National Cancer Institute

HIT and Data Integration:

Making Meaningful Users of HIT to Advance Equity in Care

Charting a Course for Quality Improvement: Addressing Health Care Disparities

Brookings Conference, DC
March 25, 2010

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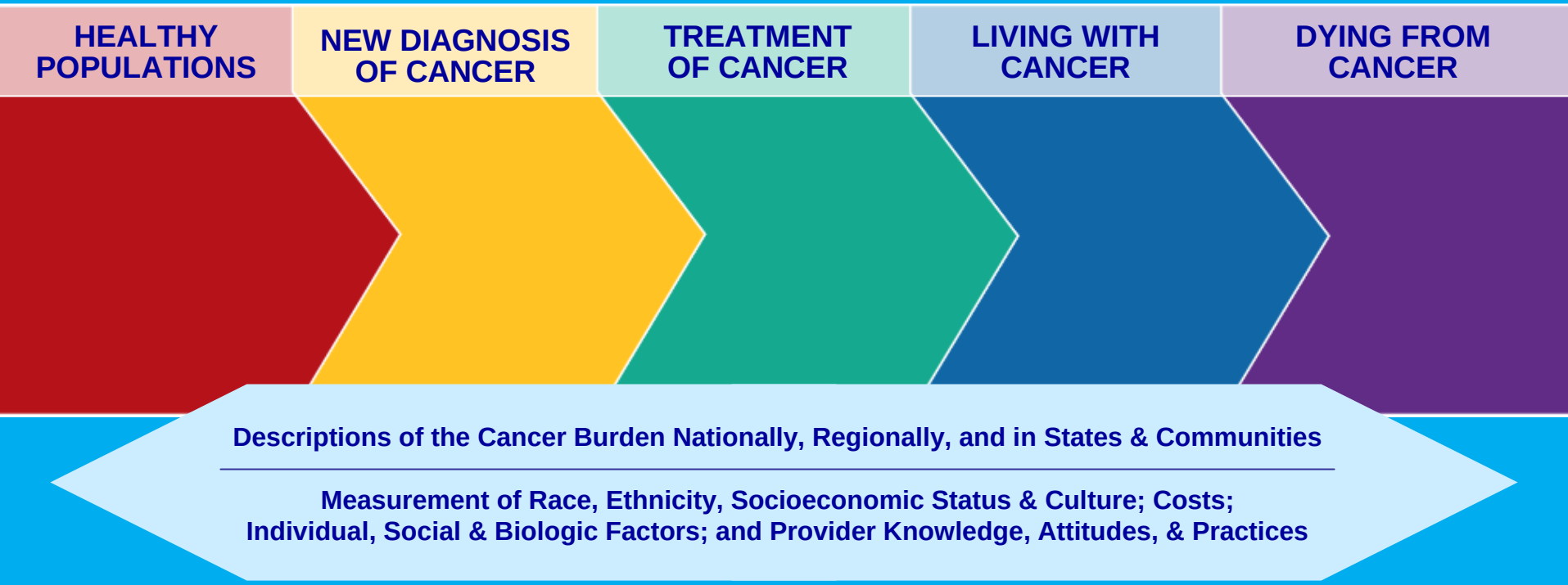
National Cancer Institute, NIH

A National Framework for Cancer Surveillance



Wingo PA, Howe HL, Thun MJ, Ballard-Barbash R, Ward E, Brown ML, Sylvester J, Friedell GH, Alley L, Rowland JH, Edwards BK, Cancer Causes and Control 2005;16:151-170

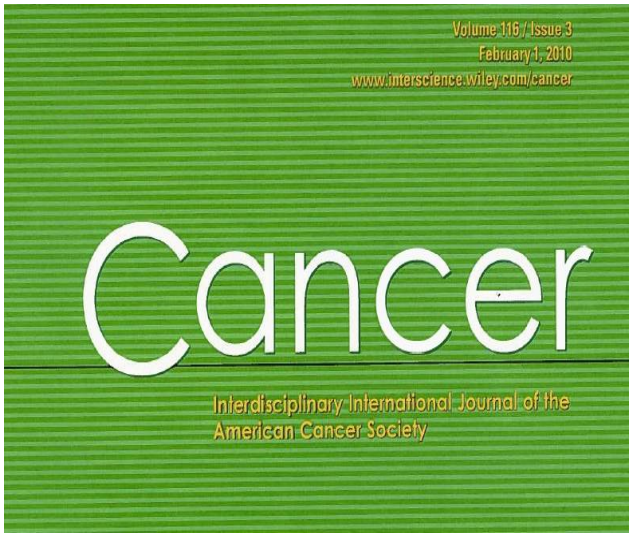
Swan J, Wingo P, Clive R, West D, Miller D, Hutchison C, Sondik EJ, Edwards BK, Cancer 1998; 83:1282-1291

Monitoring the Impact of Cancer & Progress to Reduce Cancer

- Important for ongoing surveillance
  - All sites, common or rare
  - All populations, by age, sex, race & ethnicity, geography
- Identifying unusual patterns
  - Rapid changes in incidence
    - Relevance to etiology
    - Relevance to public health
      - Planning
      - Evaluating the impact of public health interventions

Annual Report to the Nation on the Status of Cancer

- Coordinated & shared responsibility since 1998
  - National Cancer Institute
  - Centers for Disease Control & Prevention
  - American Cancer Society
  - North American Association for Central Cancer Registries
- Latest data on cancer incidence & mortality
- Requires data linkages, methods development
- Special feature:
  - Tobacco control & lung cancer
  - American Indian & Alaska Natives; Hispanics
  - Treatment patterns
  - Cancer control
  - Survival
  - Cancer and aging population



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Commentary

Annual Report to the Nation on the Status Of Cancer, 1975-2006, Featuring Colorectal Cancer Trends and Impact of Interventions (Risk Factors, Screening, and Treatment) to Reduce Future Rates

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Rates of new diagnoses and rates of death from all cancers combined declined significantly in the most recent time period for men and women overall and for most racial & ethnic US populations

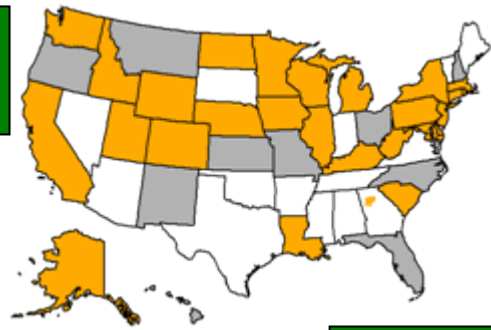
- **Incidence: - 0.7 % per year from 1999-2006**
- **Deaths: - 1.6% per year from 2001-2006**

United States improved coverage for population-based cancer incidence

NAACCR 2002-2006
86%

2006

NAACCR 1997-2006
71%



2000

1995

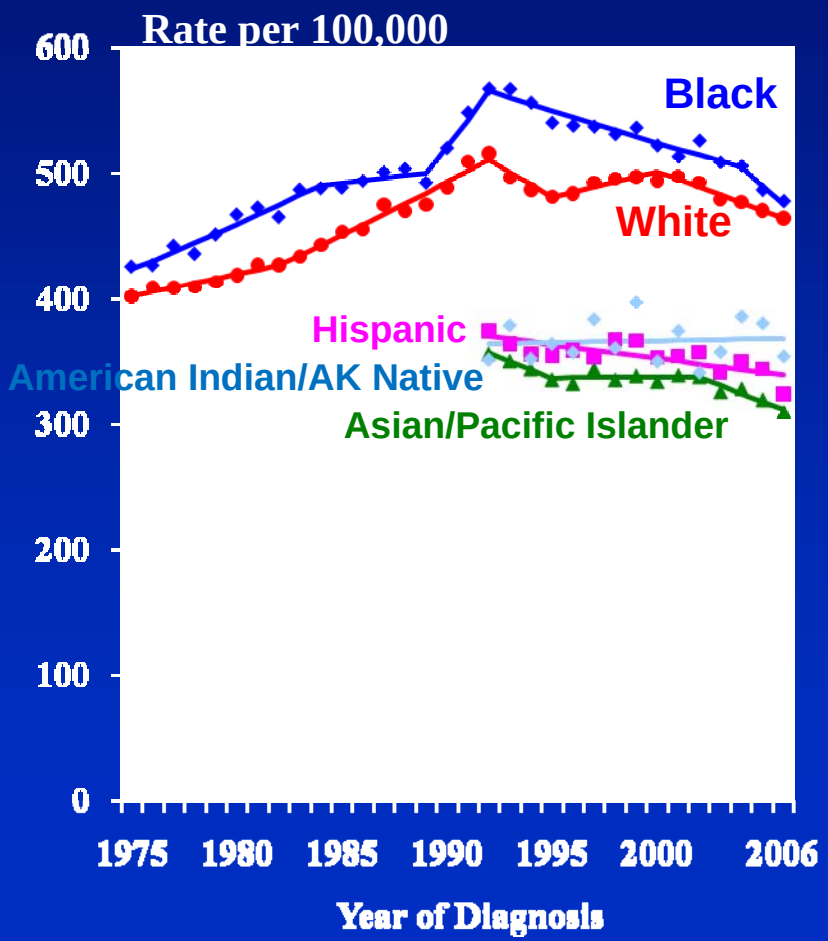
SEER 1975- 2006
10%

SEER 9: 1975-2006 (9.4%)
SEER 13: 1992-2006 (14%)
SEER 17: 2000-2006 (26%)
NAACCR: 2002-2006 (86%)
USCS: 2005 (01/08) (100%)

