Developing and Accessing Data at the National, Regional, and Tribal Specific Levels

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Looking back and looking ahead: Collaborating to Advance Cancer Control in American Indian/Alaska Native Communities

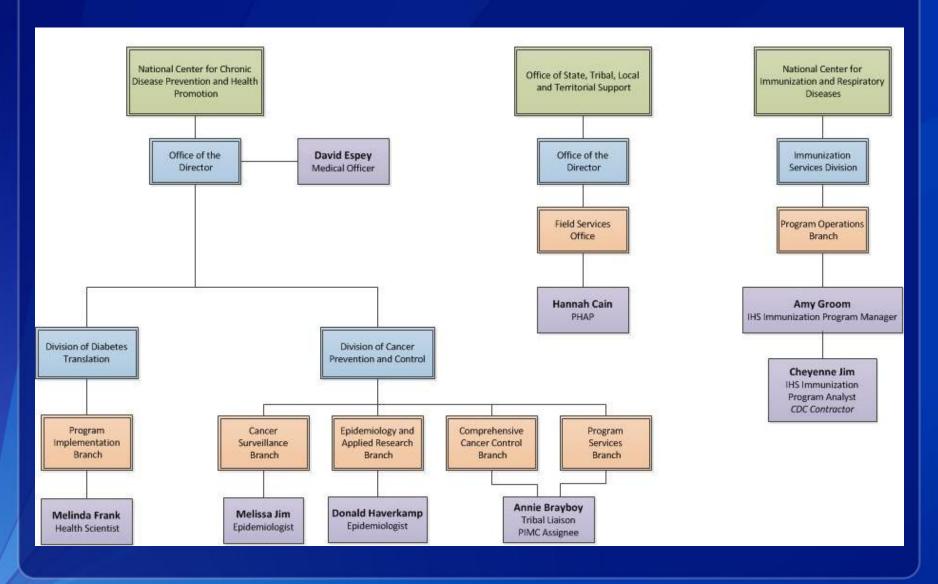
April 26, 2016



Shiprock, NM



Albuquerque Assignees



Background

 Race misclassification of AI/AN occurs in cancer surveillance & vital statistics databases

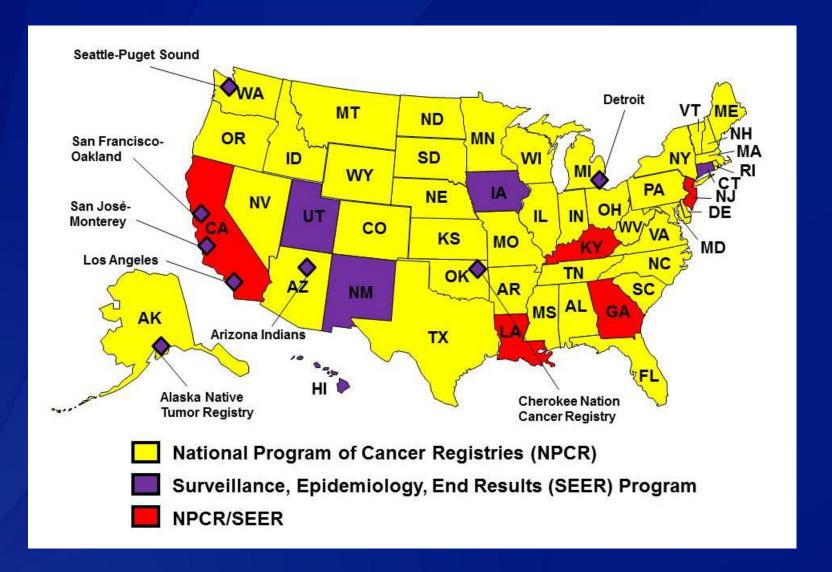
Varies by state

 Decreasing misclassification can improve accuracy of health indicators and program planning/resource allocation

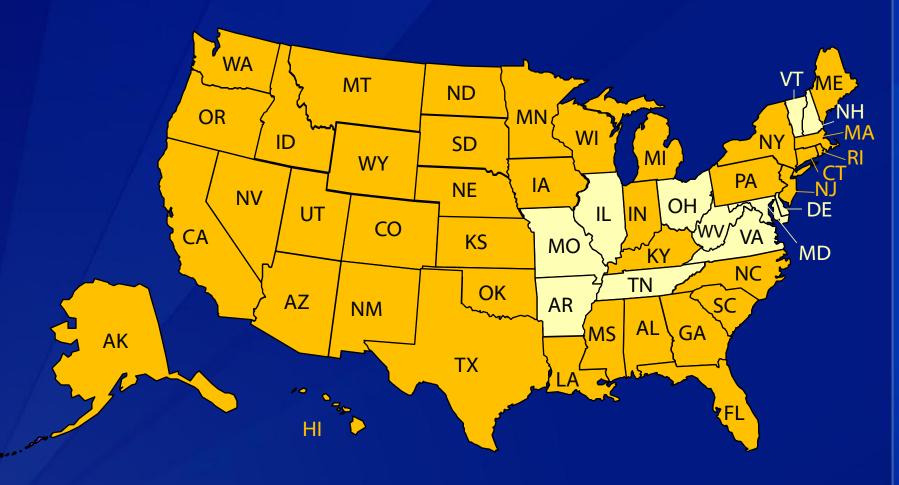
IHS Linkage: NPCR & SEER

- Link administrative records from IHS with records from central cancer registries
 - Centers for Disease Control and Prevention's
 - National Program of Cancer Registries (NPCR)
 - National Cancer Institute's
 - Surveillance, Epidemiology, and End Results (SEER)
- Identify AI/AN cases misclassified as non-Native
- Results are captured in "IHS Link" variable (NAACCR item #192)

