

North American Association of Central Cancer Registries

***Registry Certification –
Past, Present and Future***

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University of Kentucky**

NAACCR

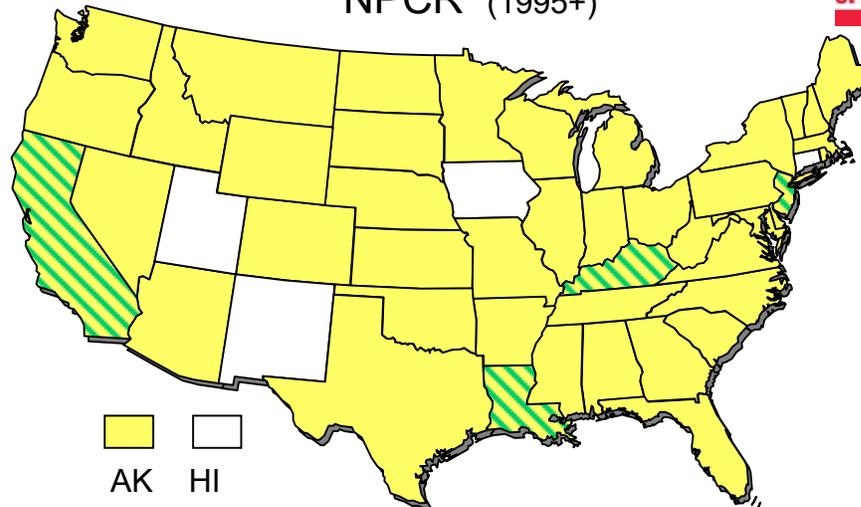
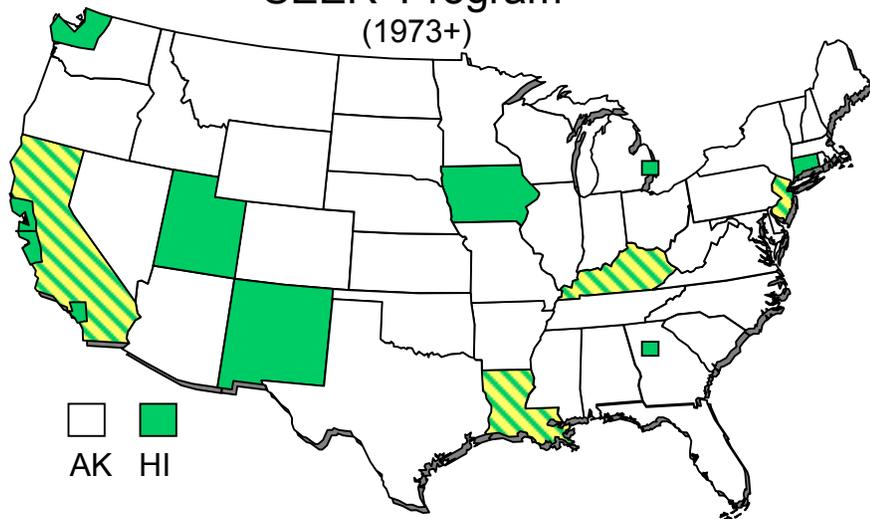
- ◆ Umbrella organization includes
 - cancer registries, government agencies and professional associations throughout USA and Canada
- ◆ Consensus standards for cancer registries
- ◆ *Cancer In North American (CINA)*
- ◆ Certification

U.S. Cancer Registries



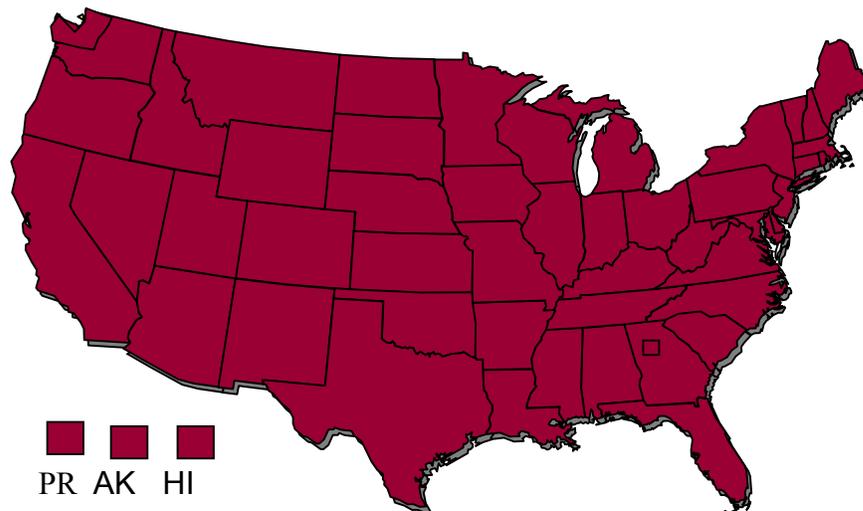
SEER¹ Program
(1973+)

NPCR² (1995+)