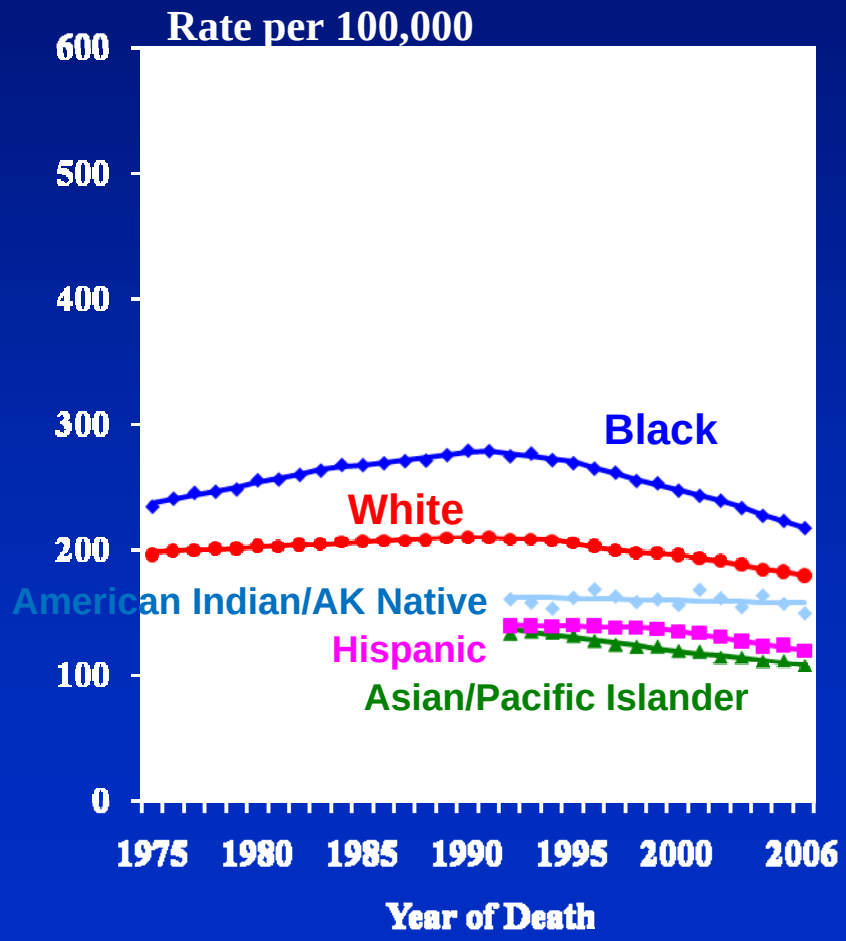
All Cancers, SEER Incidence and US Death Rates

Joinpoint Analyses for Whites & Blacks 1975-2006
Asian/Pacific Islanders, American Indians/Alaska Natives & Hispanics 1992-2006