NPCR & SEER



IHS Linkage: NPCR & SEER





Link every year



Link every 5 years

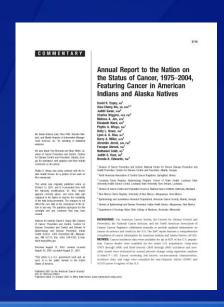
IHS Race Recode

■ Race 1, Race 2 and IHSLink

Patient	Race 1	Race 2	IHSLink	IHS Race Recode
А	Black	AI/AN	1	Black
В	API	AI/AN	1	API
С	AI/AN	White	0	AI/AN
D	Black	Other	1	Black
Е	White	Other	1	AI/AN
F	White	AI/AN	0	AI/AN
G	Other	Unknown	1	AI/AN
Н	Unknown	Unknown	1	AI/AN

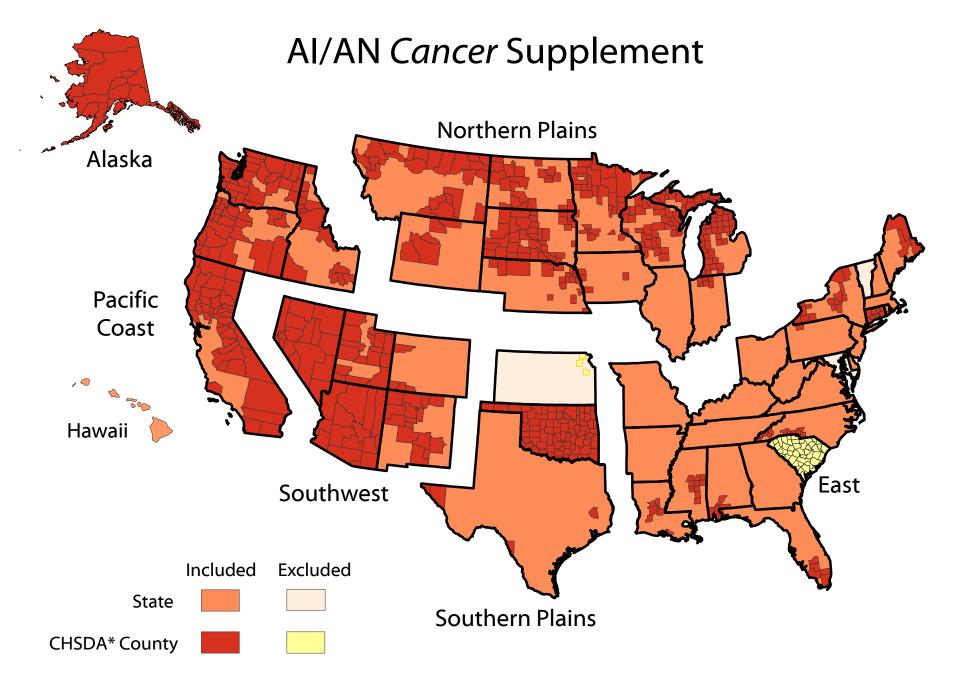
Results from IHS Linkage: NPCR & SEER

- Use "improved" data to report cancer burden of AI/AN
 - Annual Report to the Nation on the Status of Cancer, 1975-2004,
 Featuring Cancer in American Indians and Alaska Natives
 - http://onlinelibrary.wiley.com/doi/10.1002/cncr.23044/pdf
 - Cancer Supplement: An Update on Cancer in American Indians and Alaska Natives, 1999-2004
 - http://onlinelibrary.wiley.com/doi/10.1002/cncr.v113:5%2B/issuetoc

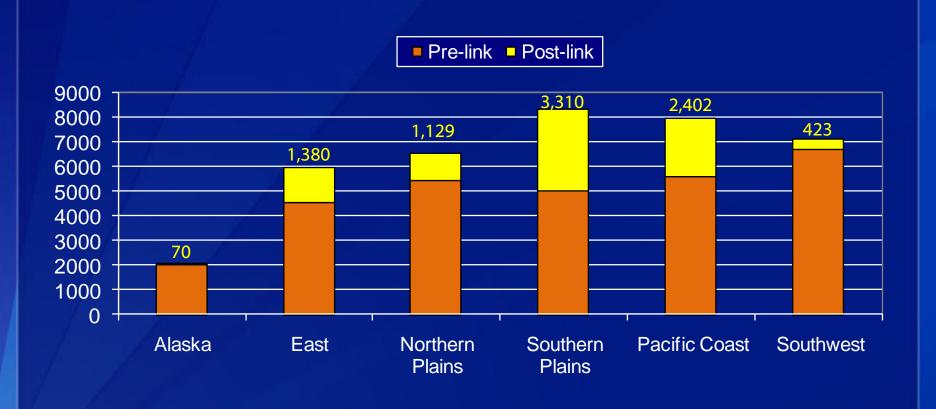




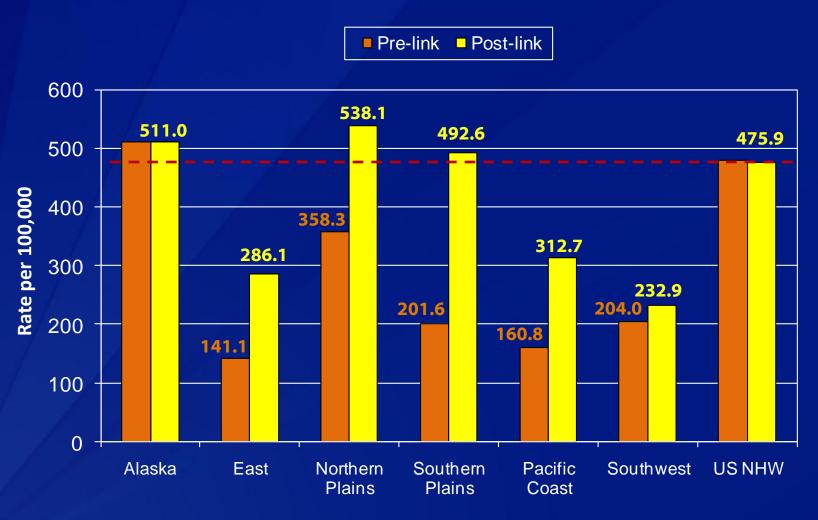




Number of individuals identified by IHS linkage for 2006 data submission



Al/AN cancer rates for all sites by IHS region, compared to US NHW, both sexes, 1999-2004