SEER
SEER 2000+/
NPCR 1995+

NPCR
NPCR 1995+/
SEER 2000+



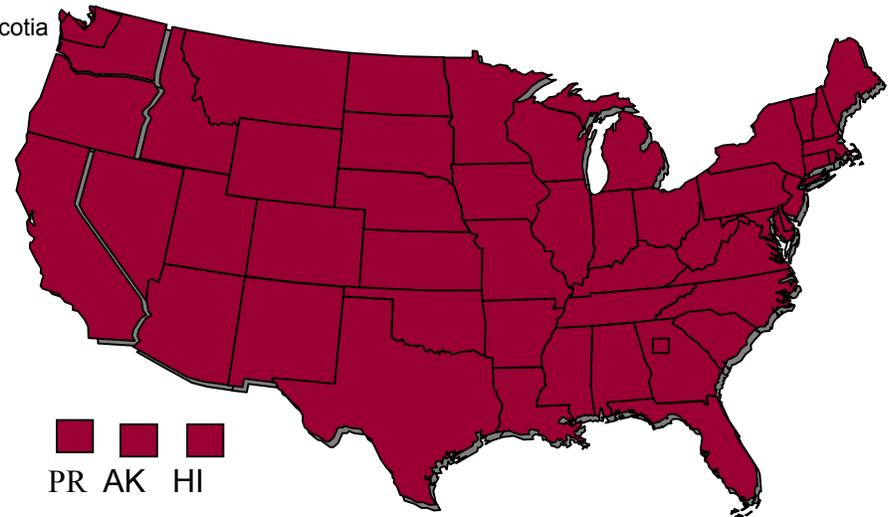
NAACCR member registries

Surveillance, Epidemiology, and End Results, National Cancer Institute
National Program of Cancer Registries, Centers for Disease Control and Prevention
North American Association of Central Cancer Registries
Registries meeting NAACCR standards of data quality for combined 1995-99 data (2002 Report to the Nation; 53% of U.S. population)

NAACCR Member Registries



Canadian
Cancer
Registries



U.S. Cancer
Registries

NAACCR member registries

NAACCR

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Registry Certification Goals

- ◆ To establish a process by which individual population-based cancer registries receive objective evaluation and confidential feedback regarding their performance in the areas of case completeness, completeness of information abstracted on critical variables, accuracy of data and timeliness

Goals (continued)

- ◆ To establish criteria for recognizing population-based cancer registries which achieve excellence in these areas
- ◆ To identify areas of strengths and weaknesses and to provide information for helping population-based cancer registries to plan future activities and to allocate resources

Elements of Certification

1. **Completeness of case ascertainment**
2. **Completeness of critical information for incidence reporting**
3. **% death certificate-only cases**
4. **Duplicates in the database**
5. **Quality of the information (EDITS)**
6. **Timeliness**

Cancer Registries Certified by NAACCR, United States



Population-based registry



NAACCR-certified

Cancer Registries Certified by NAACCR, Canada



-  Population-based registry
-  NAACCR-certified

Frequently Asked Questions and Comments

- ◆ Which cases are evaluated in certification ?
- ◆ What is case completeness and how do you estimate it ?
- ◆ Completeness should not be derived from small populations (e.g. unstable rates)
- ◆ Data used in estimating case completeness are not representative
 - Why use all US mortality rather than SEER area mortality ?
 - SEER black populations do not represent rural black populations
- ◆ Why did my completeness estimates drop in recent years ?
- ◆ Can I estimate my expected cases and why do expected case counts change each year ?

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Which cases are evaluated in Certification ?

The NAACCR Call-for-Data includes all
invasive cancers (including *in situ* bladder)
and *in situ* breast

...but only major invasive cancer sites are used to estimate case completeness

Major site groups include:

- Oral cavity and pharynx
- Esophagus
- Stomach
- Colon and rectum
- Liver
- Pancreas
- Lung and bronchus
- Melanoma (white only)
- Breast
- Cervix
- Corpus and uterus, NOS
- Ovary
- Bladder
- Kidney and renal pelvis
- Brain and CNS
- Hodgkin disease
- Non Hodgkin lymphoma
- Multiple myeloma
- Leukemia

Excludes

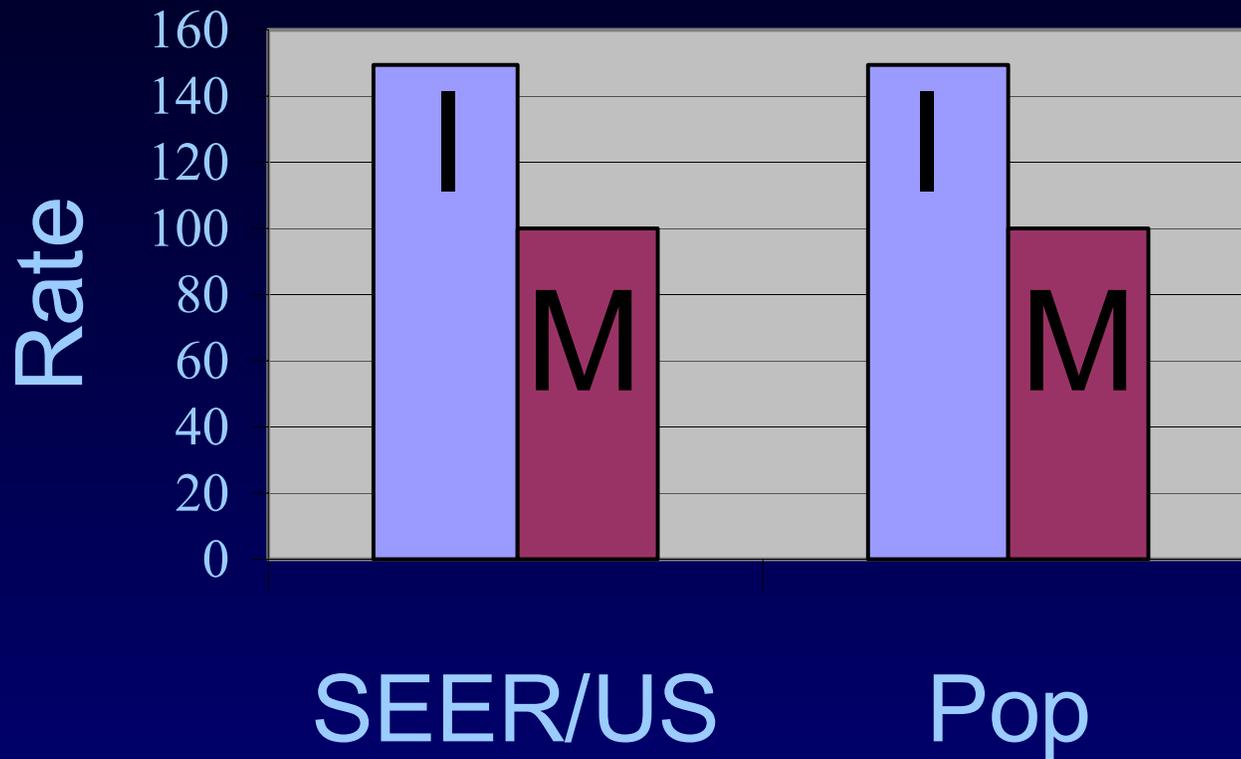
- Prostate
- Sites not listed

What is case completeness and how do you estimate it ?