Incidence

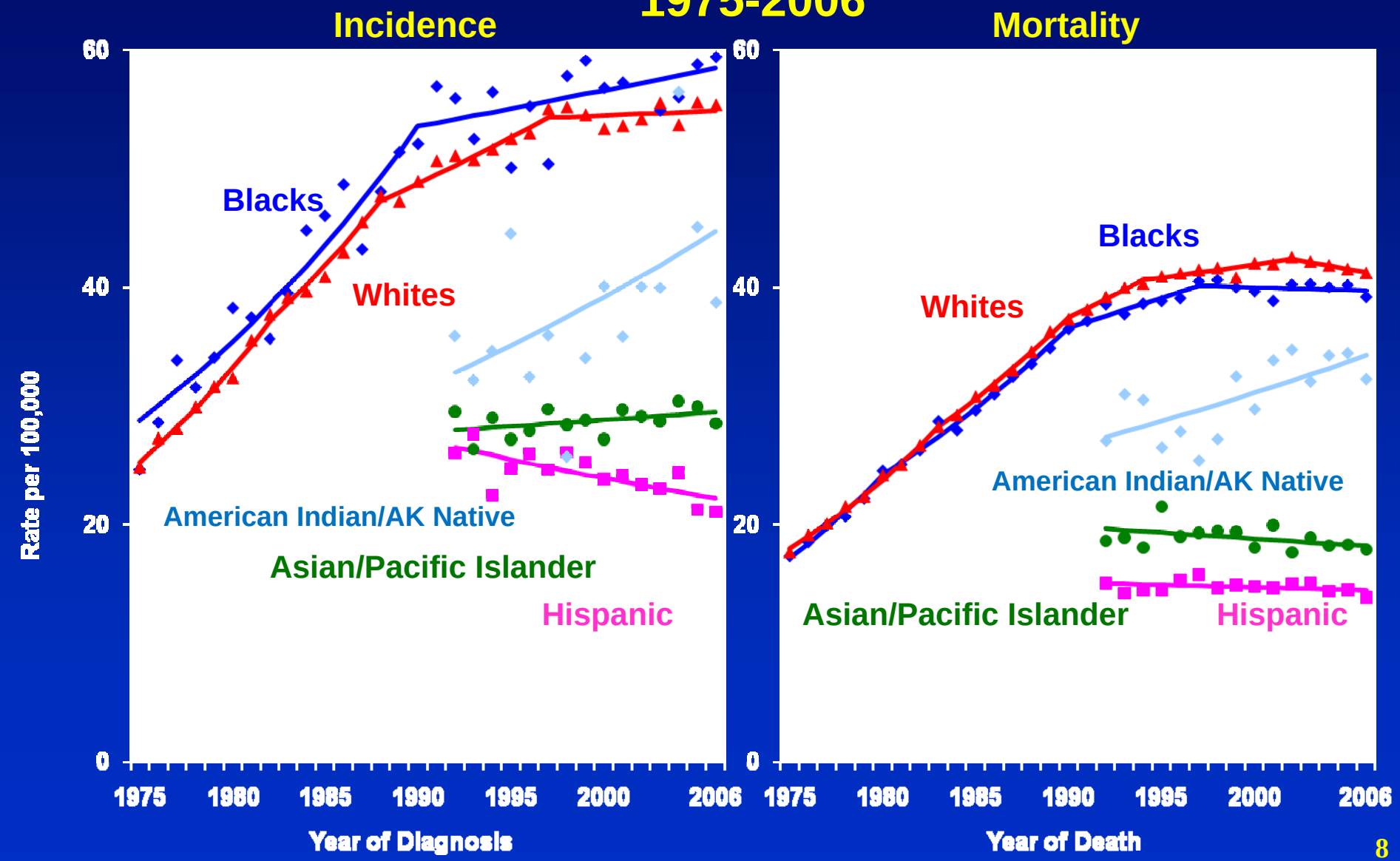


Mortality



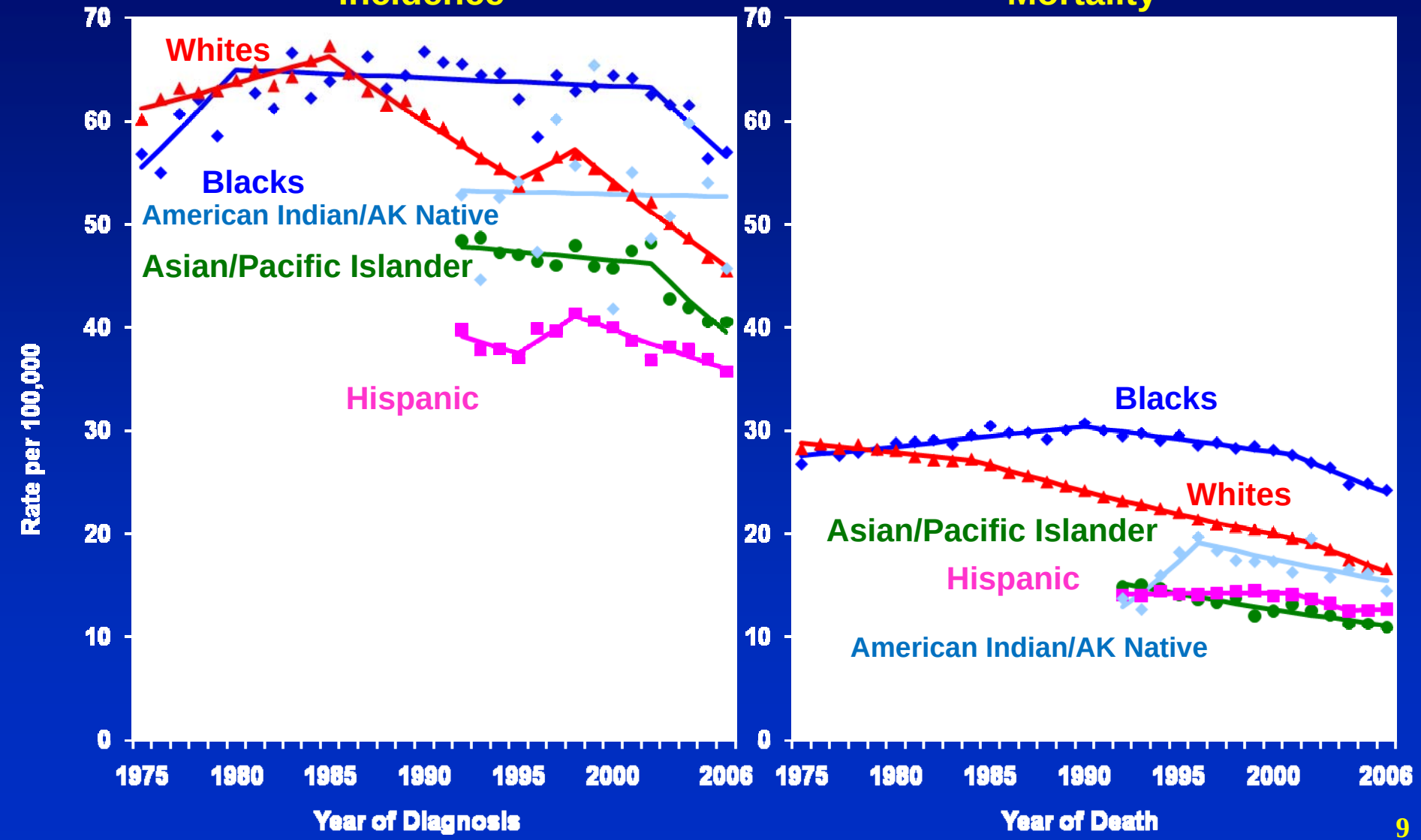
Rates are age-adjusted to the 2000 U.S. standard million population. Sources: Incidence data – NCI SEER Program; Mortality data – CDC NCHS NVSS

Female Lung & Bronchus Cancer
SEER Incidence (delay adjusted) & US Death Rates
1975-2006



Rates are age-adjusted to the 2000 U.S. standard million population. Sources: Incidence data – NCI SEER Program; Mortality data – CDC NCHS NVSS

Both Sexes Colon & Rectum Cancer SEER Incidence (delay adjusted) & US Death Rates 1975-2006



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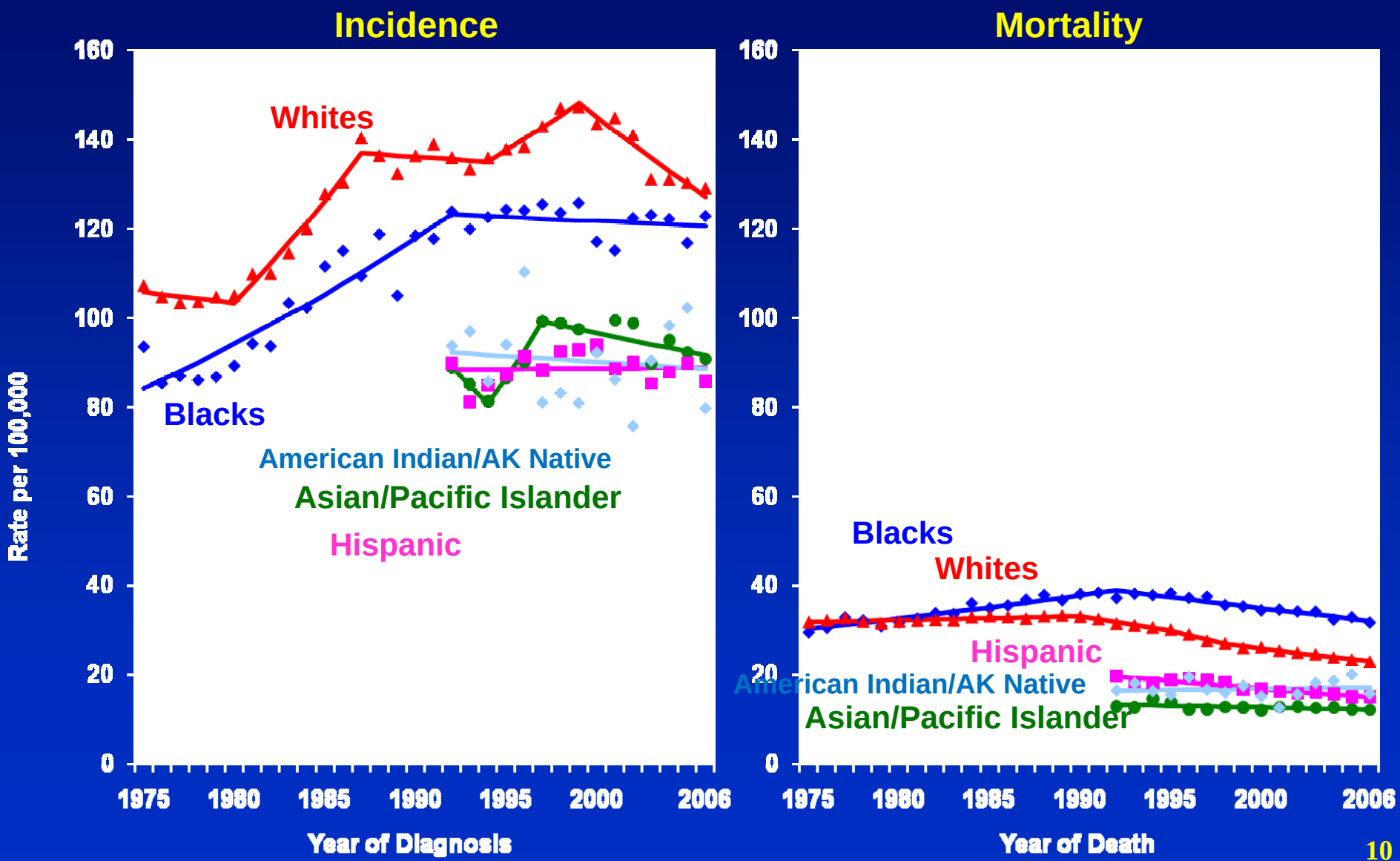
Female Breast Cancer
SEER Incidence (delay adjusted) & US Death Rates
1975-2006



