

Improving Cancer Mortality Data for American Indians and Alaska Natives in the US

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Objectives

- Background on American Indians and Alaska Natives (AI/AN) and race misclassification
- Role of data linkages
- Strengthening data in preparation for linkages
- National Death Index – next steps

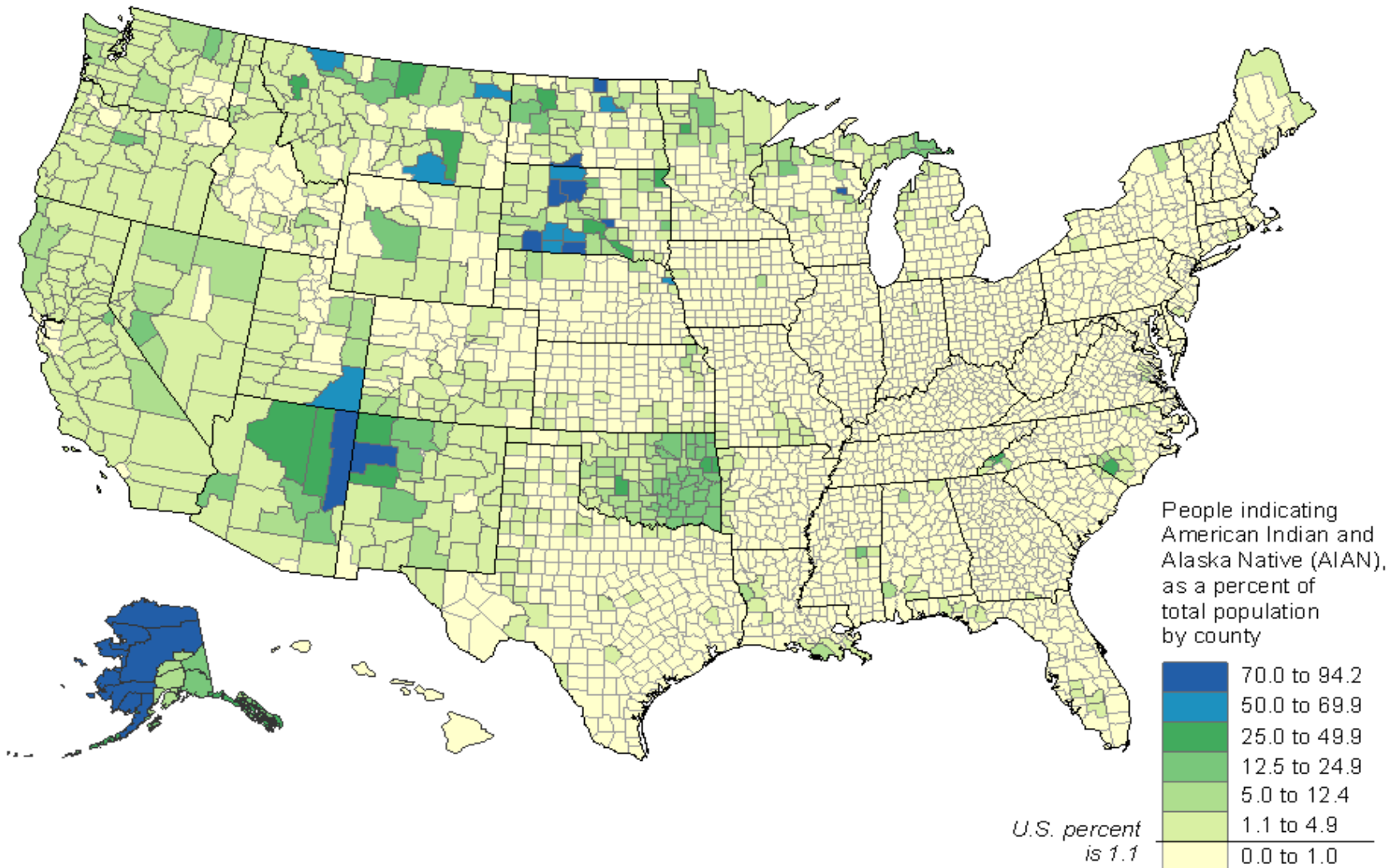


American Indian/Alaska Native Population

- Over 560 federally recognized tribes
- 47 state recognized tribes
- Highest AI/AN populations in CA, OK, AZ, TX, NM
- Total AI/AN population:
 - AI/AN alone (2.5M, 0.9%)
 - Alone or in combination (4.1M, 1.5%)
 - Bridged single race (3.1M, 1.1%)
 - 64% urban, 36% rural/reservation



