on Cancer—all work toward helping your program provide high-quality cancer care.

We strive to develop the best educational resources, offer useful training opportunities, advocate for you and your patients, and stay up to date on the latest cancer care trends and treatments. Learn more about what we have to offer your cancer program and the patients you serve.





Surveillance, Epidemiology, and End Results Program
Turning Cancer Data Into Discovery

Search SEER:

Search

Cancer Statistics

Statistical Summaries | Interactive Tools | Publications

For Researchers

Datasets and Software

For Cancer Registrars

Coding Rules, Training and Support

About SEER

Our Registries and Research

WE ARE A PREMIER SOURCE FOR CANCER STATISTICS IN THE UNITED STATES.

The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute works to provide information on cancer statistics in an effort to reduce the burden of cancer among the U.S. population.

Did You Know? Video Series

Did you know that men are more likely than women to be diagnosed with bladder cancer, with nearly three times as many cases?

[Bladder Cancer](#)



Cancer Stat Fact Sheets

Population statistics for common types of cancer:

All Sites



View

Fast Stats

Get a customized graph or table by selecting a category:

Cancer Site



View

Search the SEER Bibliography

A comprehensive bibliography of SEER Publications produced by registry and program staff. Links to PubMed and abstracts will be provided in the search results.

Begin Your Search >



Latest Releases & Highlights

[US Population Data - 1969-2013](#)

Released 1/21/2015



[Cancer Statistics Review \(CSR\), 1975-2011](#)

Updated 12/17/14



[Special Issue: Collaborative Staging and Its Impact on Cancer Registry](#)

[Data: Information for Data Users](#)

Released 12/1/2014



[Monograph: Cancer Survival From a Policy and Clinical Perspective—SEER Program, 1975-2010](#)

Released 11/24/14



[SEER Data, 1973-2011](#)

Released 4/15/14



[SEER*Stat Software 8.1.5](#)

Released 3/31/14



SEER In the News

- August 11, 2014 - Medical News Today
[Decline in US lung cancer rates, varying by race, gender, age](#)
- August 4, 2014 - NCI Cancer Center News
[Fred Hutchinson researchers find that recent use of some birth control pills may increase breast cancer risk](#)
- July 17, 2014
[Surveillance Research Program Job Opportunity: Surveillance Systems Branch Chief](#)

Data Submission Requirements

Reporting Guidelines

Casefinding Lists

[-] Coding and Staging Manuals

[-] Collaborative Stage

Grade Coding Instructions 2014+

[-] Hematopoietic Project

Historical Staging and Coding Manuals

ICD-O-3 Coding Materials

[-] MP/H Rules

Summary Staging Manual 2000

Questions & Answers

Ask a SEER Registrar

Data Collection Answers

SEER Inquiry System

Software & Services

ICD Conversion Programs

[-] SEER Abstracting Tool (SEER*Abs)

SEER API

SEER Data Viewer

[-] SEER*Rx - Interactive Drug Database

Data Documentation & Variable Recodes

Training

Information for Cancer Registrars

NCI SEER promotes and guides cancer registrars to improve cancer registry data by providing pertinent information, education and training opportunities. This site will assist cancer registrars by providing:

- [SEER data submission requirements](#), as well as SEER data items;
- [Coding and staging manuals](#) for up-to-date reporting guidelines;
- An [interactive query system](#) and [drug database](#), some of the software and services most used by SEER registrars.
- [Registrar training](#) from SEER and our partners.
- Information on [Becoming a Cancer Registry Professional](#).

Announcements

[2015 SEER Advanced Topics for Registry Professionals pre-NCRA Conference Workshop](#)

May 19- May 20, 2015 in San Antonio, TX

Registration is now open.

- [SEER Abstracting Tool \(SEER*Abs\) version 2.7](#) (February 18, 2015)
- [Hematopoietic Database Software Version 3.0.1](#) (February 5, 2015)
- [SEER Data Viewer version 1.5.1](#) (January 30, 2015)
- [Hematopoietic and Lymphoid Neoplasm Coding Manual and Database](#) (January 14, 2015)
- [2015 Data Submission Requirements](#) (January 14, 2015)

Mailing List

- [Sign up](#) to receive announcements pertinent to NCI SEER, other standard setters, and cancer registries.