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Background

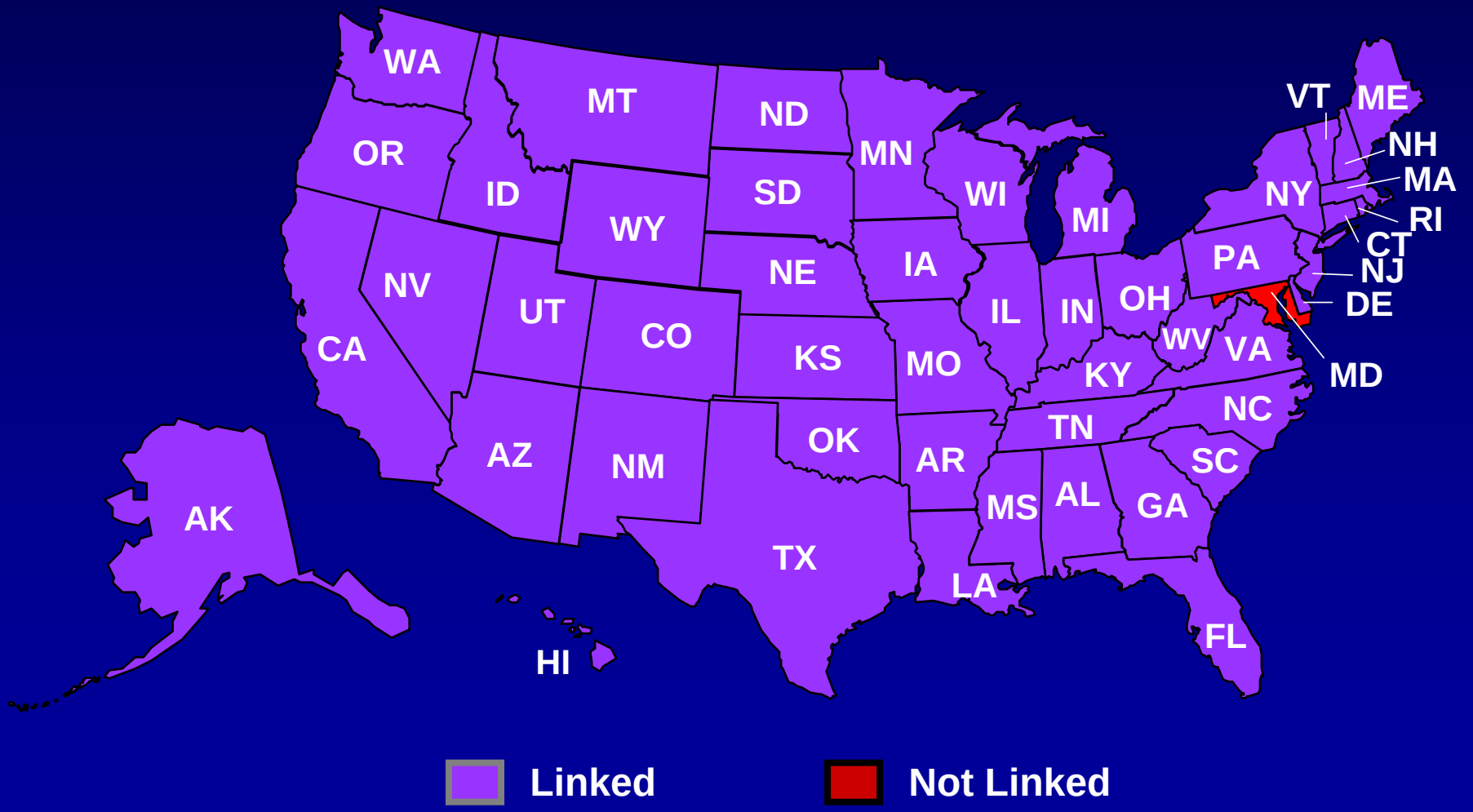
- Race mis-classification of AI/AN occurs in cancer surveillance and vital statistics data bases
- Varies by state
- Decreasing mis-classification can improve accuracy of health indicators and program planning/resource allocation

Improving the quality of cancer surveillance data for AI/AN

- Link records from central cancer registries (NPCR and SEER) with administrative records from the IHS (NPIRS)
- Identify AI/AN cases misclassified as non-Native
- Use “improved” data to report cancer burden of AI/AN

2006 NPCR & SEER Linkages

19,623,101 records representing
18,114,103 individuals linked

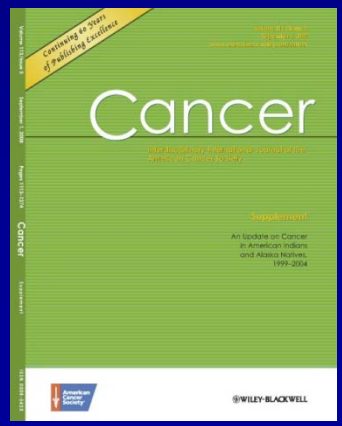


Registry linkages

- **Linkage status captured in "IHS Link" variable that is part of NAACCR layout**
  - **Annual Report to the Nation on the Status of Cancer , 1975-2004, Featuring Cancer in American Indians and Alaska Natives**
  - ***Cancer* Supplement: An Update on Cancer in American Indians and Alaska Natives, 1999-2004**


COMMENTARY

Annual Report to the Nation on the Status of Cancer, 1975-2004, Featuring Cancer in American Indians and Alaska Natives



Cancer AI/AN Supplement

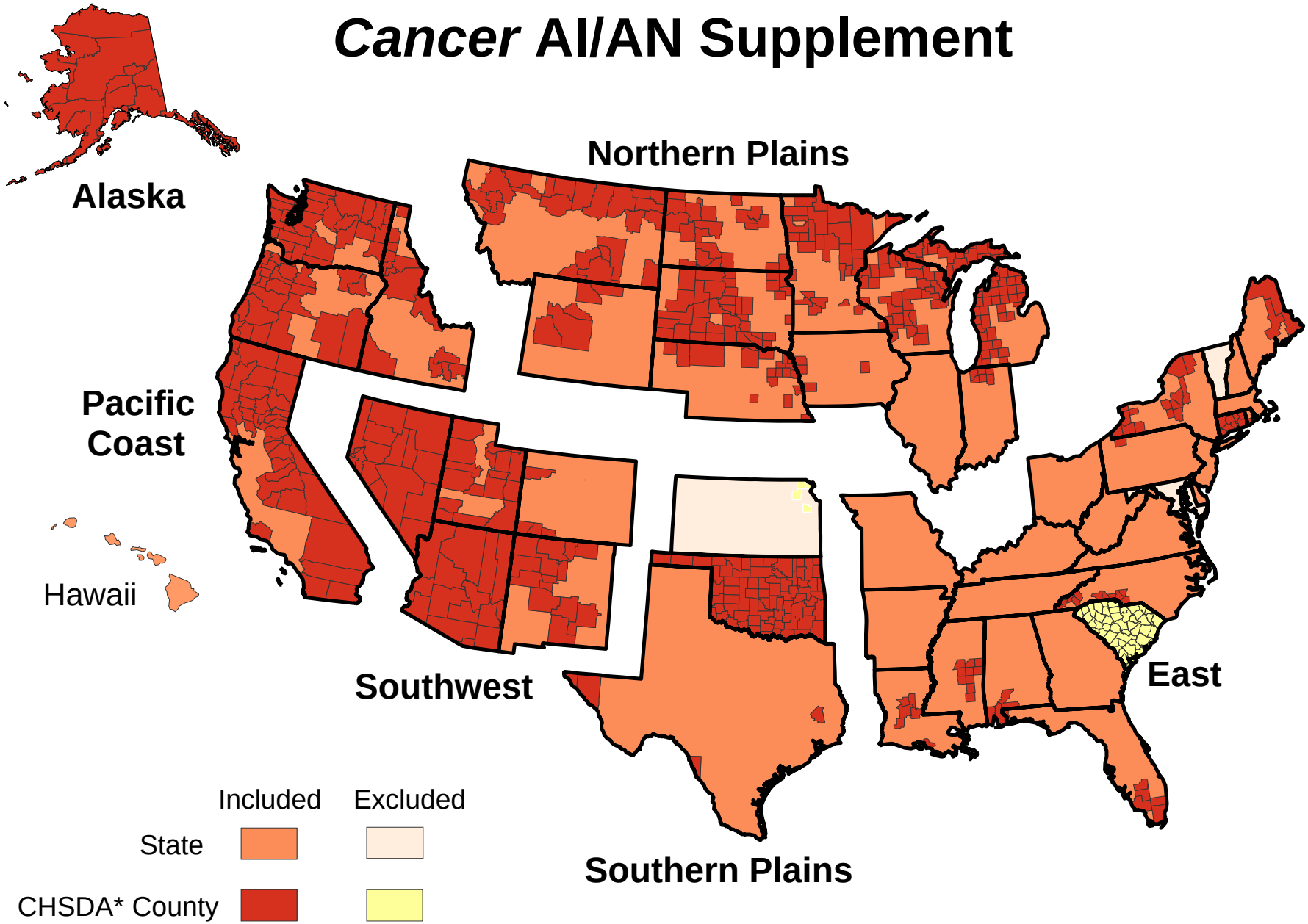
- www3.interscience.wiley.com/journal/28741/home