2016 NPCR/SEER-IHS Linkage

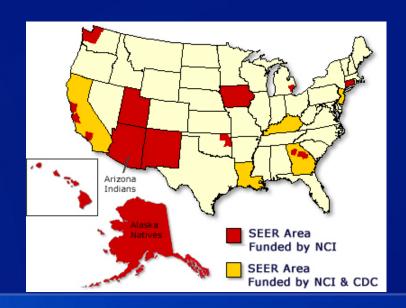
- AI/AN Incidence Database (AID)
 - 1999-2009 dx years
 - Incorporates IHS Link variable
 - Aggregated at IHS Region for 1999-2009
 - IHS Area or county-level contingent upon registry approval
 - Update in May 2017
 - 1999-2014 dx years

Potential papers

- AI/AN Cancer Survival
 - Contingent on updating IHS-NDI linkage
- ACS AI/AN Cancer Stats article
 - cancer risk factors, screening, incidence, & mortality
 - contingent on updating IHS-NDI linkage
- Another supplement ????

Additional Cancer Data Sources

- CDC's United States Cancer Statistics
 - Access via:
 - Web-based report that uses NPCR/SEER data
 - CDC Wonder
 - Incorporates IHS Link
 - Al/AN cannot be broken out for DE, IL, KS, KY, NJ, NY, SC
 - Cell suppression value of 16 cases
- NCI's SEER Data, 1973-2013
 - Access via:
 - SEER*Stat
 - Compressed data files
 - Incorporates IHS Link
 - Available for 9, 13, or 18 registries databases
 - US Mortality also available



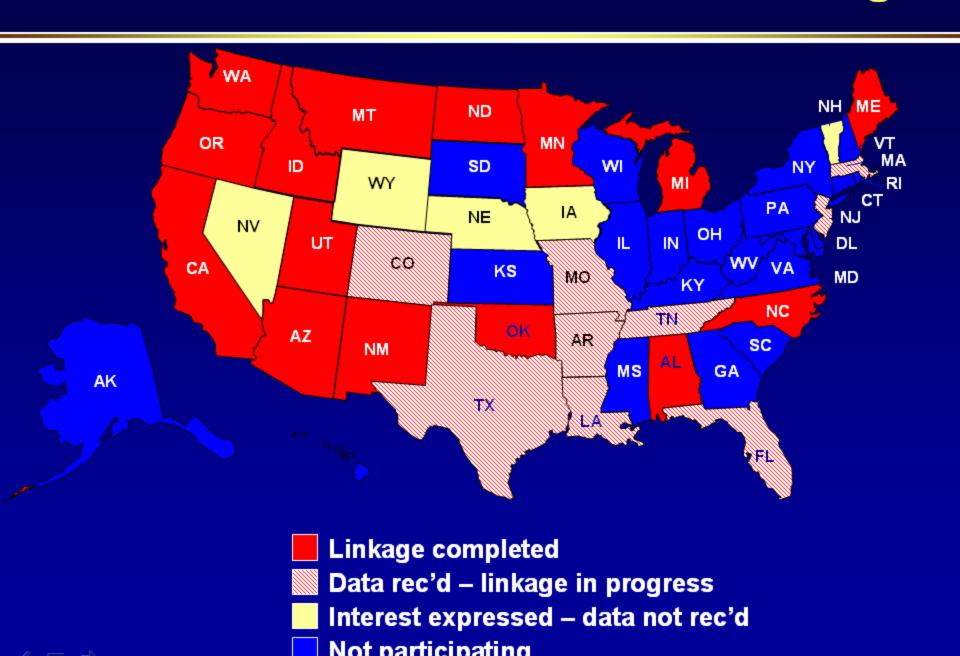
IHS-NDI Linkage Saga

A long time ago in a federal office building far, far away...

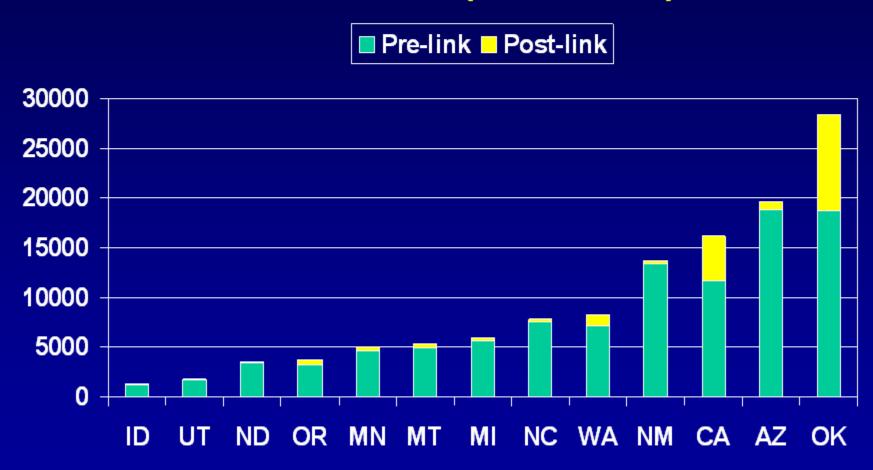
IHS-NDI Linkage

- Link records from the NDI with IHS
 - National Death Index is a central index of death record information on file in the state VS offices
- Identify AI/AN deaths misclassified as non-AI/AN
- Use "improved" data in the AJPH AI/AN Mortality Supplement

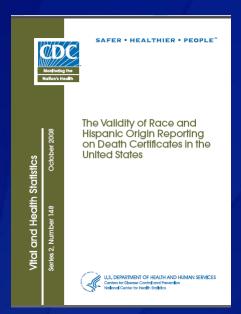
IHS/state death records data linkage



Linkage of death records from State VS with administrative records from the Indian Health Service (1990-2003)



