Duke Cancer Institute
UNC
Improving AI/AN Cancer Surveillance Data in the US
May 1
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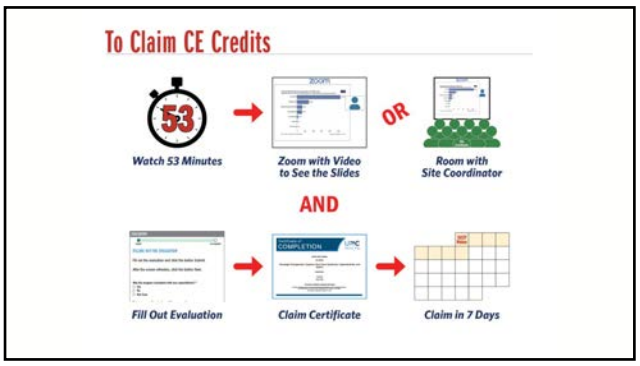
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Our Presenter

Melissa Jim, MPH (Diné)

Melissa A. Jim, MPH (Diné) graduated from the MPH program at the University of New Mexico School of Medicine in 2004. She has been an Epidemiologist with the Cancer Surveillance Branch in the Division of Cancer Prevention and Control at the Centers for Disease Control and Prevention in Albuquerque, NM since 2005. She conducts data linkages between all central cancer registries in the United States with the Indian Health Service (IHS) patient registration database, with results so significant that the linkage has become an annual central cancer registry requirement. She is co-PI on a project involving the linkage of the National Death Index which is maintained by the National Center for Health Statistics with the IHS patient registration database to improve the quality of race data for death records. She also provides technical assistance and analytic support to HIS and tribal organizations. Prior to working for CDC she worked at the New Mexico Tumor Registry for 5 years.

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Our Presenter

9

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10

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13

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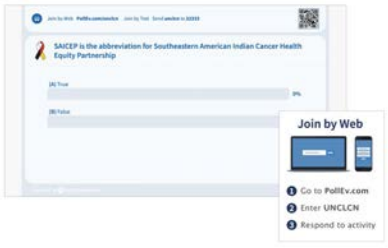
Sample Poll Everywhere Question



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ACCME Disclosure

This activity has been planned and implemented under the sole supervision of the Course Director, Stephanie Wheeler, PhD, MPH, in association with the UNC Office of Continuing Professional Development (CPD). The course director received research support from AstraZeneca (ended June 2023) and Pfizer Medical Foundation (ended December 2023). These financial relationships have been mitigated. CPD staff have no relevant financial relationships with ineligible companies as defined by the ACCME.

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SAICEP is the abbreviation for Southeastern American Indian Cancer Health Equity Partnership

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Cancer Prevention Works

Improving American Indian/Alaska Native (AI/AN) cancer surveillance data in the United States

Melissa A. Jim, MPH (*Diné*)
Epidemiologist

SAICEP Webinar
May 1, 2024

CDC

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control

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Overview

- Background
- United States Cancer Statistics
- Methods to improve the estimation of cancer burden among AI/AN
  1) IHS Linkage
  2) Restriction to IHS Purchased/Referred Care Delivery Area (PRCDA) counties
  3) Restriction to non-Hispanic populations
- USCS Data Visualization Tool

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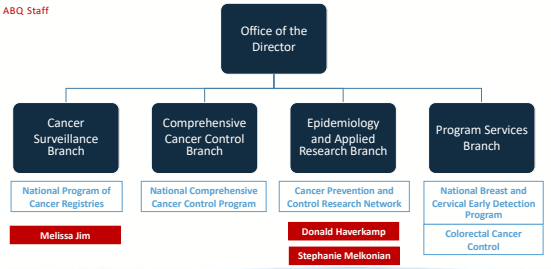
- ABQ Staff



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Background

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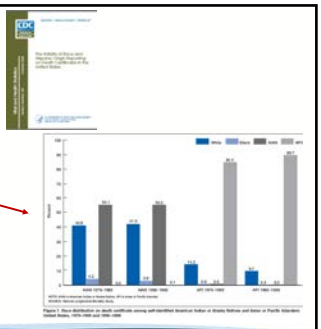
Background

- Race misclassification of AI/AN occurs in cancer surveillance & vital statistics databases
- More AI/AN are misclassified as another race on death certificate records than other race groups
- Results in underestimates of cancer incidence & death rates among AI/AN
- This project compared self-report Census race to race on the death certificate
  - Only 55% of those who self-reported as AI/AN were coded as AI/AN on the death certificate
  - 41% of those who self-reported as AI/AN were coded as White on the death certificate