... is the extent to which all expected incident cases of invasive cancer occurring in a defined population are included in the cancer registry database

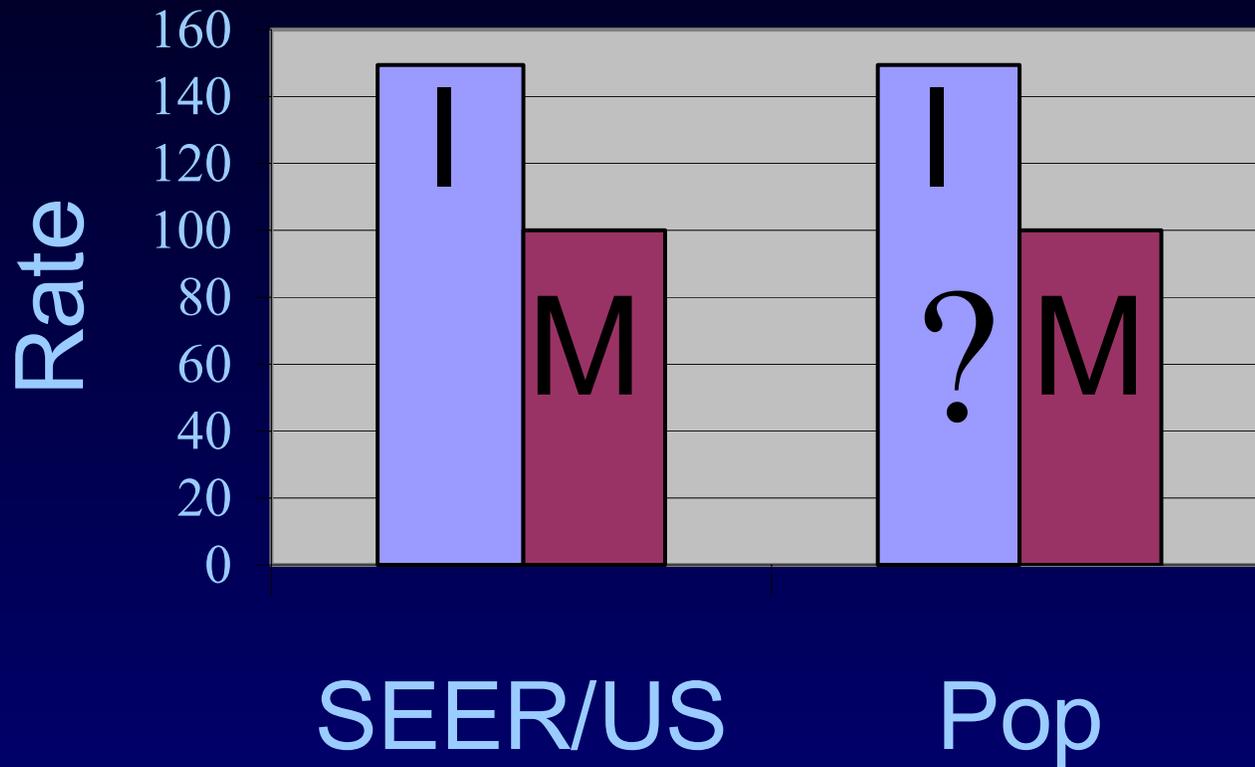
Observed / Expected

Start with an assumption.....



Rearrange the equation...

$$I_{\text{Pop}} = (M_{\text{Pop}} * (I_{\text{SEER}} / M_{\text{US}}))$$



Plug in the data....

$$\text{Expected } I_{\text{Pop}} = \sum_{j=1}^2 \sum_{i=1}^{19} (M_{\text{Pop}} * (I_{\text{SEER}} / M_{\text{US}}))$$

- I_{Pop} = ?? age-adjusted incidence rate in population (1 yr)
- M_{Pop} = age-adjusted death rate in the population (2 or 3 yrs)
- I_{SEER} = age-adjusted incidence rate in 11 SEER Programs (5 yrs)
- M_{US} = age-adjusted death rate in United States (5 yrs)
- i = 19 major invasive sites
- j = gender (male, female)

Using the mortality experience in your population...

$$\text{Expected } I_{\text{Pop}} = \sum_{j=1}^2 \sum_{i=1}^{19} (M_{\text{Pop}} * (I_{\text{SEER}} / M_{\text{US}}))$$

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The I/M ratios from...

$$\text{Expected } I_{\text{Pop}} = \sum_{j=1}^2 \sum_{i=1}^{19} (M_{\text{Pop}} * (I_{\text{SEER}} / M_{\text{US}}))$$

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Repeat for each major cancer site...