National Longitudinal Mortality Survey



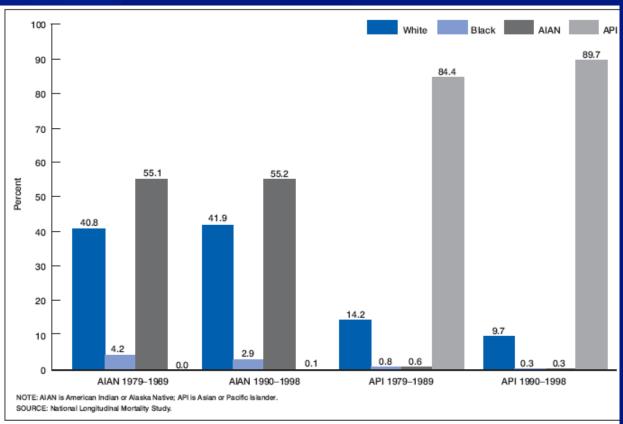


Figure 1. Race distribution on death certificate among self-identified American Indian or Alaska Natives and Asian or Pacific Islanders: United States, 1979–1989 and 1990–1998

SUPPLEMENT TO



A PUBLICATION OF AMERICAN PUBLIC HEALTH ASSOCIATION

Geographic Variation in Colorectal Cancer Incidence and Mortality | Perspectives on Mortality Data From the Indian Health Service | Racial Misclassification of American Indians



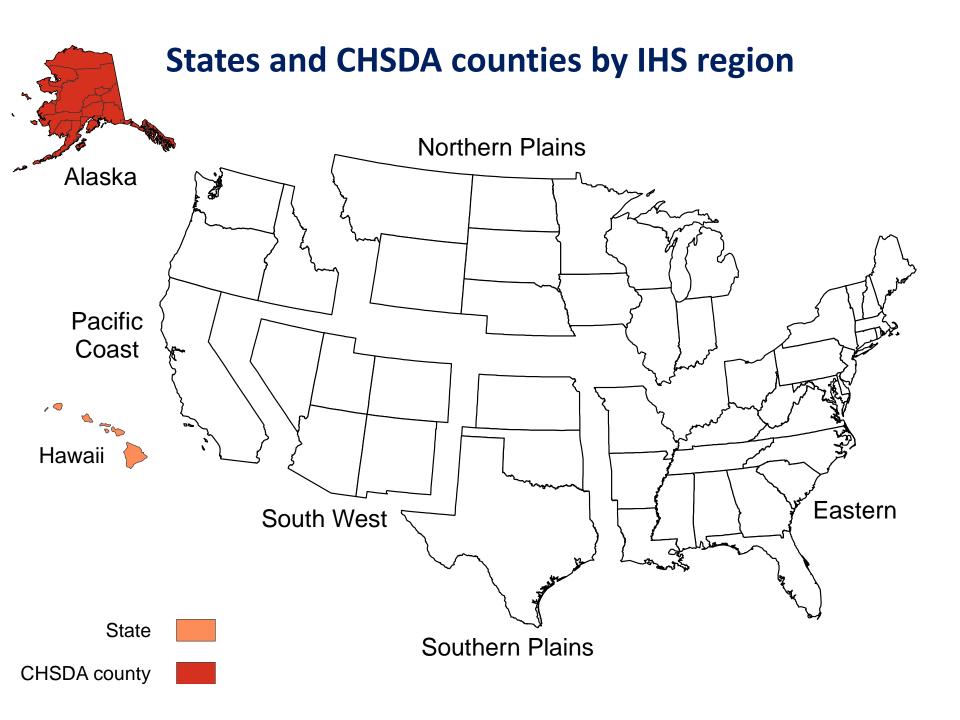
and Alaska Natives | AMERICAN INDIAN AND ALASKA NATIVE MORTALITY |

Disparities in Cancer Mortality and Incidence Among Al/AN People | American Indian Health Policy | The Alcohol-Attributable Death Rate Disparity Between American Indians and Alaska Natives and Non-Hispanic Whites | What Are the Causes of Suicide Among Young Alaska Native Men?

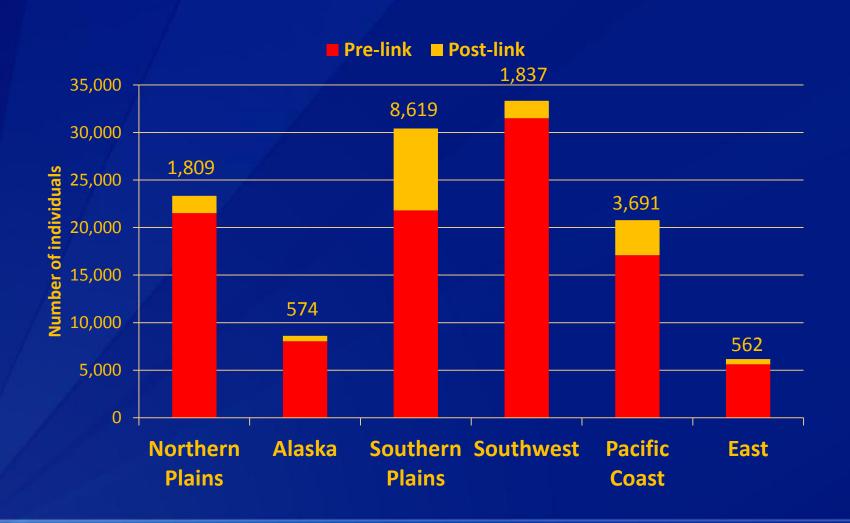




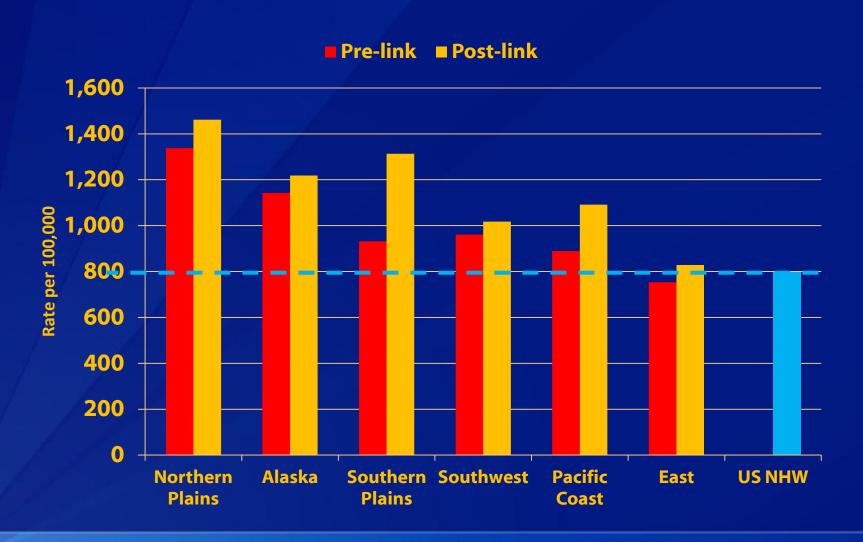
http://ajph.aphapublications.org/toc/ajph/104/S3