County population that is American Indian/Alaska Native, 2004



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

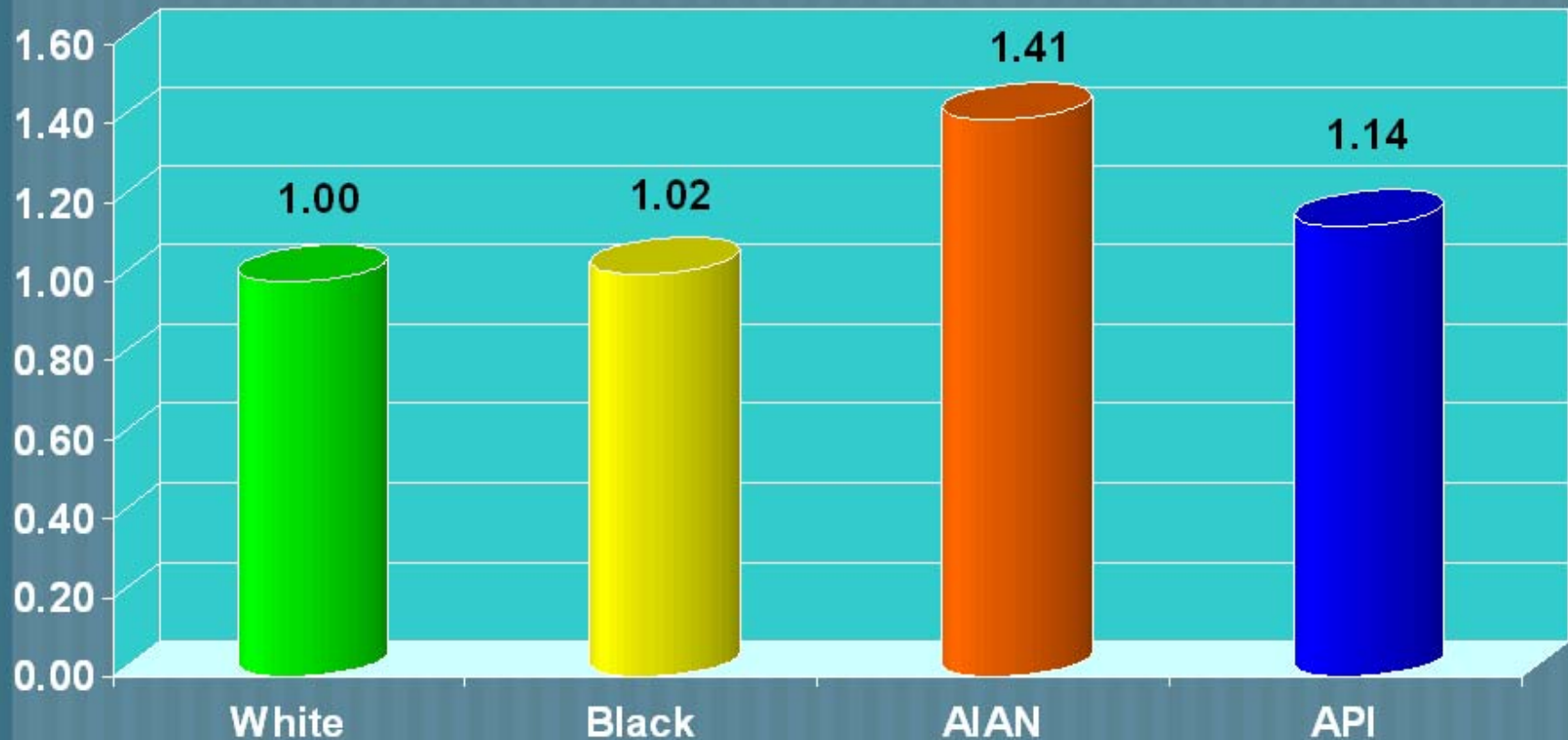


Background

- Indian Health Service (IHS) registration records are used to identify AI/ANs by linking with cancer registry records
- The National Longitudinal Mortality Study (NLMS) indicates race misclassification for AI/AN in death records