Ask a SEER Registrar

- [Submit a question to SEER](#) about coding cancer cases or other materials available for registrars on this site.

National Program of Cancer Registries (NPCR)

NPCR

Cancer Registries' Value for You

Cancer Data and Statistics Tools

About the Program

Cancer Data Access for Research

Comparative Effectiveness Research Data Collection Enhancement Project

Meaningful Use of Electronic Health Records

Informatics

Software and Tools

Training

Registry Operations Resources

Success Stories

Partners

Contact a Local Registry

Related Resources

[Cancer data and statistics](#)

[Cancer Research feature](#)

[Programa Nacional de Registros del Cáncer](#)

[More Resources >>](#)

[Cancer Home](#)

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Data collected by local cancer registries enable public health professionals to understand and address the cancer burden more effectively. CDC provides support for states and territories to maintain registries that provide high-quality data.



Features



United States Cancer Statistics

The official federal statistics on cancer incidence from registries that have high-quality data, and cancer mortality statistics for 2011.



eMaRC Plus Training Video

This mini training video shows you how to change your password.



Cyber Cancer Registry

This interactive virtual registry system helps develop and assess the skills of cancer registry personnel.



Contact Your Local Registry

Find contact information for registries in all 50 states, the District of Columbia, Puerto Rico, U.S. Pacific Island jurisdictions, and 6 cities.

Cancer Registries' Value for You

Have you ever wondered, "How do we know what causes cancer?" or "Who is most likely to get cancer and why?" Learn what a cancer registry is, and how cancer registries help answer these important questions.

[Read More >>](#)

NPCR Research

- [Using the National Death Index to identify duplicate cancer incident cases in Florida and New York](#)
- [Cancer incidence rates and trends among children and adolescents in the U.S.](#)

[More Research >>](#)



Print



Updates



Listen



Twitter

Page last reviewed: October 9, 2014

Page last updated: October 9, 2014

Content source: Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion

 [Print page](#)

 [Get e-mail updates](#)

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[USCS Fact Sheet](#)
[PDF-415KB]

Contact Us:

 Centers for Disease Control and Prevention
Division of Cancer Prevention and Control
c/o CDC Warehouse
3719 N Peachtree Rd
Building 100 MS F-76
Chamblee GA 30341

 800-CDC-INFO
(800-232-4636)
TTY: (888) 232-6348

 [Contact CDC-INFO](#)

File Formats Help:



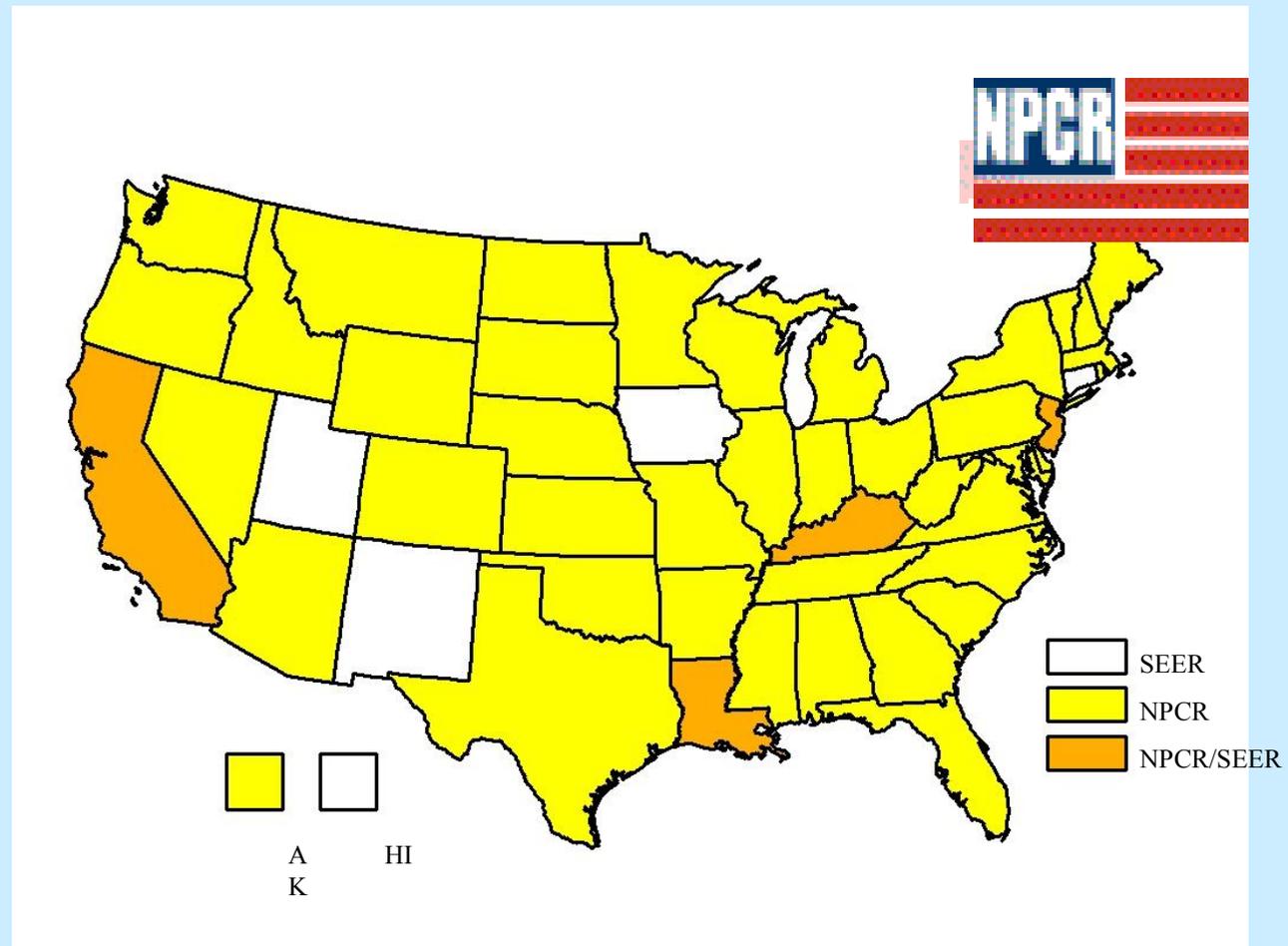
How do I view different file formats (PDF, DOC, PPT, MPEG) on this site? >>