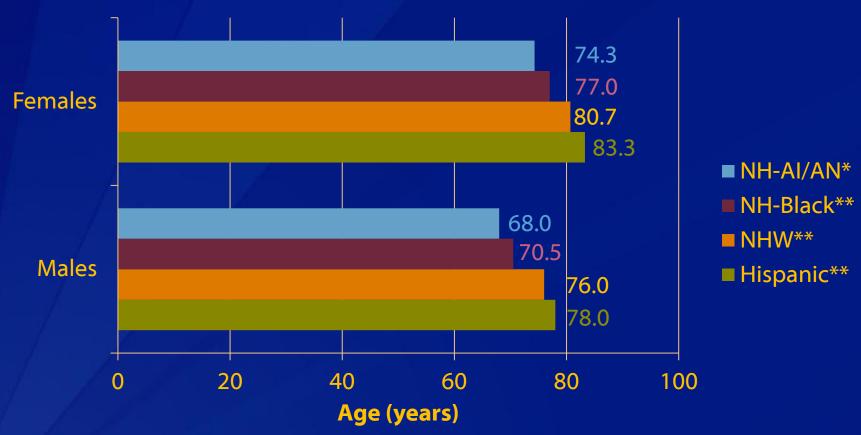
Number of individuals identified by IHS linkage with NDI, CHSDA counties, 1999-2009



Al/AN mortality rates per 100,000 for All Causes, both sexes, CHSDA counties, 1999-2009



Life Expectancy at Birth by Sex in CHSDA Counties



* 2007-2009

** 2008

Arias E, Xu J, Jim MA. Period Life Tables for the Non-Hispanic American Indian and Alaska Native Population, 2007-2009. *Am J Public Health*. 2014;104:S312-S319.

Top 10 Leading Causes of Death for AI/AN men compared with White men: CHSDA, US, 1999-2009

Cause of Death	AI/AN Rank (White)	Al/AN Rate (White)	AI/AN:White RR
All causes	•••	1381.8 (948.8)	1.46*
Heart disease	1 (1)	320.9 (262.5)	1.22*
Cancer	2 (2)	248.4 (224.7)	1.11*
Unintentional injury	3 (4)	141.3 (55.6)	2.54*
Diabetes	4 (6)	75.5 (23.6)	3.19*
Chronic liver disease	5 (11)	50.0 (12.9)	3.88*
Suicide	6 (7)	34.7 (23.2)	1.49*
CLRD	7 (3)	61.4 (56.4)	1.09*
Stroke	8 (5)	59.3 (49.6)	1.20*
Homicide	9 (21)	18.5 (3.8)	4.85*
Flu and Pneumonia	10 (8)	42.7 (22.4)	1.90*

^{*} Statistically significant

Top 10 Leading Causes of Death for AI/AN men compared with White men: CHSDA, US, 1999-2009

#	Northern Plains	Alaska	Southern Plains	Southwest	Pacific Coast	East
•	All causes	All causes	All causes	All causes	All causes	All causes
	1.89*	1.67*	1.42*	1.35*	1.33*	0.98
1	Heart disease (1)	Cancer (1)	Heart disease (1)	UI (4)	Heart disease (1)	Heart disease (1)
	1.58*	1.44*	1.33*	2.83*	1.23*	0.90*
2	Cancer (2)	UI (3)	Cancer (2)	Heart disease (1)	Cancer (2)	Cancer (2)
	1.51*	2.52*	1.31*	0.94*	1.05	0.83*
3	UI (4)	Heart disease (2)	UI (4)	Cancer (2)	UI (4)	UI (4)
	3.10*	1.29*	1.73*	0.79*	2.03*	1.39*
4	Diabetes (6)	Suicide (4)	Diabetes (6)	CLD (10)	CLD (10)	Diabetes (6)
	4.18*	2.34*	3.01*	4.74*	3.33*	2.67*
5	CLD (11)	CLRD (5)	CLD (3)	Diabetes (8)	CLRD (3)	Stroke (5)
	6.64*	1.55*	1.13*	3.91*	1.29*	1.13
6	Suicide (7)	Stroke (6)	Suicide (5)	Suicide (6)	Diabetes (6)	CLD (11)
	1.98*	1.57*	1.25*	1.08*	2.43*	2.38*
7	CLRD (3)	Homicide (10)	CLRD (11)	Homicide (18)	Stroke (5)	CLRD (3)
	1.71*	3.44*	2.87*	4.51*	1.14*	0.69*
8	Stroke (5)	Flu/Pneumo (11)	Stroke (8)	Flu/Pneumo (7)	Suicide (8)	Kidney disease (9)
	1.30*	3.10*	1.25*	2.41*	1.19*	1.27
9	Homicide (21)	Diabetes (7)	Homicide (7)	Stroke (5)	Homicide (21)	Suicide (8)
	9.79*	1.07	1.42*	1.06	3.72*	0.69*
10	Flu/Pneumo (8)	CLD (8)	Kidney disease (10)	Kidney disease (11)	Flu/Pneumo (9)	Flu/Pneumo
	2.19*	1.28	1.93*	2.01*	1.26*	1.09

^{*} Statistically significant

Top 10 Leading Causes of Death for AI/AN women compared with White women: CHSDA, US, 1999-2009