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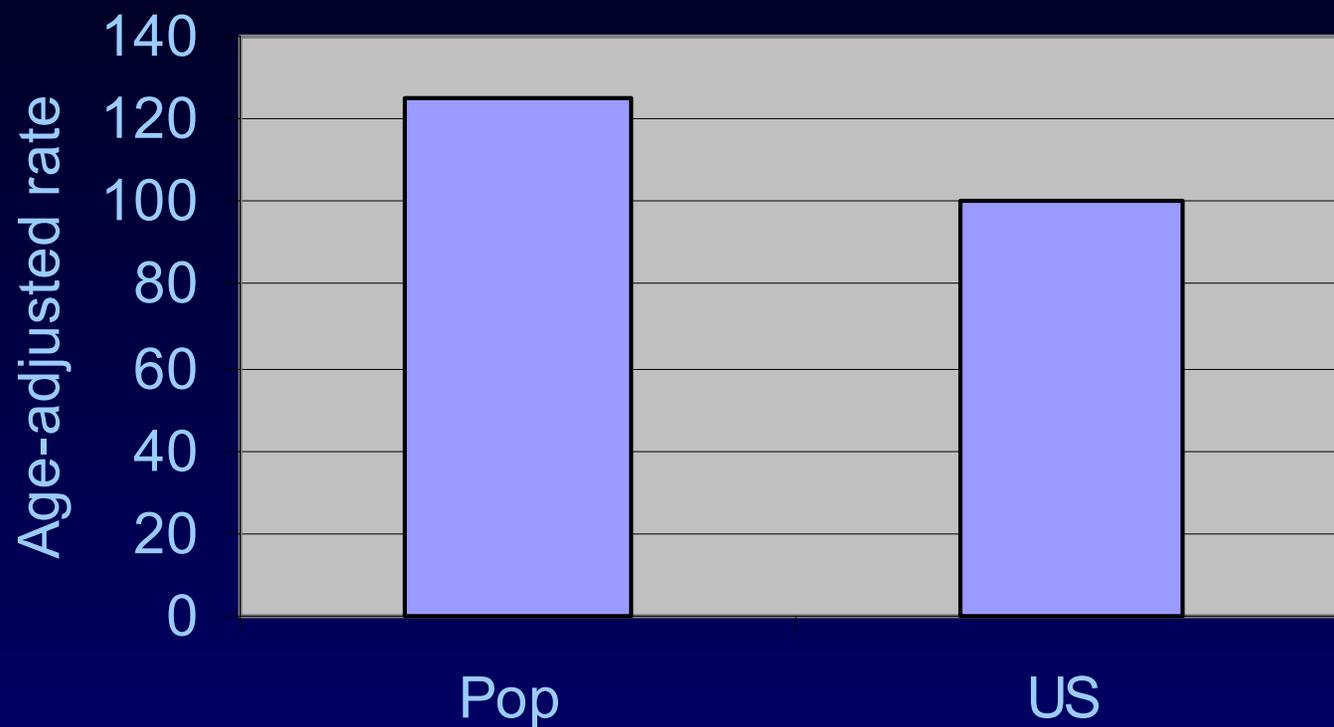
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- j = gender (male, female)

... And for males and females...