Ratios for Race Categories



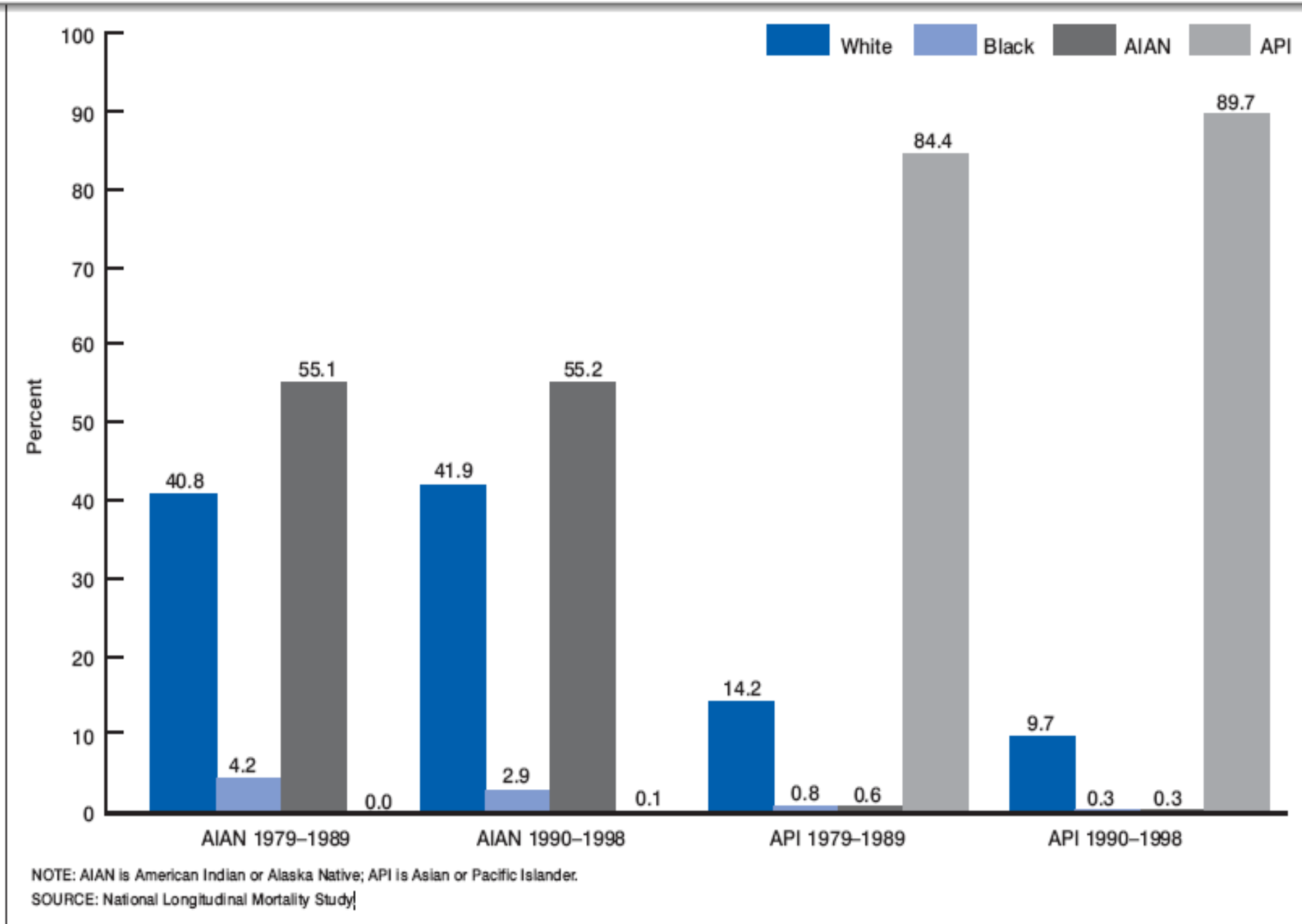


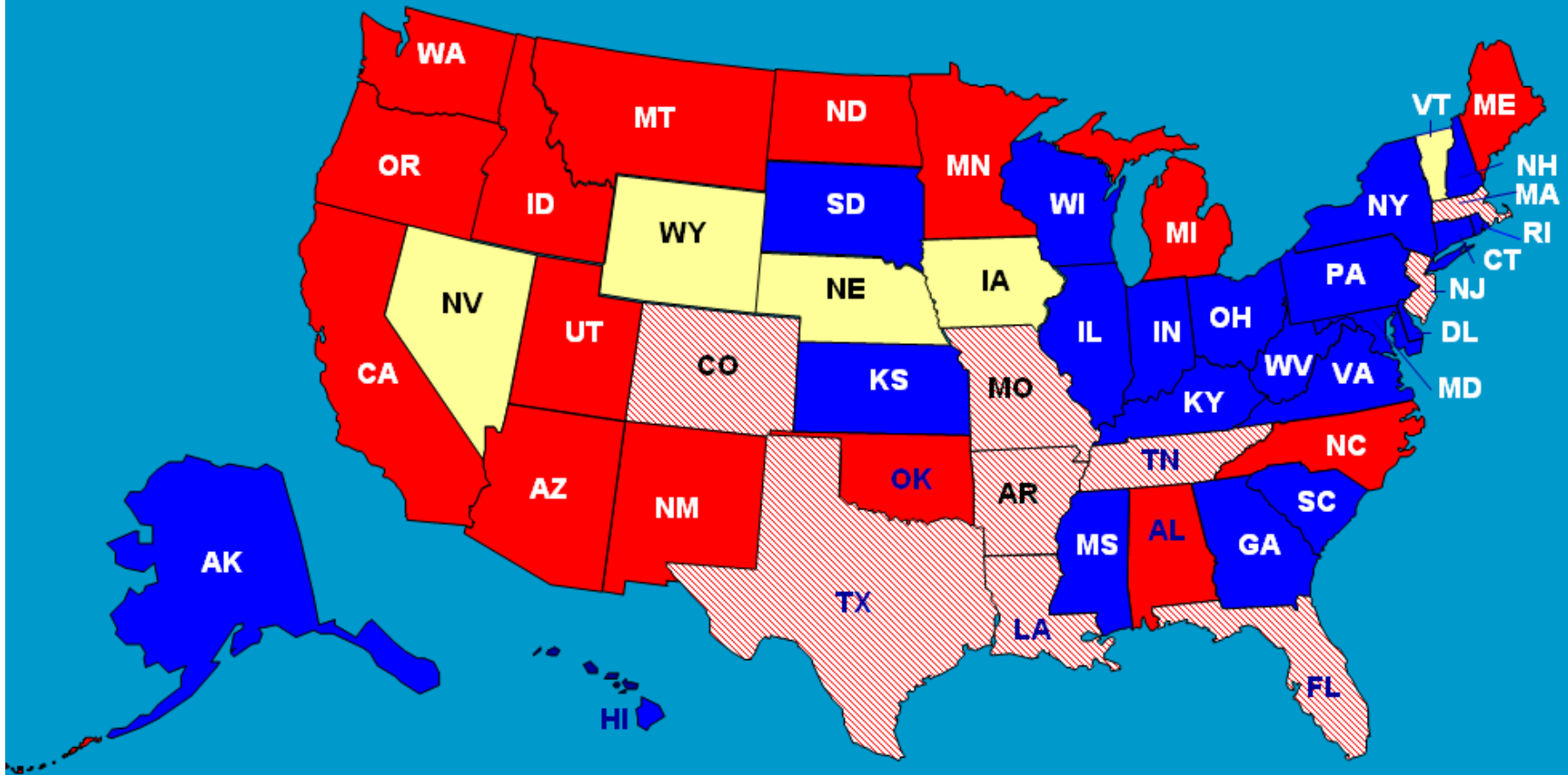
Figure 1. Race distribution on death certificate among self-identified American Indian or Alaska Natives and Asian or Pacific Islanders: United States, 1979-1989 and 1990-1998