Cause of Death	AI/AN Rank (White)	AI/AN Rate (White)	AI/AN:White RR
All causes		991.5 (678.6)	1.46*
Cancer	1 (2)	185.8 (159.1)	1.17*
Heart disease	2 (1)	204.8 (167.2)	1.22*
Unintentional injury	3 (6)	65.6 (27.0)	2.43*
Diabetes	4 (8)	69.2 (17.1)	4.04*
Stroke	5 (3)	58.9 (49.3)	1.20*
Chronic liver disease	6 (12)	34.6 (6.4)	5.36*
CLRD	7 (4)	45.4 (43.9)	1.03
Flu and pneumonia	8 (7)	31.7 (17.2)	1.84*
Kidney disease	9 (9)	25.0 (9.2)	2.72*
Septicemia	10 (10)	18.6 (7.8)	2.38*

^{*} Statistically significant

Top 10 Leading Causes of Death for AI/AN women compared with White women: CHSDA, US, 1999-2009

#	Northern Plains	Alaska	Southern Plains	Southwest	Pacific Coast	East
•	All causes	All causes	All causes	All causes	All causes	All causes
	1.92*	1.66*	1.41*	1.24*	1.33*	1.10*
1	Cancer (2)	Cancer (1)	Heart disease (1)	Cancer (2)	Cancer (1)	Heart disease (1)
	1.60*	1.50*	1.27*	0.84*	1.23*	1.06
2	Heart disease (1)	Heart disease (2)	Cancer (2)	Heart disease (1)	Heart disease (2)	Cancer (2)
	1.59*	1.35*	1.36*	0.88*	1.05	0.88*
3	UI (6)	UI (5)	UI (6)	UI (6)	UI (4)	Diabetes (8)
	3.14*	2.62*	1.78*	2.11*	2.03*	3.77*
4	Diabetes (7)	Stroke (3)	Diabetes (8)	Diabetes (8)	Stroke (10)	UI (6)
	5.11*	1.47*	3.40*	5.19*	3.33*	1.58*
5	CLD (13)	CLRD (4)	Stroke (3)	CLD (12)	CLRD (3)	Stroke (3)
	10.20*	1.58*	1.22*	5.75*	1.29*	1.08
6	CLRD (4)	CLD (10)	CLRD (4)	Flu/Pneumo (7)	Diabetes (6)	CLRD (4)
	1.92*	4.36*	1.02	2.38*	2.43*	0.81*
7	Stroke (3)	Suicide (8)	Kidney disease (9)	Stroke (4)	Flu/Pneumo (5)	CLD (13)
	1.31*	2.88*	2.35*	0.86*	1.14*	3.55*
8	Kidney disease (9)	Flu/Pneumo (9)	CLD (14)	Kidney disease (9)	CLD (8)	Septicemia (10)
	3.37*	2.66*	3.51*	3.23*	1.19*	1.68*
9	Flu/Pneumo (8)	Diabetes (7)	Flu/Pneumo (7)	Septicemia (10)	Kidney disease (21)	Kidney disease (9)
	1.92*	0.92	1.27*	2.57	3.72*	1.62*
10	Suicide (18) 2.62*		Septicemia (10) 2.03*	CLRD (3) 0.36*	Septicemia (9) 1.26*	Flu/Pneumo (7) 1.01

^{*} Statistically significant

Top 10 causes of <u>cancer</u> death for AI/AN men compared with White men: CHSDA, US, 1999-2009

Cause of Cancer Death	AI/AN Rank (White)	AI/AN Rate (White)	AI/AN:White RR
All malignant cancers	•••	248.4 (224.7)	1.11*
Lung	1 (1)	67.5 (67.0)	1.01
Colorectal	2 (3)	26.0 (20.6)	1.26*
Prostate	3 (2)	27.6 (25.2)	1.09*
Liver	4 (8)	13.4 (6.3)	2.12*
Kidney	5 (10)	11.3 (5.9)	1.92*
Pancreas	6 (4)	11.8 (12.2)	0.96
Stomach	7 (14)	10.8 (4.3)	2.49*
Esophagus	8 (6)	8.6 (8.1)	1.06
NHL	9 (5)	7.9 (9.4)	0.82*
Brain	10 (9)	3.9 (6.1)	0.63*

^{*} Statistically significant

Top 10 causes of <u>cancer</u> death for AI/AN men by IHS region: CHSDA, US, 1999-2009

#	Northern Plains	Alaska	Southern Plains	Southwest	Pacific Coast	East
•	All cancers	All cancers	All cancers	All cancers	All cancers	All cancers
	1.51*	1.44*	1.31*	0.79*	1.05	0.83*
1	Lung (1)	Lung (1)	Lung (1)	Lung (1)	Lung (1)	Lung (1)
	1.71*	1.43*	1.22*	0.34*	0.98	0.82*
2	Colorectal (3)	Colorectal (2)	Colorectal (2)	Prostate (2)	Colorectal (3)	Colorectal (3)
	1.84*	2.12*	1.48*	0.92*	1.41*	0.87
3	Prostate (2)	Stomach (11)	Prostate (3)	Colorectal (3)	Prostate (2)	Prostate (2)
	1.55*	4.43*	1.30*	0.66*	0.98	0.98
4	Liver (10)	Pancreas (4)	Kidney (8)	Stomach (14)	Liver (9)	Liver (8)
	2.75*	1.72*	2.11*	4.31*	2.11*	1.38
5	Kidney (8)	Prostate (3)	Liver (9)	Liver (8)	Pancreas (4)	Stomach (11)
	2.08*	0.93	2.18*	2.19*	1.02	1.50
6	Pancreas (4)	Liver (7)	Pancreas (4)	Kidney (10)	Esophagus (6)	Pancreas (4)
	0.94	2.12*	0.95	2.33*	1.15	0.50*
7	Esophagus (6)	Esophagus (6)	Esophagus (6)	Pancreas (4)	Kidney (10)	Kidney (9)
	1.23	1.66*	1.44*	1.01	1.23	1.13
8	Stomach (13)	Kidney (10)	NHL (5)	NHL (5)	NHL (5)	Urinary Bladder (7)
	2.44*	1.98*	1.20	0.66*	0.79	0.86
9	NHL (5)	AML (13)	Stomach (14)	Esophagus (6)	Stomach (14)	Esophagus (6)
	0.96	1.03	1.92*	0.76*	1.57*	0.58*
10	AML (11)	NHL (5)	Brain (10)	Myeloma (12)	Brain (8)	NHL (5)
	1.03	0.46*	0.93	1:38*	0.69*	0.45*