National Program of Cancer Registries

1995+

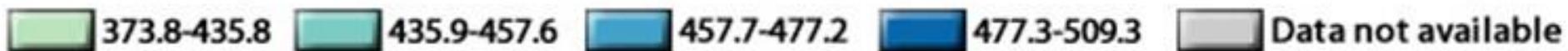
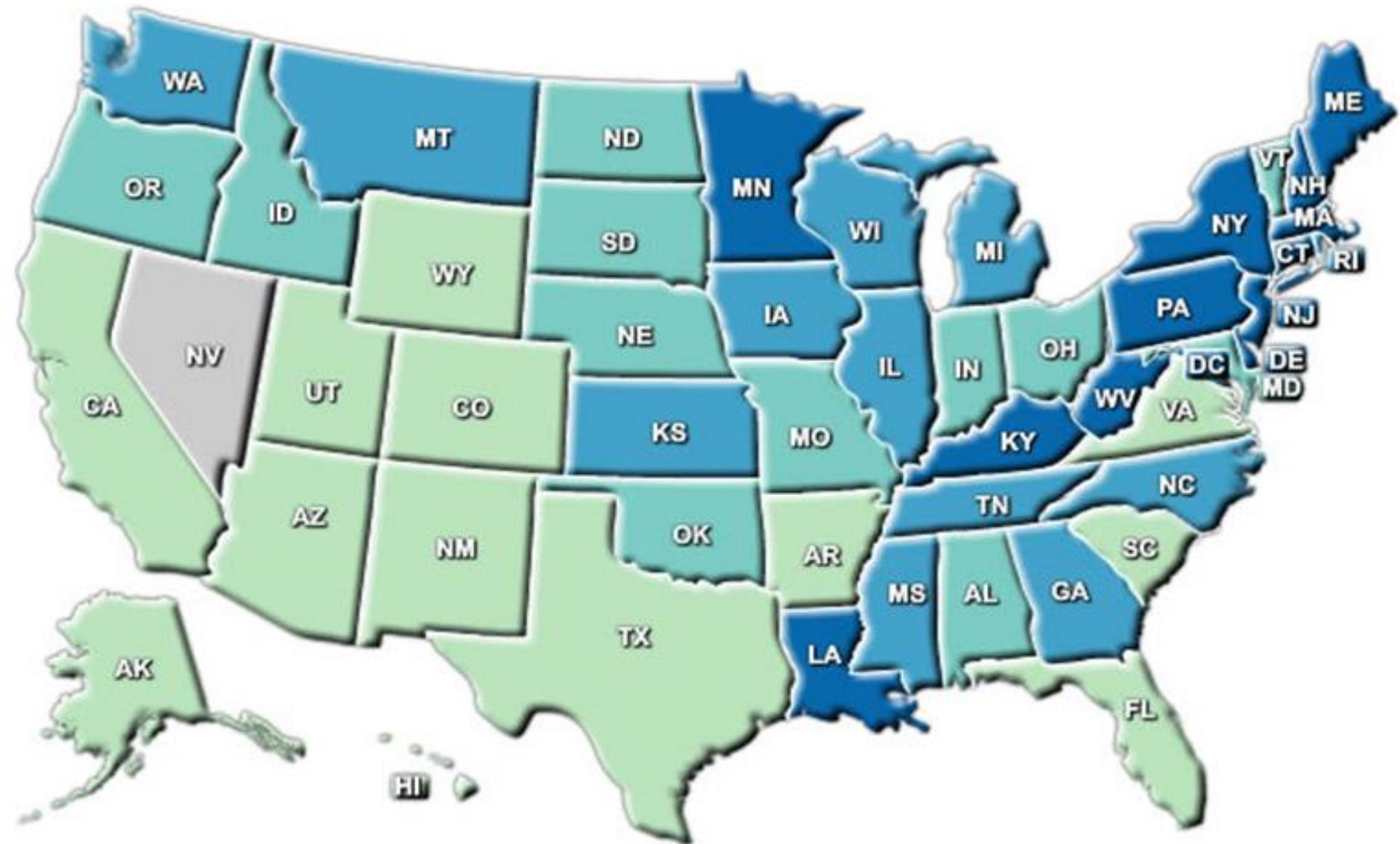
45 states, 3 territories, District of Columbia

96% population coverage



All Cancers Combined
Incidence Rates* by State, 2011†

NPCR Data





NAACCR 2015 Annual Conference

"First in Flight: Launching a New Era in Cancer Surveillance"

The NAACCR 2015 Annual Conference will provide attendees with the opportunity to learn from national experts in cancer surveillance, cancer registry operations, and cancer research. Sessions will explore the new era in cancer surveillance from multiple perspectives in North America.

Conference Registration Now Open!



ANNUAL CONFERENCE



WHO WE ARE



ELECTION NOMINATIONS OPEN



CALL FOR DATA



WEBINARS

NAACCR News

Recent NAACCR ListSers

- ▶ [2015 NAACCR Exhibitor and Sponsor Opportunities](#)
- ▶ [NAACCR 2015 Annual Conference Registration is now open!](#)
- ▶ [CBTRUS Alex's Lemonade Stand Foundation Infant & Childhood Primary Brain Tumor Report announcement](#)
- ▶ [2015 Implementation Guidelines - Revised February 2015](#)

2015 Winter Narrative is Now Available

- ▶ [2015 NAACCR Annual Conference](#)
- ▶ [Steering Committee Corner](#)

Strategic Management Plan

- ▶ [Spring 2014 Update](#)



What's New At NAACCR

- ▶ [NAACCR Surveillance Webinar Series View Listings](#)
- ▶ [Want to do Research with a Registry?](#)

If you're a researcher looking to work with a NAACCR registry but aren't sure who to work with, we have just the tool for you: The Registry Research Information Database (RRIDB). Using this tool you can retrieve a list of registries by research type with IRB info, contact info, and more.