- David K. Espey, MD (CDC/IHS Albuquerque, NM)
  Melissa A. Jim, MPH (CDC/IHS Albuquerque, NM)

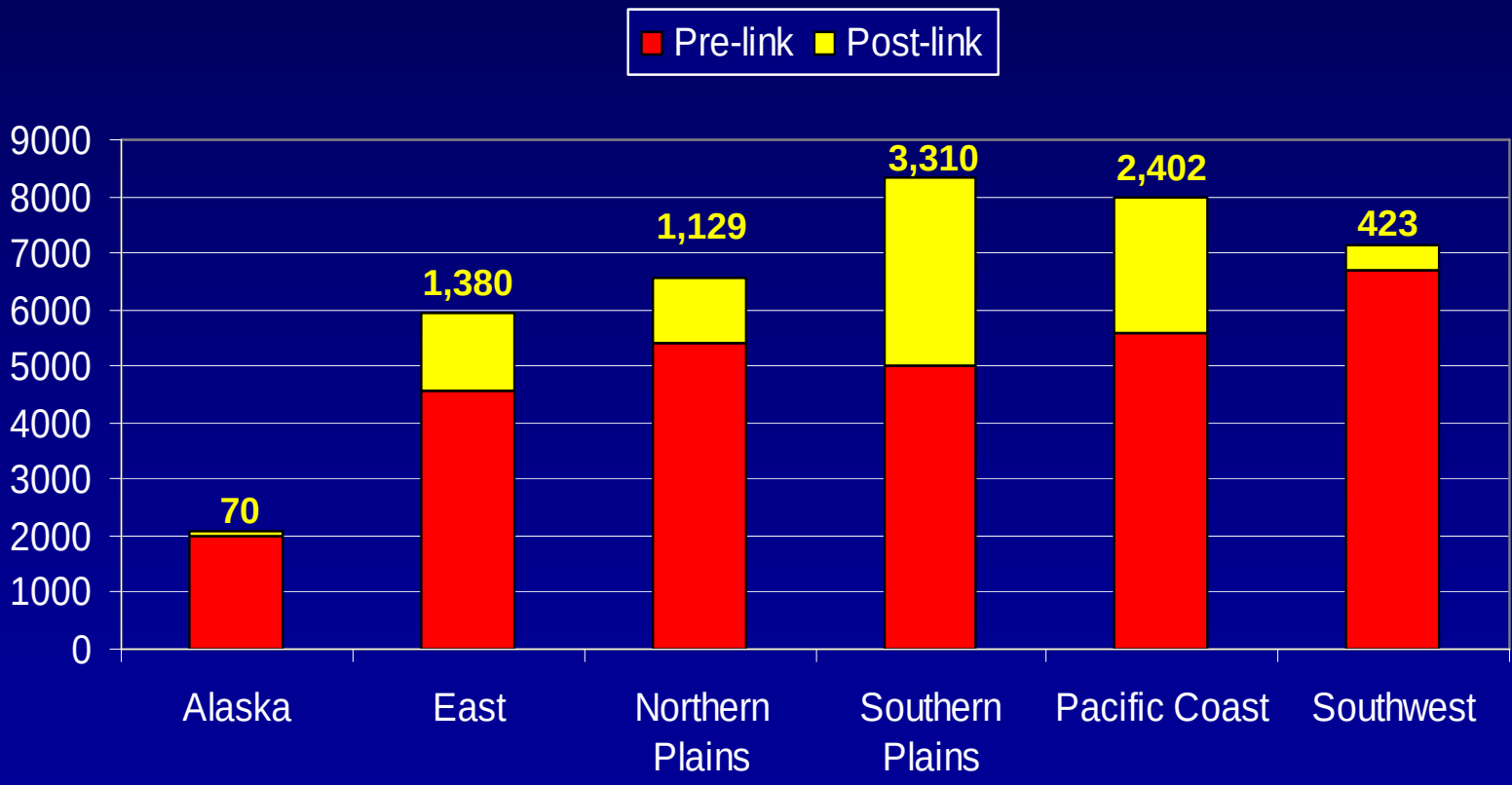
- Collaborators:

  ACS, CDC, NCI, central cancer registries, academic centers, and tribal organizations