To improve race classification of AI/AN in state death records

- A total of 8,855,141 death certificates from 1990-2003 were submitted from 14 states where 62% of the AI/AN population reside.
- Records were linked probabilistically with national IHS registration data



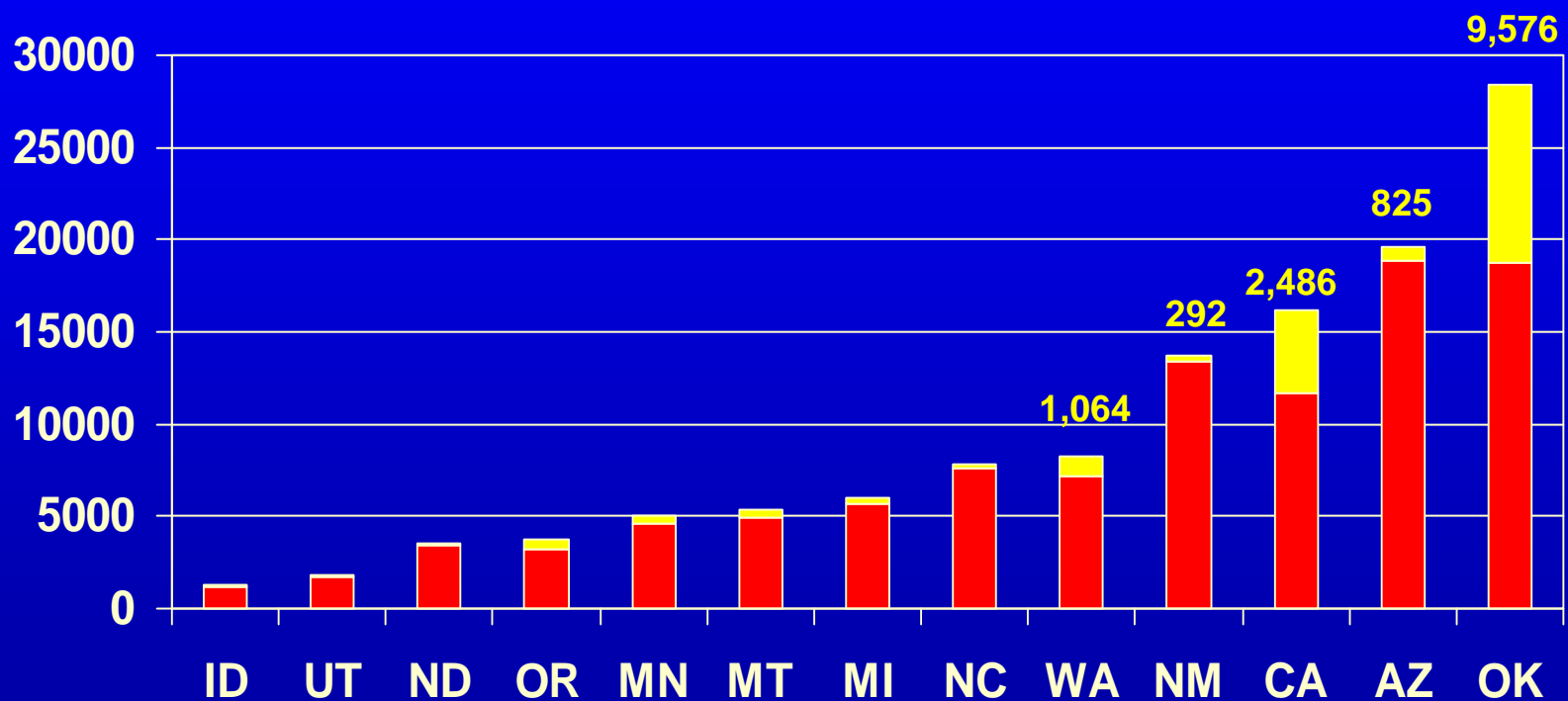
IHS/state death records data linkage



- Linkage completed
- Data rec'd - linkage in progress
- Interest expressed - data not rec'd
- Not participating

Linkage of death records from State VS with administrative records from the IHS (1990-2003)

Pre-link Post-link



Limitations

- **IHS:**
 - Not all AI/AN are included in IHS files
 - IHS coverage varies by geographic region
 - Urban AI/AN population more difficult to characterize
- **State VS data:**
 - Differing data layouts and coding schemes
 - Layouts sometimes varied by year for the same state
 - Missing data



Individual state → NDI

- To improve the completeness and accuracy of the IHS patient registration database for a linkage between IHS and the National Death Index (NDI)



METHODS