▶ [CLICK HERE TO LAUNCH THE](#)

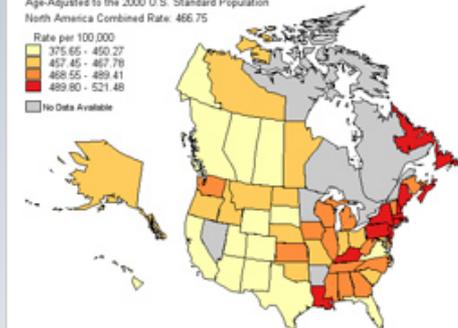
Search Site Search Publications

Quick Cancer Stats and Maps

CLICK TO VIEW QUICK CANCER STATS

Age-Adjusted Invasive Cancer Incidence Rates in North America
All Sites, 2007-2011
By State/Province
Age-Adjusted to the 2000 U.S. Standard Population
North America Combined Rate: 466.75

Rate per 100,000
 375.65 - 450.27
 457.45 - 467.76
 468.55 - 489.41
 489.80 - 521.48
 No Data Available



NAACCR FastStats

Cancer In North America Volumes

Annual Report to the Nation

Canadian Cancer Statistics

Additional Resources

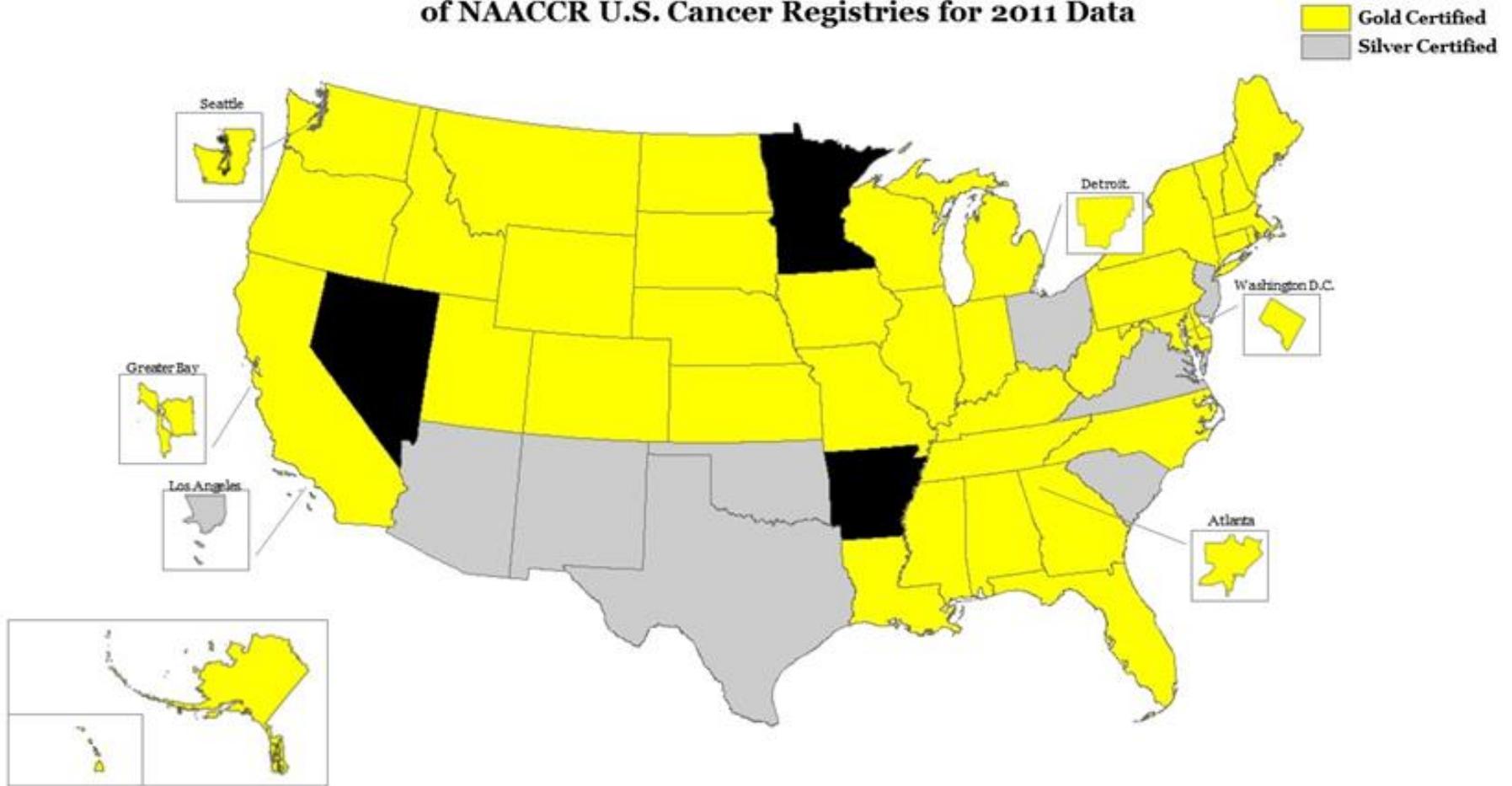
Media

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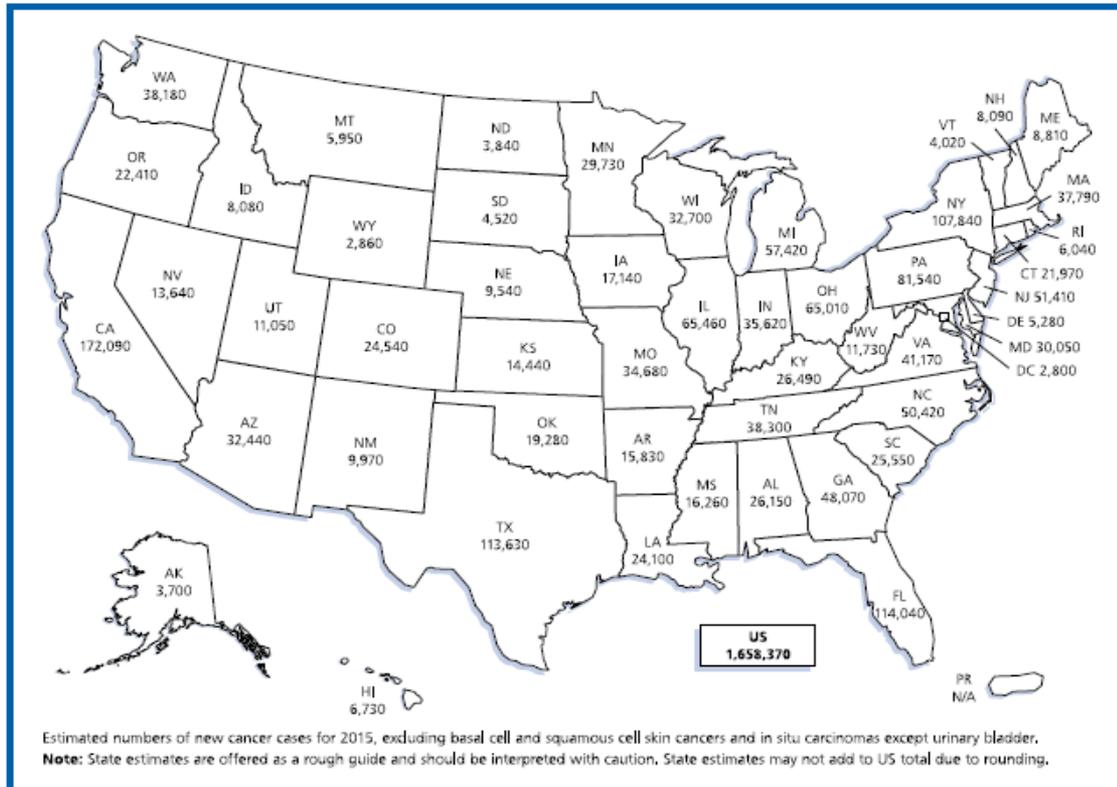
Gold and Silver Level Certification Status of NAACCR U.S. Cancer Registries for 2011 Data