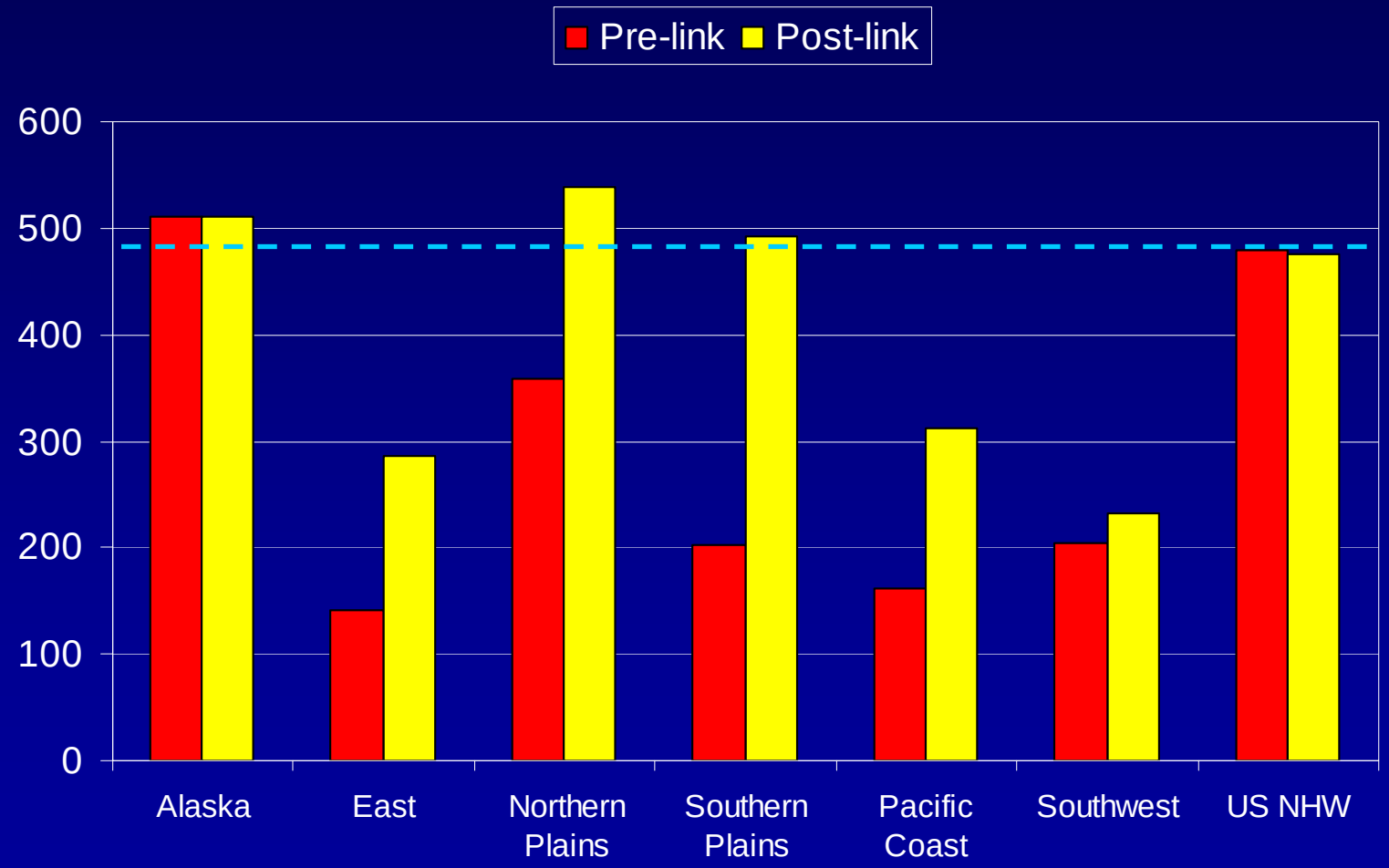
Cancer AI/AN Supplement



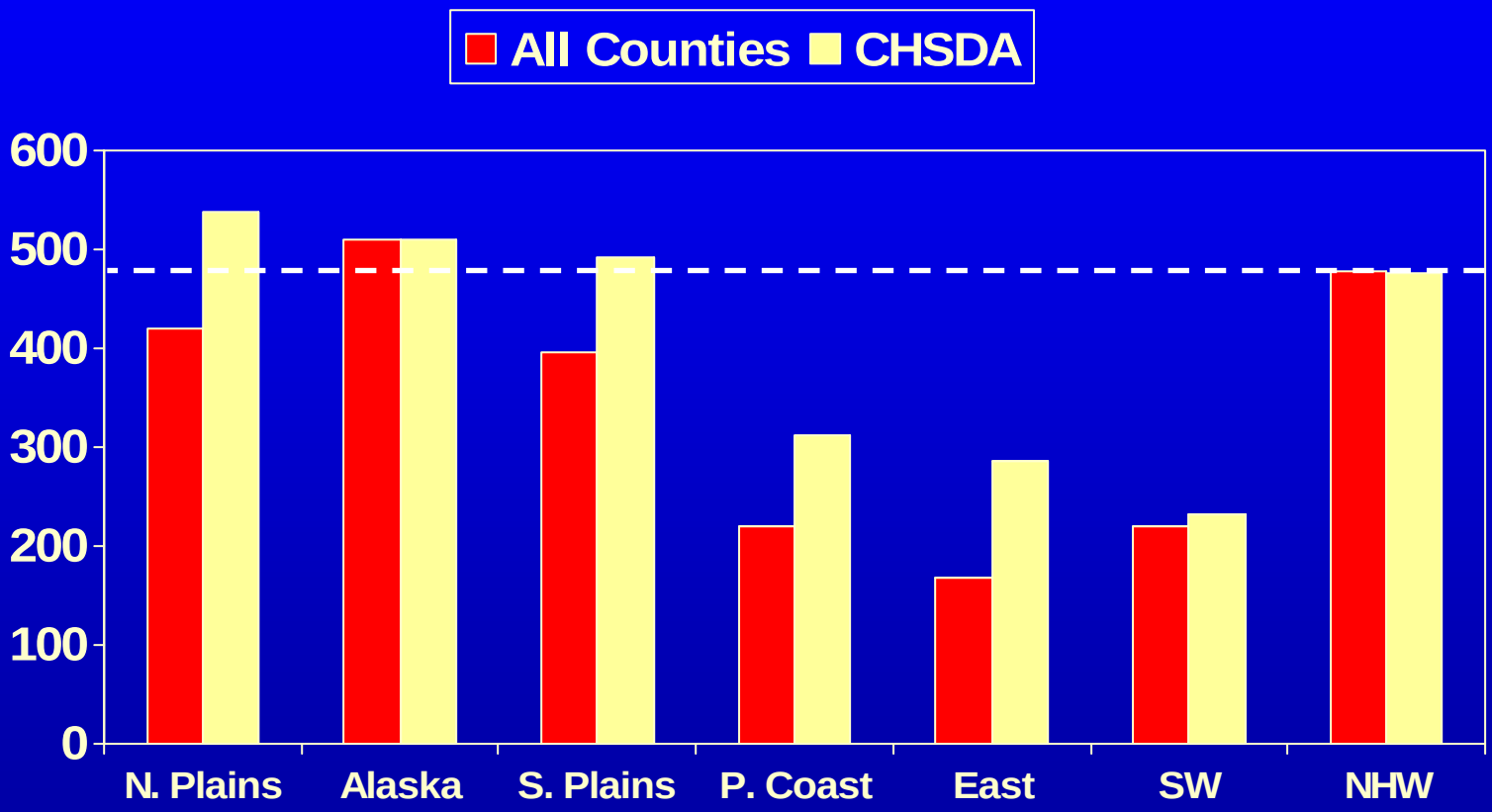
Number of individuals identified by IHS linkage in 2006



AI/AN cancer pre- and post- rates per 100,000 for All Sites, by region, both sexes, compared to US NHW rate, 1999-2004



AI/AN cancer rates per 100,000 for All Sites, by region, both sexes, compared to US NHW rate, 1999-2004



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Incidence: CHSDA vs. Total AI/AN

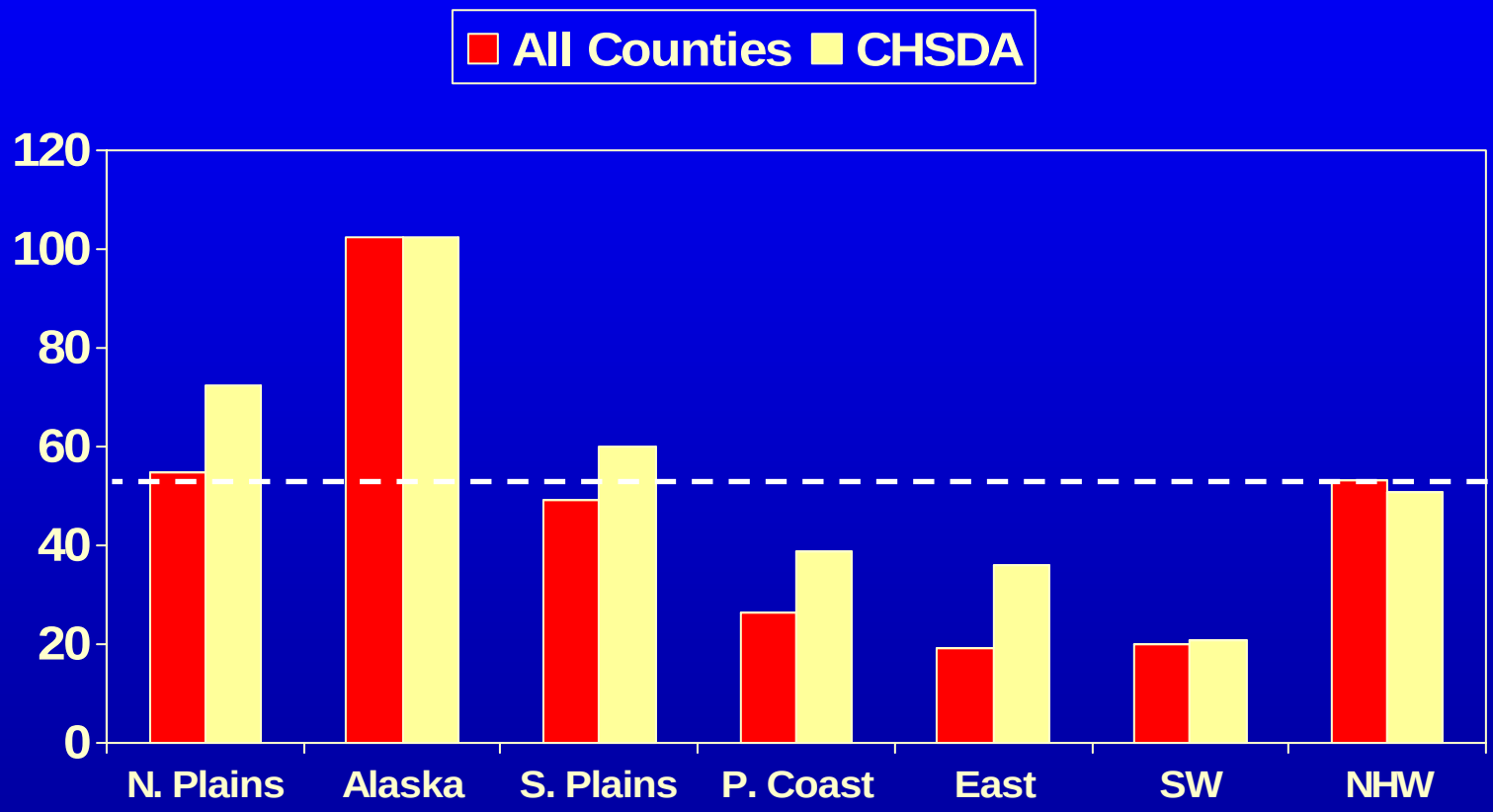
- IHS Contract Health Service Delivery Area counties contain or are adjacent to tribal lands
  - Compared to other counties, higher proportion of AI/AN and less AI/AN race misclassification

Table. Incidence Rates in CHSDA and Total AI/AN, Diagnosis Years 1995-2004 (cases per 100K).