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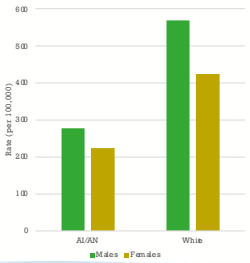
AI/AN cancer incidence, 1992-1999

- 12 SEER geographic areas
  - AK, Atlanta, CT, Detroit, HI, IA, Los Angeles, NM, San Francisco-Oakland, San Jose-Monterrey, Seattle-Puget Sound, and UT
- 818,685 AI/AN cases
  - 32% lived in NM
  - 21% lived in AK
  - 12% lived in Seattle-Puget Sound
  - 11% lived in Los Angeles



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CDC's role in cancer surveillance

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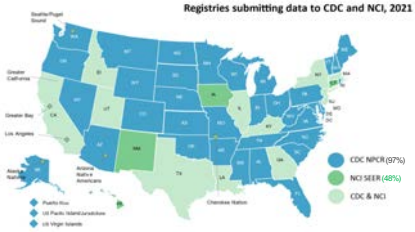
Cancer surveillance in the United States
Covers 100% of U.S. population

USCS U.S. Cancer Statistics
The Official Federal Cancer Statistics

NPCR NATIONAL PROGRAM of CANCER REGISTRIES

SEER

Registries submitting data to CDC and NCI, 2021



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Improving cancer surveillance data in AI/AN populations

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Method 1: Link with IHS administrative records

- Link administrative records from IHS with cancer records from:
  - CDC's National Program of Cancer Registries (NPCR)
  - NCI's Surveillance, Epidemiology, and End Results (SEER)
- Identify AI/AN cases misclassified as non-AI/AN
- Results captured in IHS Link (NAACCR data item 192) in NPCR & SEER annual data submissions
- Race recode (Race1, Race2, and IHS Link)
  - Various USCS databases
  - USCS AI/AN Incidence Analytic Database (AIAD)
  - Various SEER databases

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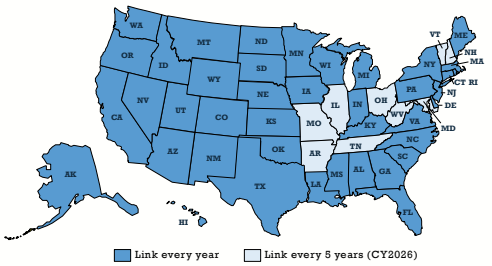
IHS-NPCR/SEER Linkage Schedule



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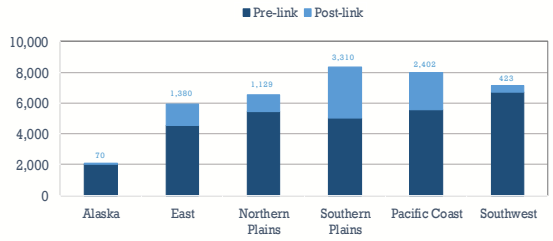
Number of AI/AN individuals identified by IHS linkage for 2006 data submission



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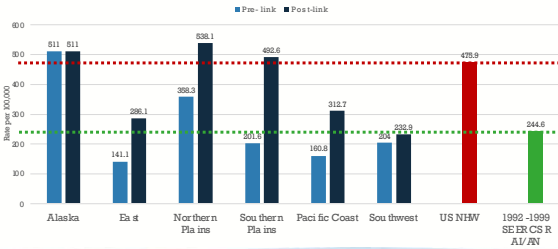
AI/AN cancer rates for all cancer sites combined by IHS Region, Males and Females, 1999-2004



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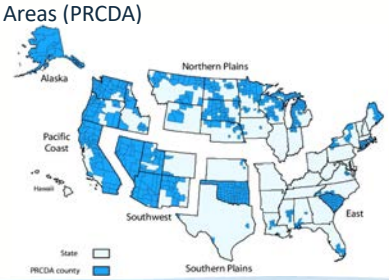
Method 2: Restriction to IHS Purchased/Referred Care Delivery Areas (PRCDA)



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Sensitivity & classification ratios for decedents that linked to IHS: US, NPCR/SEER, 1990-2009