- ◆ IHS patient registration data were linked to the Social Security Administration's (SSA) Death Master File (DMF) prior to the NDI linkage in order to improve the completeness and accuracy of key linkage variables such as name, social security number, dates, etc in the IHS file.

IHS
1985-2010
3,569,435 records



SSA's DMF
1984-2009
54,927,230 records

13 linkages completed – SSA's DMF files were split into 2 year intervals
Total linkage time: 185 hours 18 min
22,343 clerical reviews done by 14 reviewers

181,975 True Matches

RESULTS

Date Of Birth	
Identical DOB	166,106
IHS DOB unknown	93
Different DOB	15,776



Date Of Death	
Identical DOD	69,303
IHS DOD unknown	89,093
Different DOD	23,579



Social Security Number

Identical SSN	176,823
IHS SSN unknown	2,453
Different SSN	2,699



Last Name

Identical LN	180,493
IHS LN unknown	2
Different LN	1,480

First Name

Identical FN	158,786
IHS FN unknown	18
Different FN	23,171



Future Directions

- Improve mortality data:
 - NDI linkage currently underway
 - Benefits for improving measures of cancer burden
 - Descriptive epidemiology
 - Survival
 - Case control and cohort studies
 - Many other programs and partners would benefit (CVD, DM, Injury, HIV, other ID, etc)