Gender	Cancer Site	CHSDA AI/AN	Total AI/AN
Male	All sites	406.9	297.4
Male	Colon and rectum	51.5	36.8
Female	Breast	84.7	62.9
Female	Kidney and renal pelvis	13.9	9.3

Reference: Epsey DK et al. (2007). Annual Report to the Nation on the Status of Cancer, 1975-2004, Featuring Cancer in American Indians and Alaska Natives. *Cancer*. 110(10):2119-2152.

AI/AN colorectal cancer rates per 100,000, by region, both sexes, compared to US NHW rates, 1999-2004



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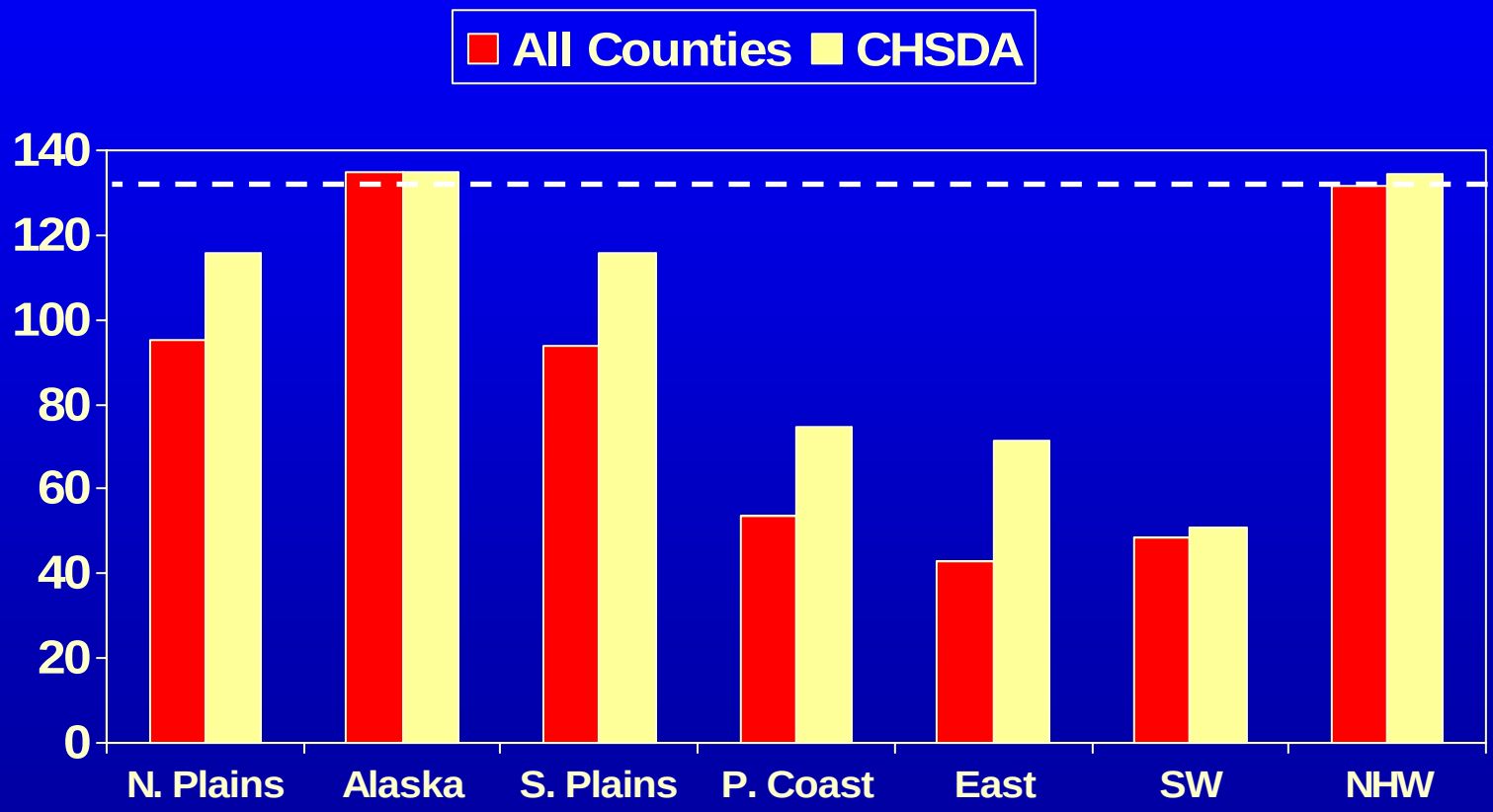
AI/AN breast cancer rates per 100,000, by region, females, compared to US NHW rates, 1999-2004



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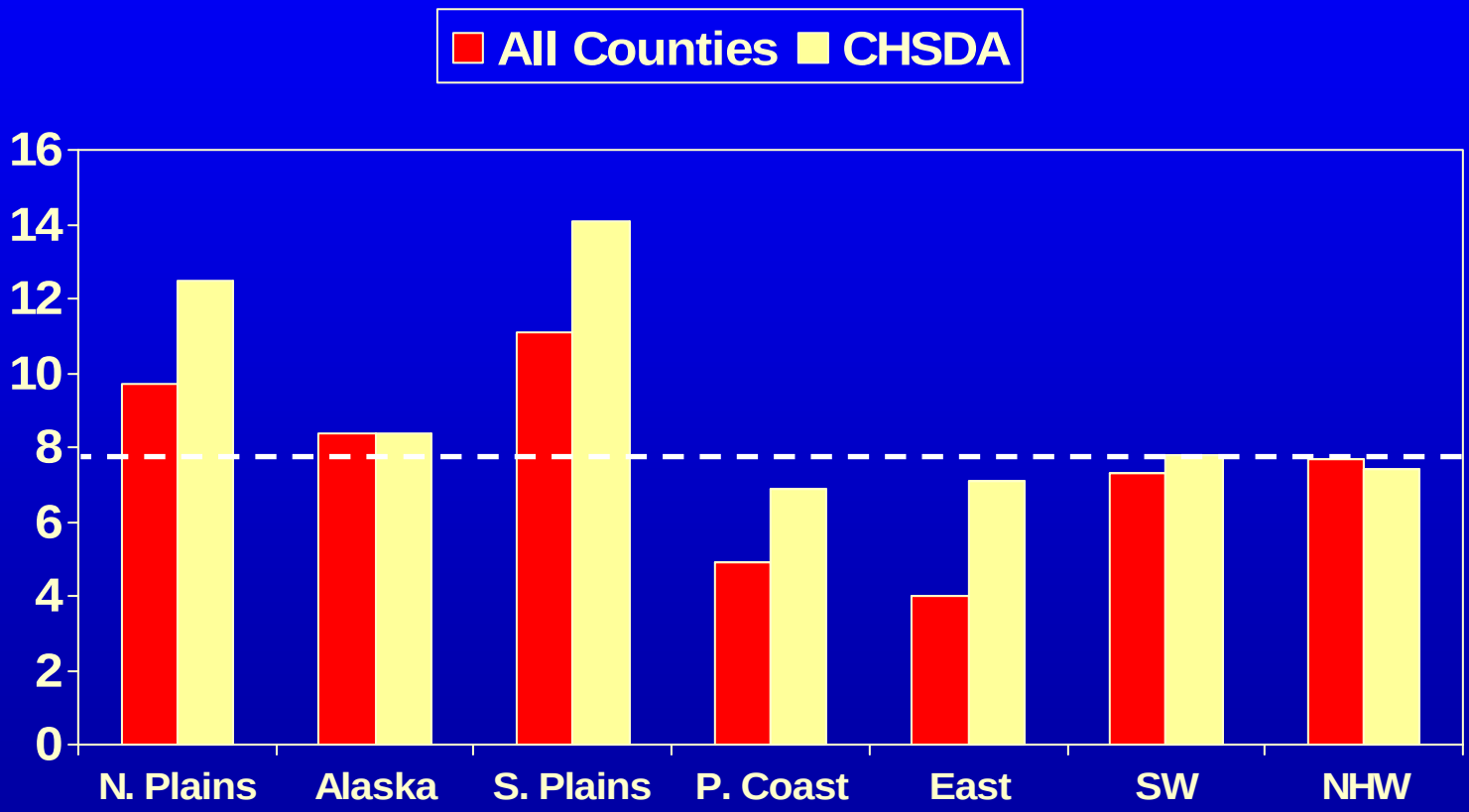
AI/AN cervical cancer rates per 100,000, by region, females, compared to US NHW rates, 1999-2004