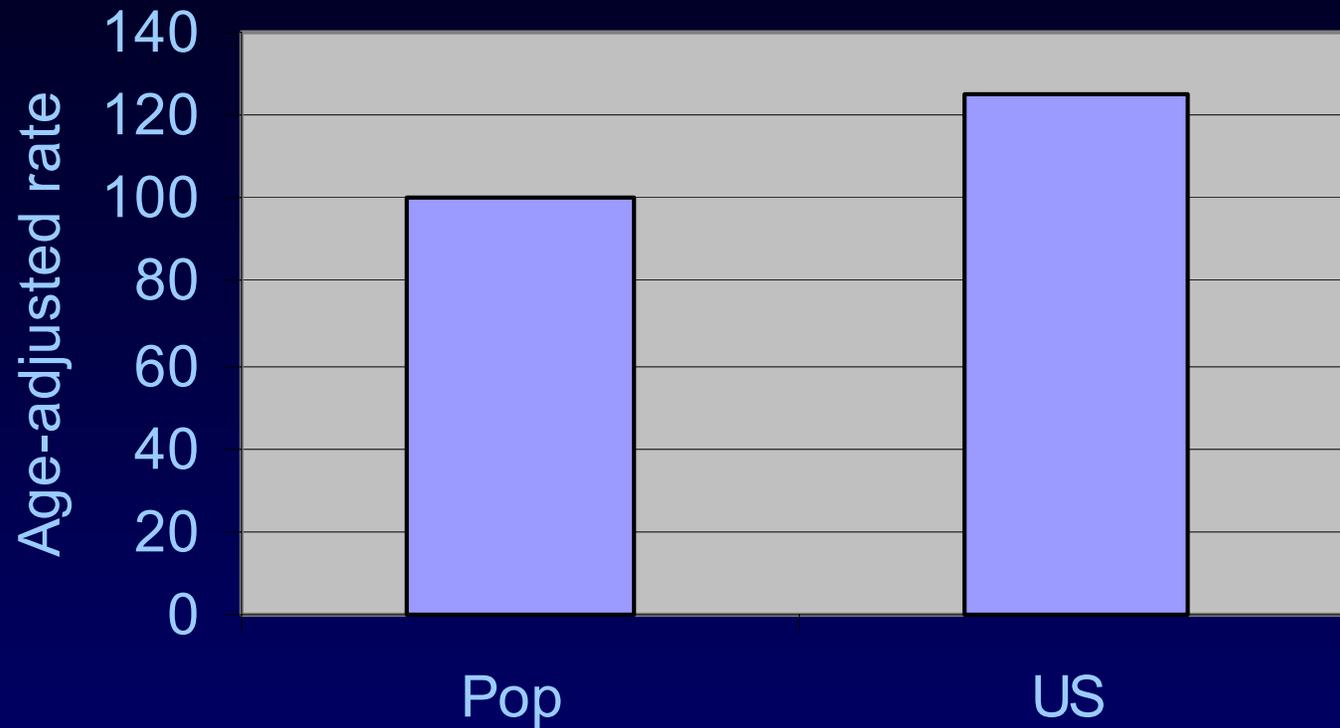
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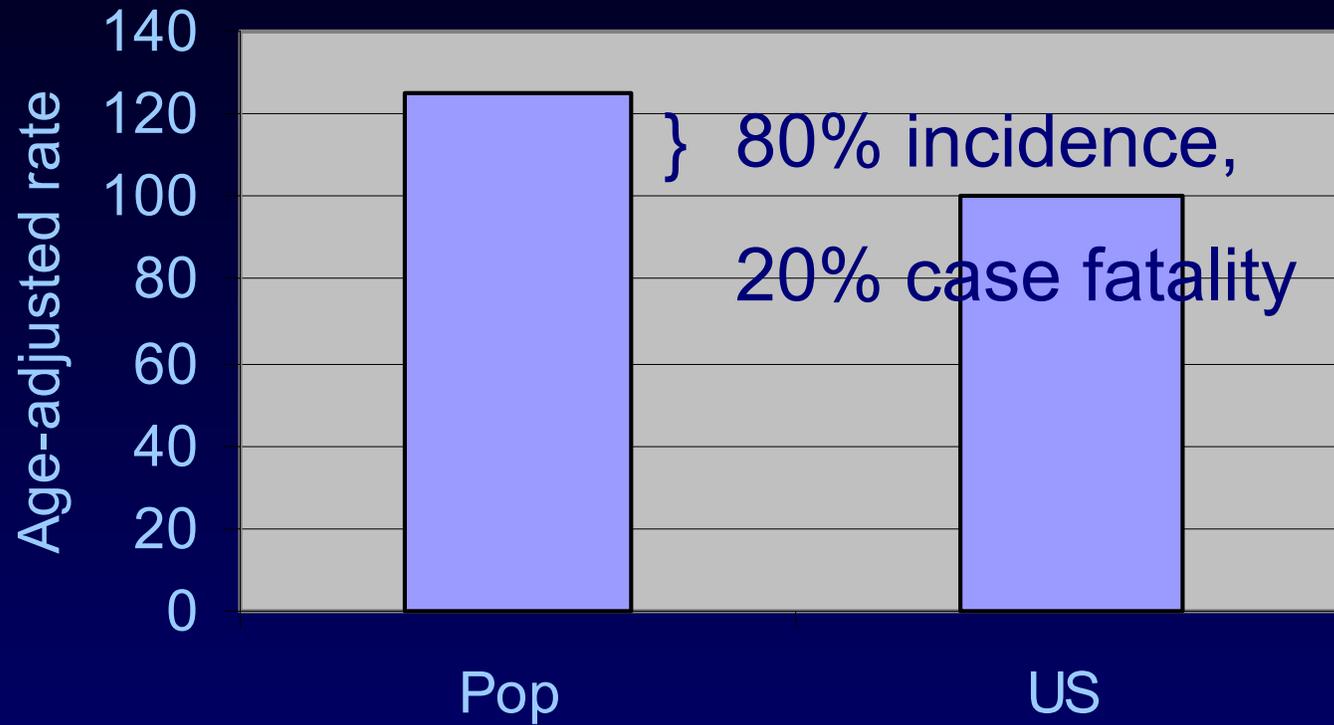
... then adjust the completeness estimate for background mortality