Acknowledgements

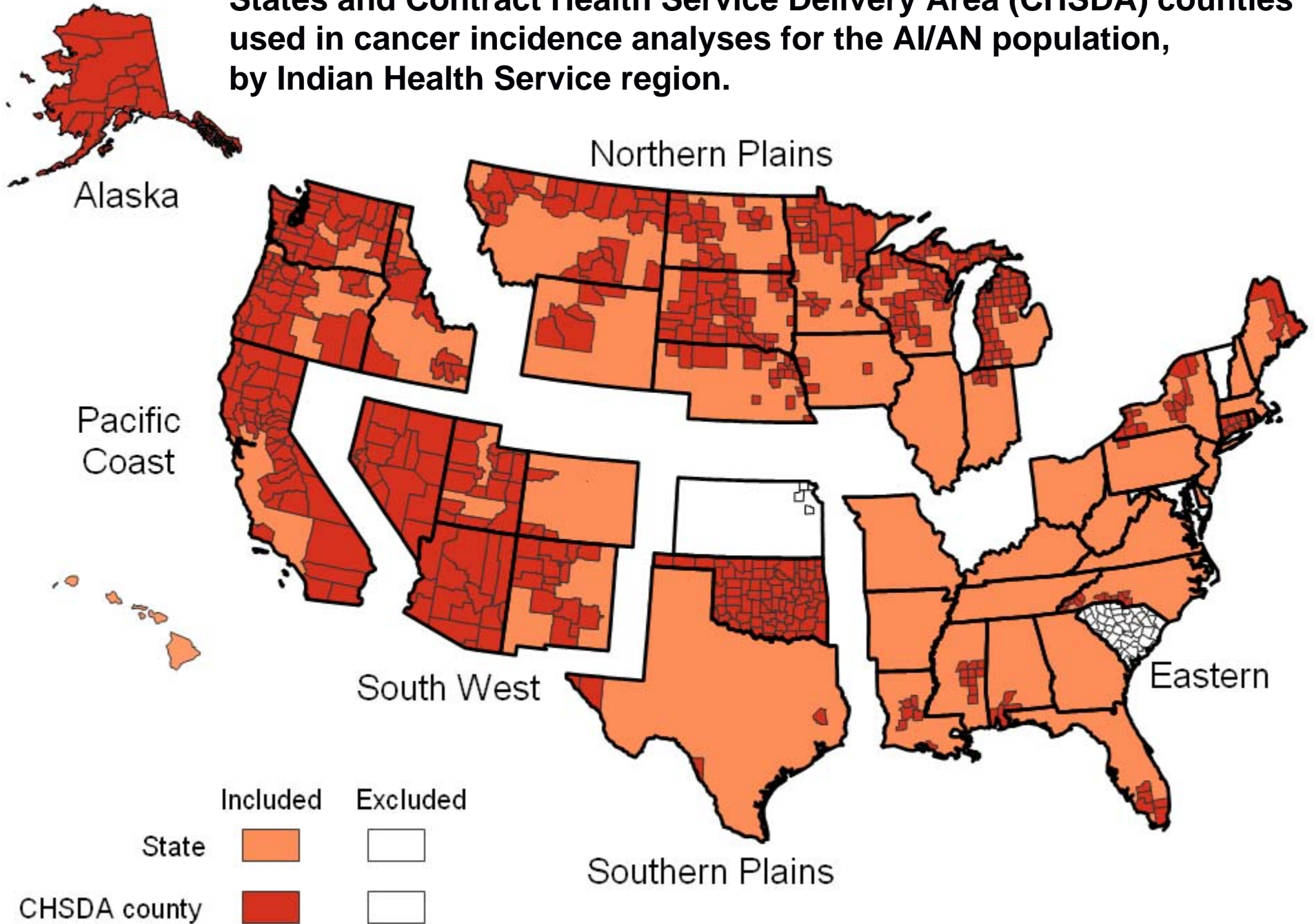
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- NDI/NCHS staff
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Questions?