^{*} Statistically significant

Top 10 causes of <u>cancer</u> death for AI/AN women compared with White women: CHSDA, US, 1999-2009

Cause of Cancer Death	AI/AN Rank (White)	AI/AN Rate (White)	AI/AN:White RR
All malignant cancers	•••	185.8 (159.1)	1.17*
Lung	1 (1)	46.2 (43.4)	1.06*
Breast	2 (2)	22.2 (24.1)	0.92*
Colorectal	3 (3)	19.3 (14.7)	1.31*
Pancreas	4 (4)	10.1 (9.3)	1.08
Ovary	5 (5)	9.0 (9.2)	0.98
Liver	6 (10)	7.7 (2.7)	2.84*
NHL	7 (6)	6.4 (6.0)	1.07
Stomach	8 (14)	5.9 (2.1)	2.77*
Kidney	9 (12)	5.4 (2.7)	2.02*
Cervix	10 (19)	4.2 (2.0)	2.11*

^{*} Statistically significant

Top 10 causes of <u>cancer</u> death for AI/AN women by IHS region: CHSDA, US, 1999-2009

#	Northern Plains	Alaska	Southern Plains	Southwest	Pacific Coast	East
	All cancers	All cancers	All cancers	All cancers	All cancers	All cancers
	1.60*	1.50*	1.36*	0.84*	1.18*	0.88*
1	Lung (1)	Lung (1)	Lung (1)	Breast (2)	Lung (1)	Lung (1)
	2.11*	1.38*	1.34*	0.64*	1.18*	0.83*
2	Breast (2)	Breast (2)	Breast (2)	Lung (1)	Breast (2)	Breast (2)
	1.13	1.26*	1.18*	0.28*	0.88	0.71*
3	Colorectal (3)	Colorectal (3)	Colorectal (3)	Colorectal (3)	Colorectal (3)	Colorectal (3)
	1.53*	2.43*	1.64*	0.72*	1.38*	1.30*
4	Pancreas (4)	Stomach (17)	Pancreas (4)	Ovary (5)	Pancreas (5)	Pancreas (4)
	1.14	7.11*	1.27*	1.10	1.23*	0.93
5	Cervix (20)	Pancreas (4)	Ovary (5)	Pancreas (4)	Ovary (4)	Ovary (5)
	4.15*	1.06	1.15	1.02	1.01	0.61*
6	Ovary (5)	Liver (10)	NHL (6)	Liver (9)	Liver (10)	Liver (10)
	0.92	3.14*	1.40*	3.14*	2.84*	1.67
7	Liver (12)	Ovary (5)	Liver (11)	Stomach (15)	NHL (6)	Kidney (13)
	3,25*	1.08	2.54*	3.61*	1.21	1.56
8	Stomach (16) 3.28*		Kidney (9) 1.81*	Kidney (11) 2.36*	Uterus (8) 1.19	Cervix (19) 1.69
9	Kidney (9)	Kidney (12)	Cervix (13)	NHL (6)	Stomach (16)	Uterus (7)
	2.04*	1.91	1.58*	0.91	2.47*	1 00
10	NHL (6)	NHL (6)	Uterus (8)	Cervix (17)	Kidney (12)	Myeloma (9)
	1.11	0.70	1.22	2.05*	1.78*	1.42

^{*} Statistically significant

Mortality to Incidence Ratio (MIR)

- Indicator of survival that compares fatality between groups
- Calculated as:

Age-adjusted death rate

Age-adjusted incidence rate

- Thought to be more accurate than "relative survival"
- Easy to calculate from existing data
 - Cancer incidence data
 - Mortality data
- Potentially useful proxy for estimating cancer survival
- Not widely used; few publications

Mortality to Incidence Ratio (MIR) for All Cancer Sites Combined by Region, for Al/AN compared with NHW, CHSDA counties, 1999-2009

Region	AI/AN MIR	NHW MIR	AI/AN: NHW RATIO
Northern Plains	0.53	0.40	1.33*
Alaska	0.49	0.37	1.32*
Southern Plains	0.46	0.42	1.09*
Southwest	0.51	0.40	1.27*
Pacific Coast	0.49	0.39	1.26*
East	0.51	0.38	1.34*
Total US	0.49	0.39	1.26*

^{*} Statistically significant

Mortality to Incidence Ratio (MIR)

- Consistently less favorable for AI/AN compared to NHW for nearly all cancers
- Disparities likely related to lower SES and lack of healthcare access
- AI/ANs consistently diagnosed at later stages particularly for screenable cancers

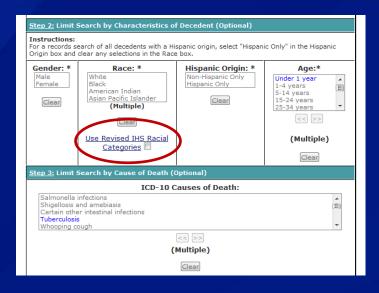


IHS-NDI Update

- AI/AN Mortality Database (AMD)
 - 1990-2009 death years
 - Incorporates IHS Link
 - Update
 - 2010-2014 death files are ready

 - Amended uses:
 - Access to IHS OPHS staff
 - Access to Tribal Epi Centers



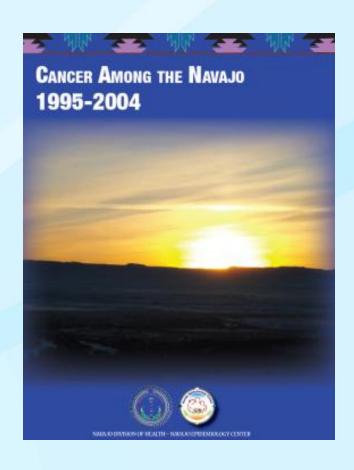


- The American Indian population does not reside within reservation boundaries in Oklahoma, and is, therefore, more heterogeneously distributed throughout the population of the state. As a result the standard way of classifying race does not reliably document the American Indian births and deaths. Special attention should be given to the data when studying information related to race.
- The revised IHS Racial Categories is a work in progress where Oklahoma Vital Records are matched with IHS records those individuals that were in the IHS database are considered Native Americans, and those not matched are unchanged.

http://www.health.state.ok.us/ok2share/Vital_Statistics/Death/Final/Statistics10.shtml

Update on Cancer Among the Navajo, 2005-2012(?)