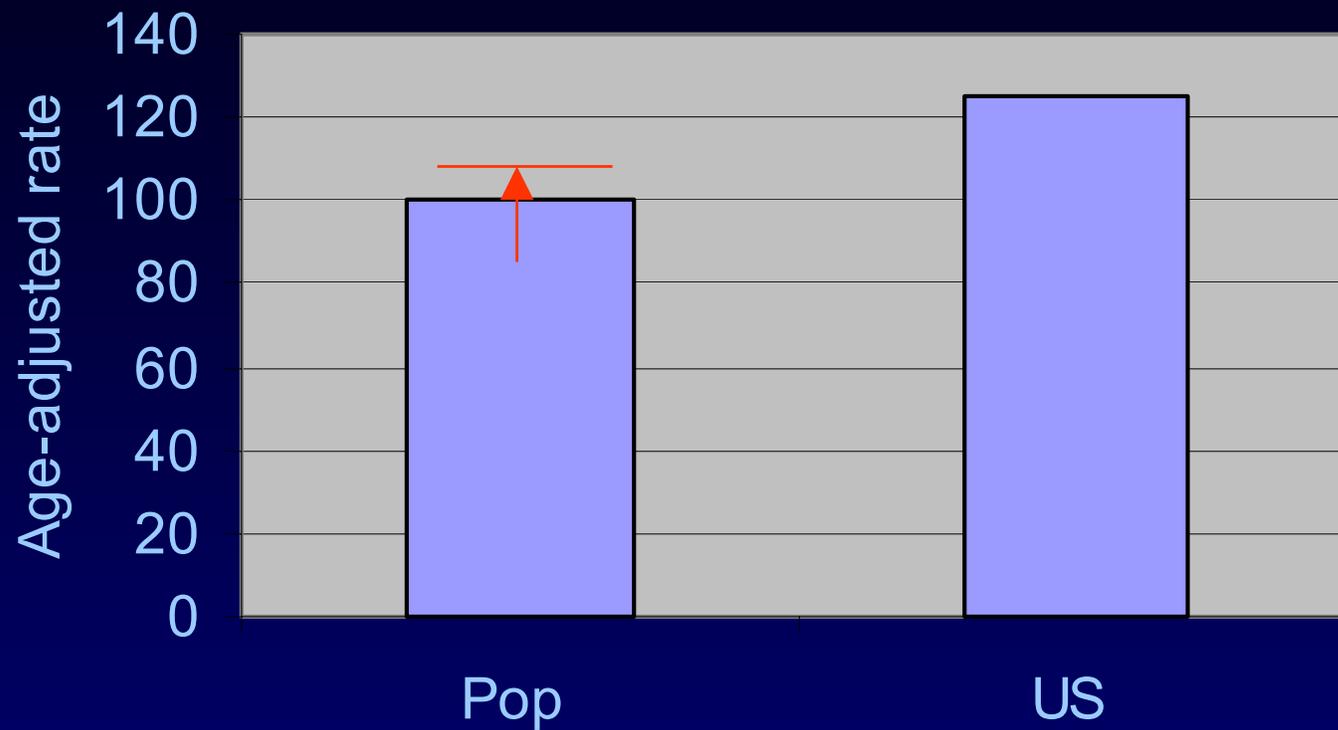
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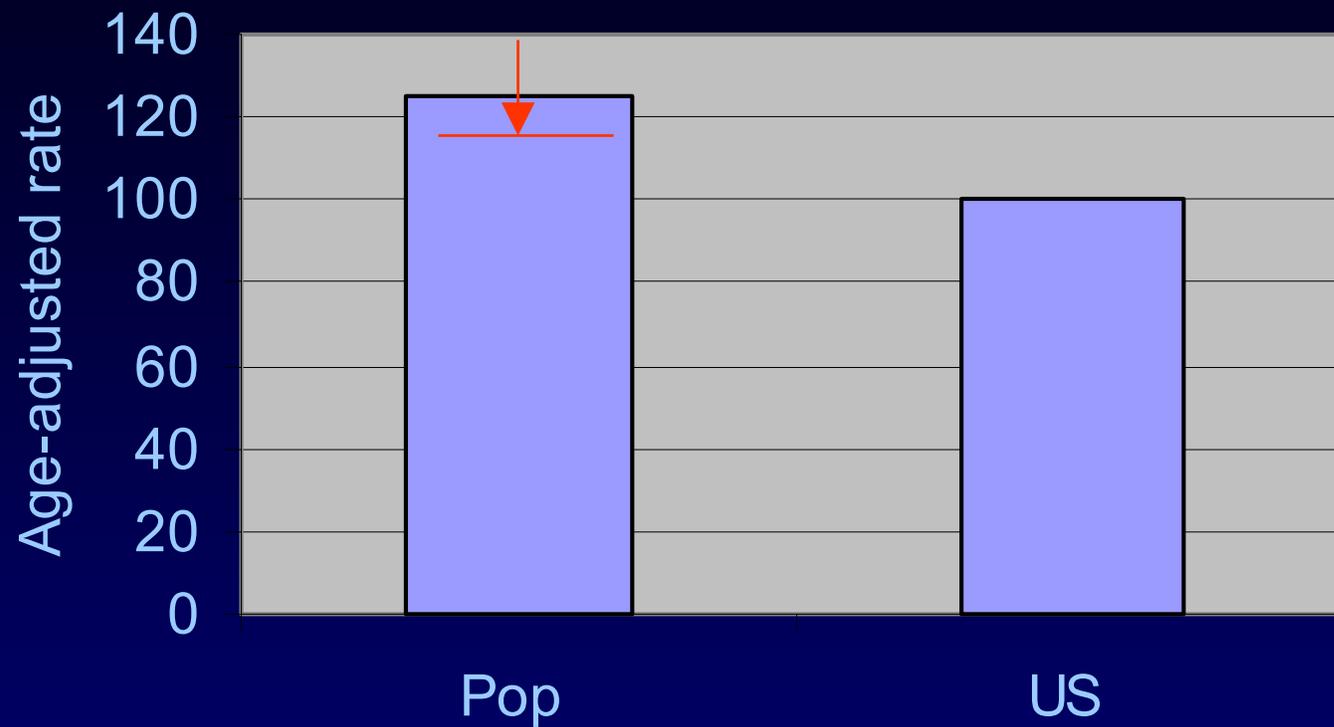
Assuming.....