Certified in 2014 for 2011 data

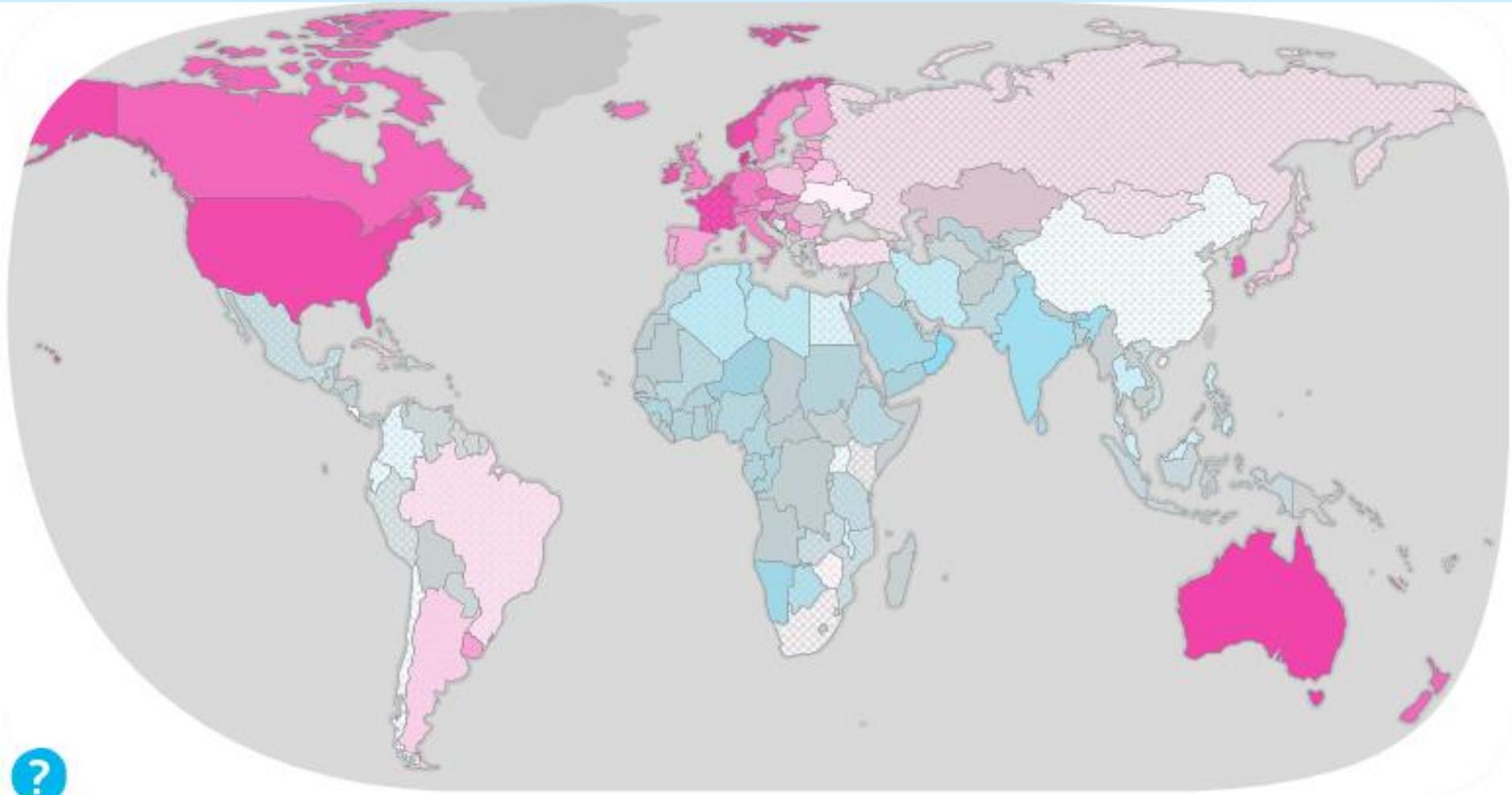
www.naacr.org

Cancer Facts & Figures 2015



Info from
central
registries &
NCDB

Special Section:
Breast Carcinoma In Situ
see page 26



Worldwide cancer incidence — 14,090,149 cases per year.

Pink – higher than average
Blue – lower than average

Grey – CA statistics less reliable