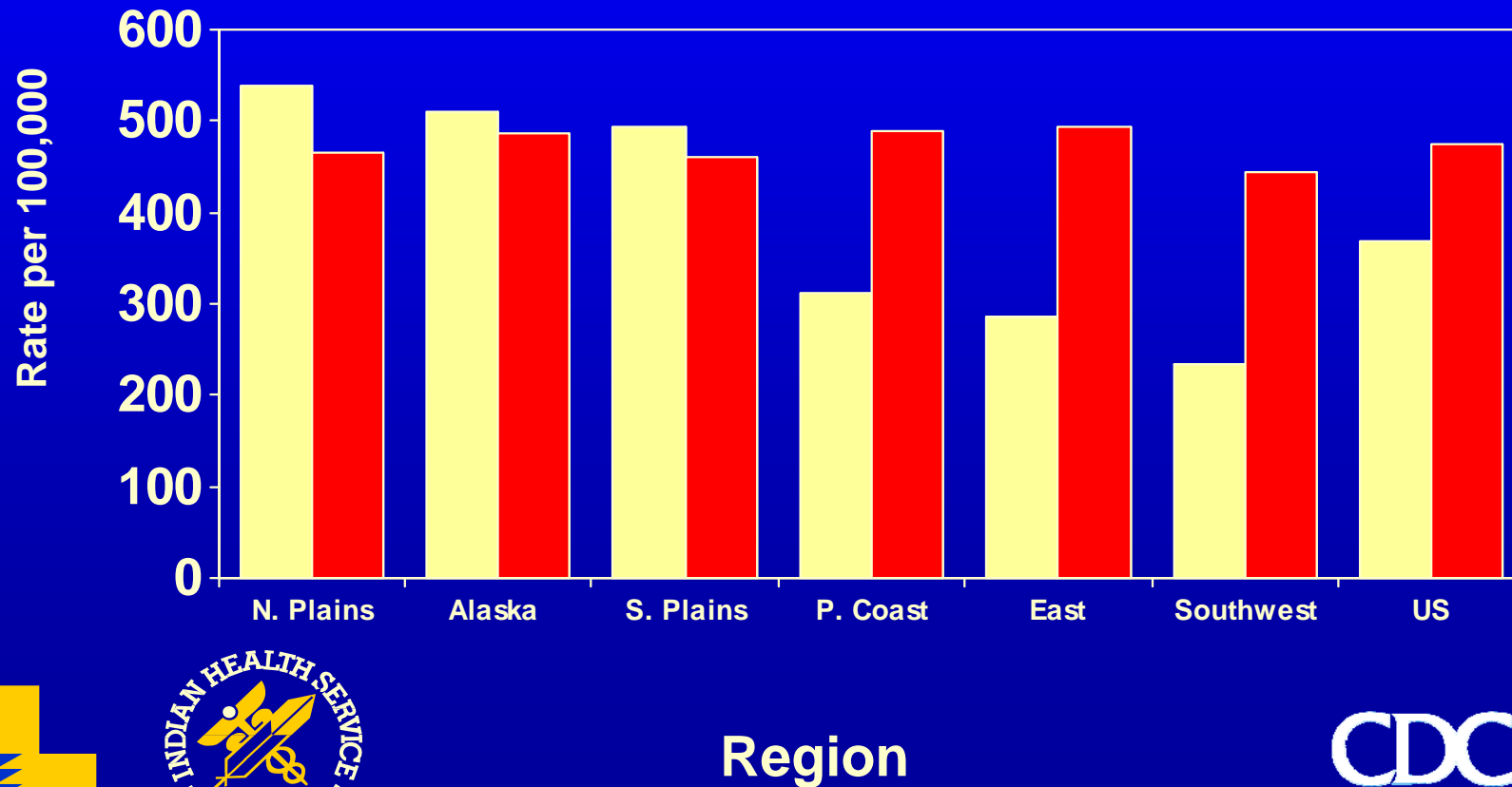


States and Contract Health Service Delivery Area (CHSDA) counties used in cancer incidence analyses for the AI/AN population, by Indian Health Service region.



AI/AN and NHW incidence rates, all cancers combined, by region, both sexes, 1999-2004

■ AI/AN ■ NHW



Region



Limitations

- **Recent linkage between the Michigan cancer registry and tribal roster of a Michigan AI/AN tribe**
- **1995-2004 diagnosis years**
 - IHS identified 614 individuals that were not identified as AI/AN by the registry
 - Tribal roster identified 242 individuals that were not identified as AI/AN by the registry OR by linkage with IHS