Adjust mortality up if US mortality is higher



Adjust mortality down if US mortality is lower



Example: lung and bronchus, white males, Kentucky

US

$$- M_{5 \text{ yrs}} = 76.6$$

Kentucky

$$- M_{2 \text{ yrs}} = 117.2$$

$$- M_{5 \text{ yrs}} = 114.0$$

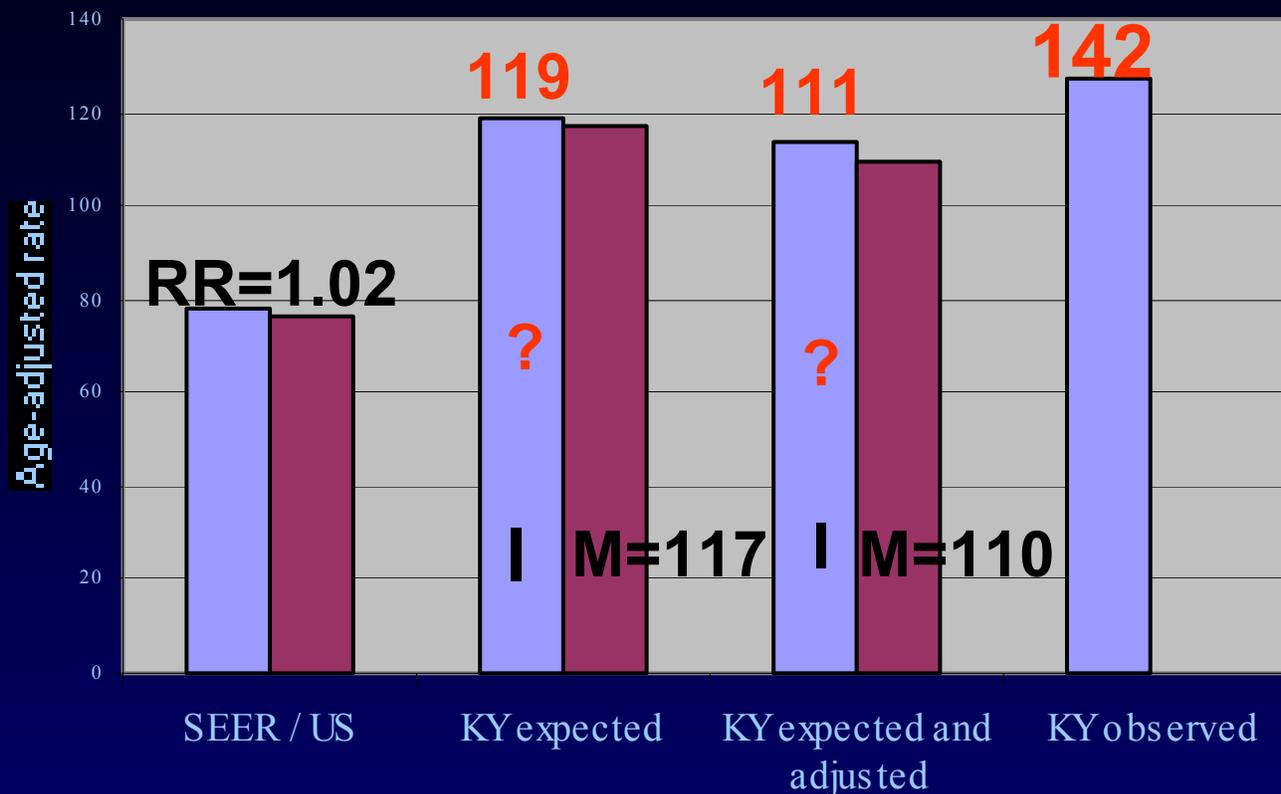
Mortality rate difference:

$$76.6 - 114.0 = - 37.4 \text{ deaths per } 100,000$$

$$20\% \text{ due to case fatality: } (0.2) (-37.4) = - 7.5$$

$$\text{Adj } M_{\text{KY}} = 117.2 - 7.5 = \sim 110$$

Lung and bronchus cancer, white males, Kentucky



Estimate overall race proportional completeness

Kentucky					
White		Black		Race Proportional	
% complete	Population	% complete	Population	% complete	Population
100.9%	3,709,328	96.9%	312,451	100.6%	4,021,779

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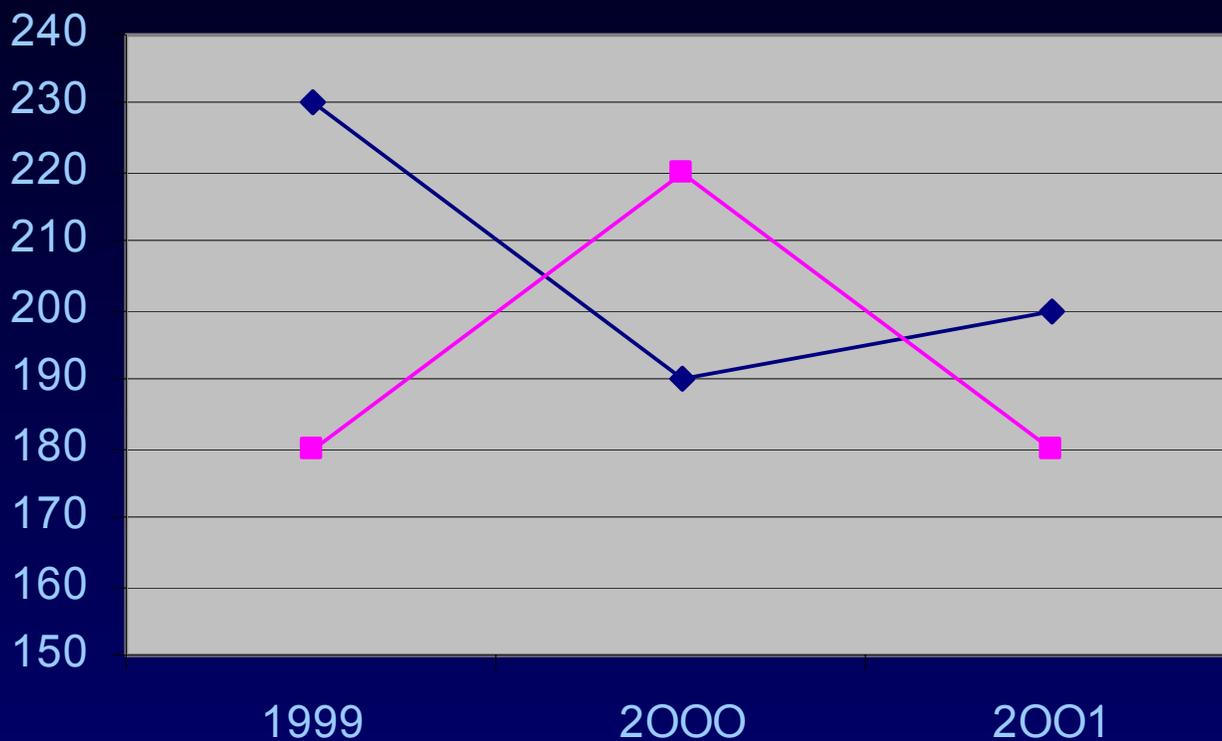
Completeness estimates derived from small populations can be unstable

White		Black		Race Proportional	
% complete	Population	% complete	Population	% complete	Population
93%	800,000	40%	5,000	92%	805,000