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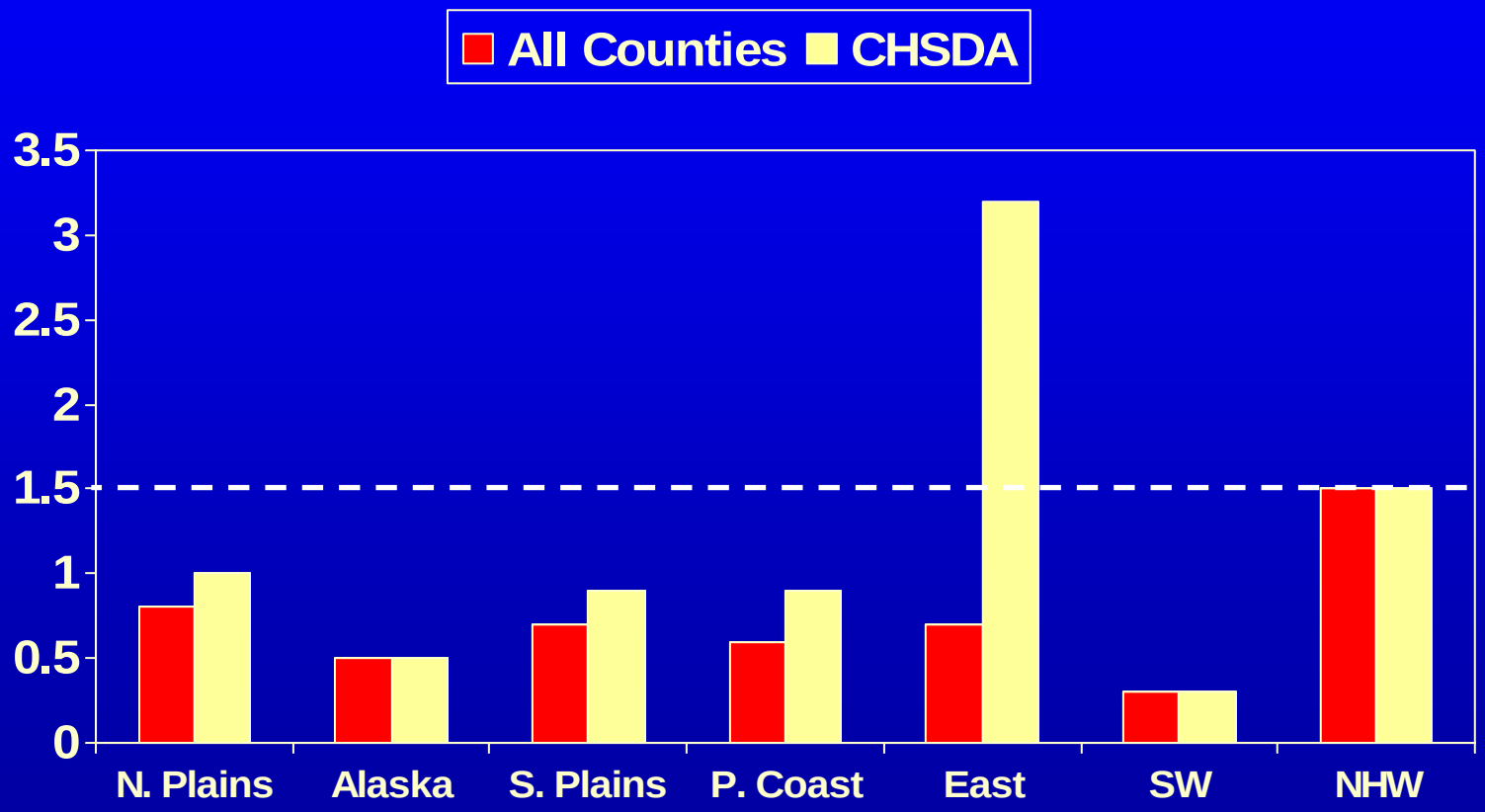
AI/AN renal cancer rates per 100,000, by region, both sexes, compared to US NHW rates, 1999-2004



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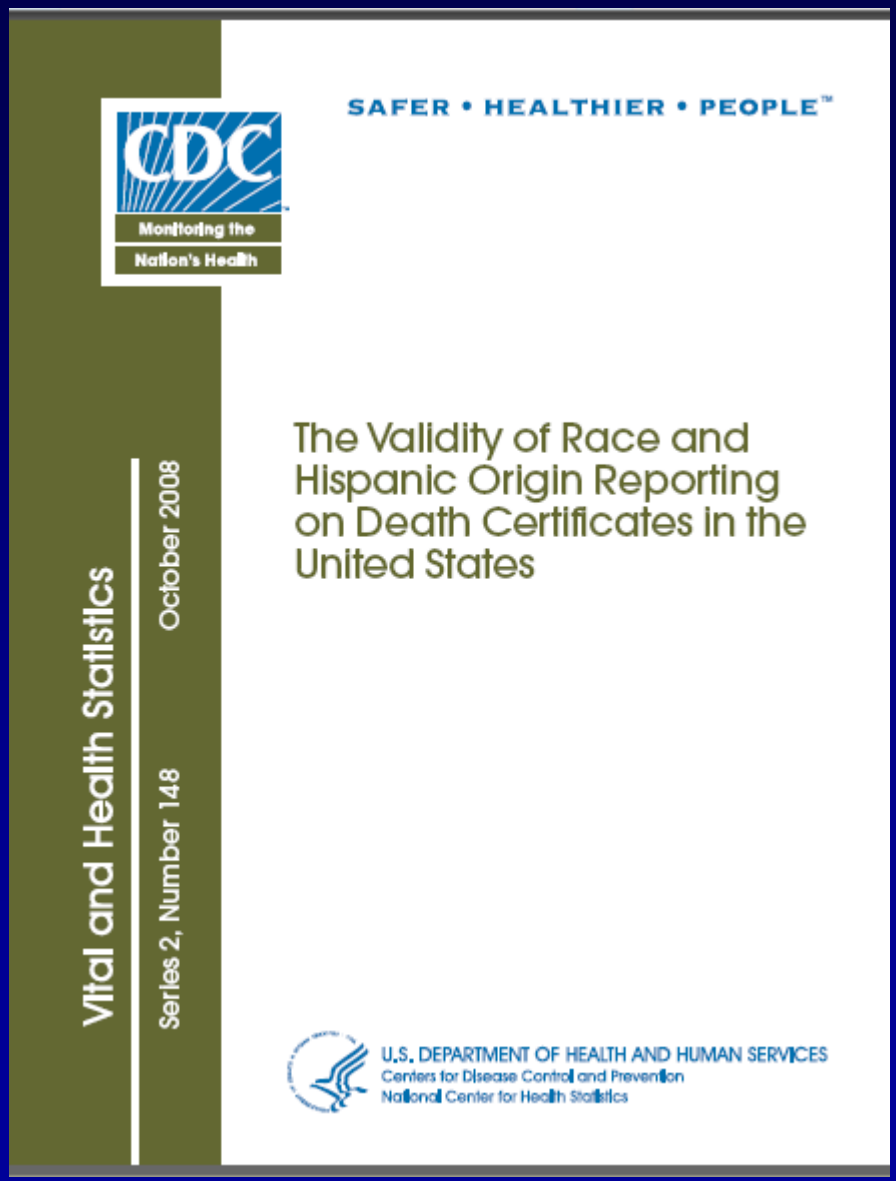
Limitations

- IHS only covers 57% of the AI/AN population
- Linkage between a state cancer registry and a Bemidji Area Tribe
  - 1995-2004 diagnosis years
    - IHS identified 614 individuals that were not identified as AI/AN by the registry
    - Bemidji Area Tribe identified 242 individuals that were not identified as AI/AN by the registry OR by linkage with IHS

National Longitudinal Mortality Survey



NCI: SEER Linkage(s)

- **SEER-Medicare**
  - Annual linkage for follow-up status & survival statistics
  - Every 2-3 years linkage to yield a “research file” of SEER & CMS data
- **SEER-SSA**
  - Annual linkage for follow-up status & survival statistics
- **SEER-NDI**
  - Annual linkage for follow-up status (cause of death) & survival statistics
- **SEER-NLMS**
  - Research file to investigate socio-economic determinants of cancer, racial/ethnic misclassification, and health disparities