- Report was produced in response to professional & community concerns that cancer may be increasing among the Navajo
- □ First report covered 1999-2004
- □ Tribal-specific cancer report
 - Navajo Nation Tribal Epi Center
 - Del Yazzie, MPH
 - ABQ Area SW Tribal Epi Center
 - Dornell Pete, MPH
 - IHS Navajo Area
 - Christine Benally, MPH
 - NM Department of Health
 - Sam Swift, MPH
 - New Mexico Tumor Registry (SEER)
 - Chuck Wiggins, PhD
 - Arizona Cancer Registry (NPCR)
 - CDC DCPC
 - Melissa A. Jim, MPH



Update on Cancer Among the Navajo Data Sources

Incidence data

- Navajo-specific
- New Mexico Tumor Registry
- Arizona Cancer Registry

Mortality data

- Compared US Mortality vs AMD
 - Very little difference so opted to use US Mortality data available via SEER*Stat – data is more up to date
- Navajo-proxy
 - AZ: Apache, Coconino, and Navajo counties
 - NM: McKinley and San Juan counties
 - UT: San Juan county

Health Disparities, Cancer, among the Haudenosaunee (People of the Longhouse)

- Roswell Park Cancer Institute
 - Rodney C. Haring, PhD, MSW (Seneca)
- Centers for Disease Control and Prevention
 - Melissa A. Jim, MPH (Diné)
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□ Haudenosaunee Nations

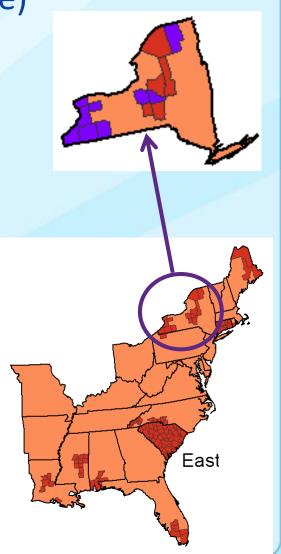
- distinctly connected by clans, bloodlines, culture, traditions, politics, environment, and European contact
- largest Confederacy of tribes that are distinctly related in the East
- previously lumped into a category of "all East tribes"

□ Goal

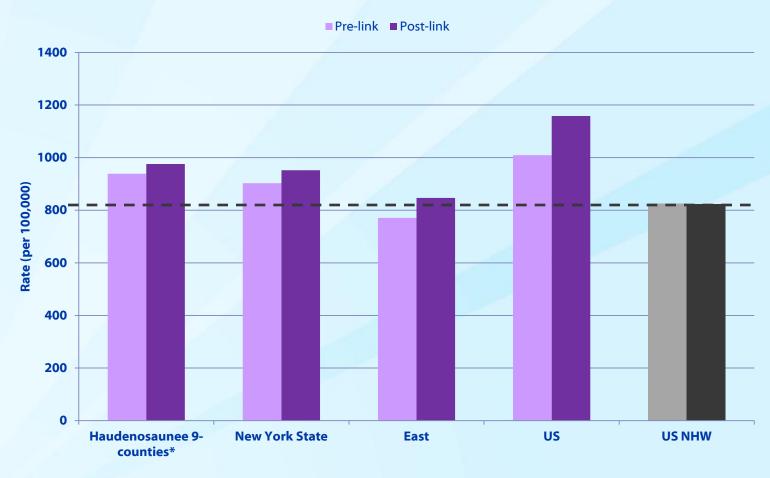
- Analyze aggregate mortality data to provide an accurate picture of health disparities for all enrolled/non-enrolled members of the Haudenosaunee
- Help Haudenosaunee Nations provide current data for modifying interventions and health systems
- Follow up with cancer incidence data once the AID is updated Spring 2017

Health Disparities, Cancer, among the Haudenosaunee (People of the Longhouse)

- □ Analyses restricted to the following territories:
 - Allegany
 - Cattaraugus county
 - Cattaraugus
 - Erie, Cattaraugus, & Chautauqua counties
 - Oil Springs
 - Cattaraugus & Erie counties
 - Oneida Indian Nation
 - Madison county
 - Onondaga
 - Onondaga county
 - St. Regis Mohawk
 - Franklin county
 - Tonawanda
 - Genesee, Erie, & Niagara counties
 - Tuscarora
 - Niagara county



AI/AN all cause mortality rates before and after IHS linkage, CHSDA counties: Males & Females, 1990-2009

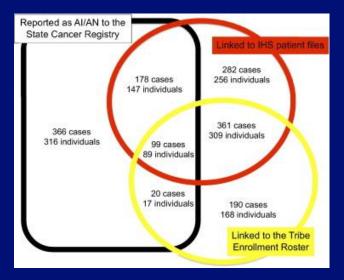


^{*} Counties include: Allegany, Cattaraugus, Chautauqua, Erie, Franklin, Genesee, Madison, Niagara, and Onondaga. Source: Al/AN Mortality Database (1990-2009): IHS amended National Vital Statistics System Mortality Files

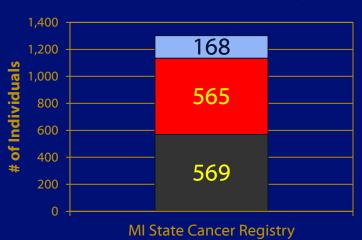
Conclusion

 Racial misclassification can be addressed through data linkages to provide better data

- Limitation
 - IHS only covers ~ 64.2% of the AI/AN population
 - Tribal linkages



- AI/AN reported by registry
- Al/AN identified by IHS linkage
- AI/AN identified by ITCMI linkage



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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