Completeness estimates derived from small populations can be unstable

White		Black		Race Proportional	
% complete	Population	% complete	Population	% complete	Population
94%	700,000	165%	3,000	94%	703,000

Completeness estimates derived from small populations can be unstable



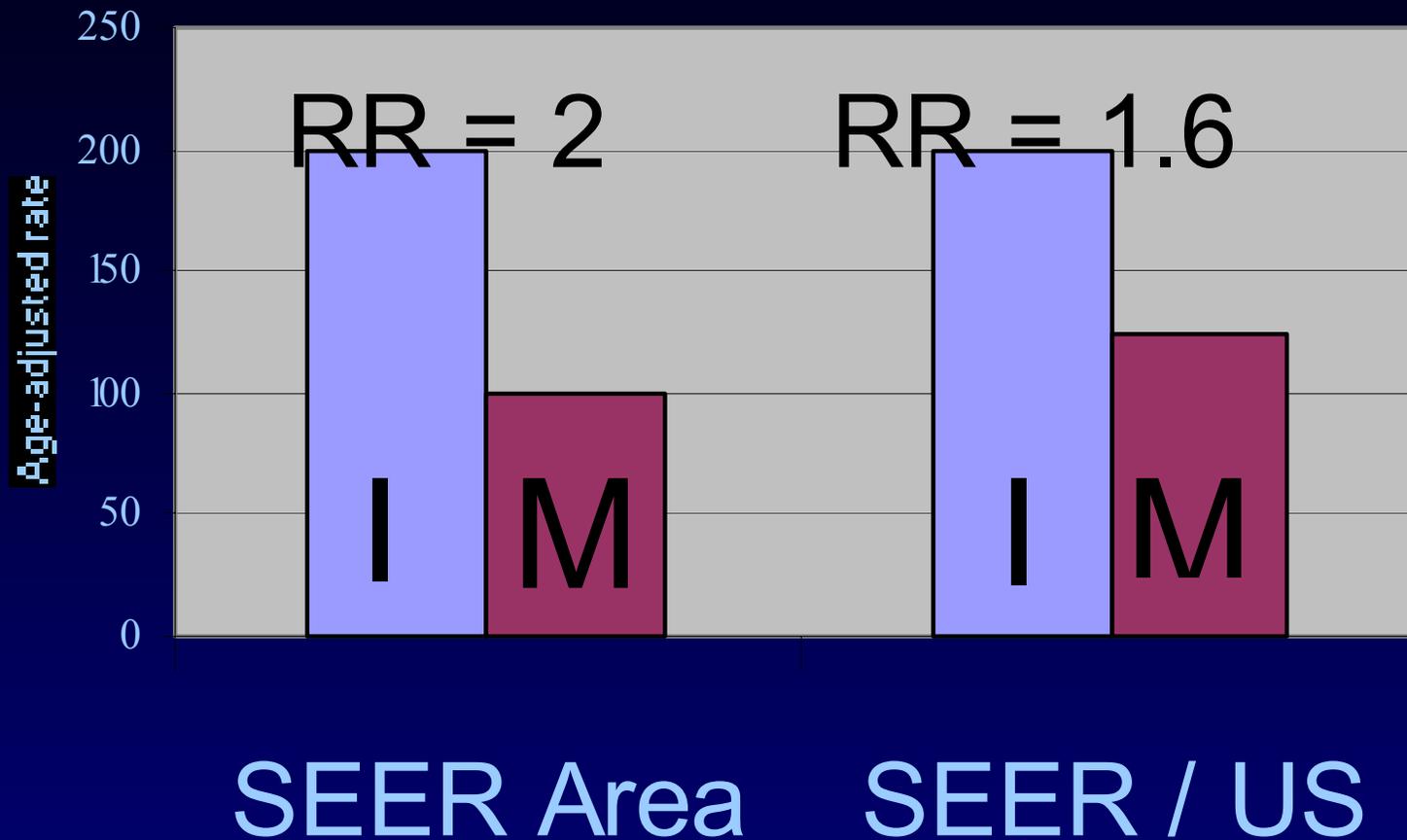
Completeness estimates based on 2 and 3 yrs. of mortality data

Population Size	2 yr. 95-96	3 yr. 94-96
Small	81.7	93.8
Small	88.5	90.6
Small	80.7	83.8
Medium	89.6	87.5
Medium	108.7	108.8
Large	96.6	96.5

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Why do you use US mortality rather than mortality from SEER areas?



...SEER black populations do not represent rural black populations

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Why did my completeness estimates drop in recent years?

Completeness estimates for....	1999	2000
State A	98.5	96.6
State B	91.1	88.7
State C	95.8	92.7
State D	98.3	92.4
State E	91.1	88.7

... because of the newly revised population estimates following the 2000 census

Site Specific SEER incidence to US mortality rate ratios	1995-1999	1996-2000
Breast	4.93	5.18
Lung	1.23	1.25
Colon and rectum	2.55	2.64



Consider what happens to your completeness estimates over time

Completeness estimates for dx year 1999 data as reported in		
	2001	2003
State A	80.2%	91.4%
State B	85.3%	87.9%
State C	79.8%	94.5%

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**Can I estimate the completeness of my data
before I submit it ?**

**Worksheet for Completeness
of Case Ascertainment**

Source: NAACCR website (<http://www.naacr.org>), search for “case completeness worksheet”

Expected Cases

Observed cases = 21,000

Completeness estimate = 92.95%

Expected case = $21,000 / .9295 = 22,593$

Limitations

- ◆ **NAACCR method for estimating the completeness of case ascertainment is intended to give an estimate of overall completeness**
- ◆ **Certification evaluates selected data elements necessary for reporting incidence data**

Future Work

- ◆ **NAACCR High Quality Data workgroup continues to refine the case completeness method**