Group	Sensitivity		Classification Ratio	
	CHSDA	Non-CHSDA	CHSDA	Non-CHSDA
Male and Female	77.6	39.0	1.29	2.56
Male	77.3	39.8	1.29	2.51
Female	77.9	38.4	1.28	2.60
Northern Plains	88.2	71.4	1.13	1.40
Alaska	99.4	NA	1.01	NA
Southern Plains	56.2	13.9	1.78	7.22
Southwest	89.1	63.2	1.12	1.58
Pacific Coast	86.6	57.1	1.15	1.75
East	52.8	15.2	1.90	6.60
Urban	72.9	41.6	1.37	2.40
Rural	80.8	52.1	1.24	1.92

Sensitivity
- % of cases that linked to IHS and were correctly classified by cancer registries

Classification ratio
- IHS linkage identified an additional X% of AI/AN cases compared to cancer registries alone

Less misclassification in CHSDA counties

Jim MA, Arias E, Seneca DS, Hoopes MJ, Jim CC, Johnson NJ, Wiggins CL. Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area. *Am J Public Health*. 2014; 104:S295-S302.

32

Sensitivity & classification ratios for decedents that linked to IHS: US, IHS-NVSS, 1990-2009

Group	Sensitivity		Classification Ratio	
	CHSDA	Non-CHSDA	CHSDA	Non-CHSDA
Male and Female	83.6	54.8	1.20	1.82
Male	84.3	55.9	1.19	1.79
Female	82.7	53.6	1.21	1.87
Northern Plains	91.9	74.2	1.09	1.35
Alaska	93.5	NA	1.07	NA
Southern Plains	65.3	38.4	1.53	2.61
Southwest	94.3	72.3	1.06	1.38
Pacific Coast	75.2	52.9	1.33	1.89
East	83.2	38.8	1.20	2.57
Urban	77.8	55.4	1.29	1.81
Rural	87.1	53.1	1.15	1.88

Sensitivity better in CHSDA counties

Classification ratios reflect significantly better agreement between IHS and the death certificate in CHSDA counties

Jim MA, Arias E, Seneca DS, Hoopes MJ, Jim CC, Johnson NJ, Wiggins CL. Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area. *Am J Public Health*. 2014; 104:S295-S302.

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Sensitivity & classification ratios for self-reported AI/AN decedents: US, National Longitudinal Mortality Study, 1990-2002

Group	Sensitivity		Classification Ratio	
	CHSDA	Non-CHSDA	CHSDA	Non-CHSDA
Male and Female	68.8	28.3	1.18	1.81
Male	69.7	30.2	1.20	1.77
Female	67.8	26.8	1.16	1.84
Northern Plains	85.5	38.6	1.00	1.20
Alaska	95.3	NA	0.96	NA
Southern Plains	42.6	29.9	1.51	2.00
Southwest	79.9	2.8	1.14	1.18
Pacific Coast	64.9	10.7	1.16	3.34
East	12.3	28.9	3.34	1.90
Urban	49.5	23.2	1.36	1.86
Rural	81.4	36.9	1.08	1.74

AI/AN decedents were significantly more likely to be classified on death certificates in CHSDA than in non-CHSDA counties

An exception in the East – likely due to small sample size

Jim MA, Arias E, Seneca DS, Hoopes MJ, Jim CC, Johnson NJ, Wiggins CL. Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area. *Am J Public Health*. 2014; 104:S295-S302.

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Method 3: Restriction to non-Hispanic population

- Modified race process increasing size of Hispanic AI/AN & API populations
  - After edits & imputations

Modified race	2000	2010
Hispanic AI/AN	↑ 39%	↑ 115%
Hispanic API	↑ 99%	↑ 152%

100 / 100,000 = 100 per 100,000

100 / 139,000 = 71.9 per 100,000

100 / 215,000 = 46.5 per 100,000

Rate decreases when:
- Numerator stays the same
- Denominator increases

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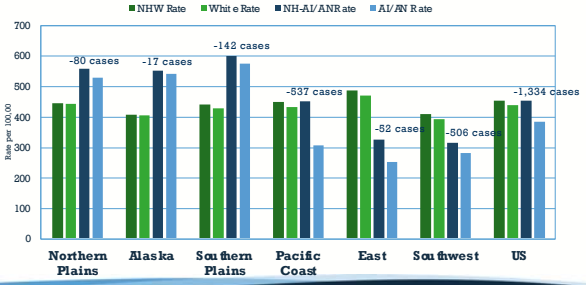
All malignant cancer sites combined, US, PRCDA, 2013-2017



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USCS AI/AN Incidence Analytic Database (USCS AIAD)

https://www.cdc.gov/cancer/uscs/about/tools/AIAN-incidence-analytic-db.htm

- Aggregated at IHS Region
  - Northern Plains
  - Alaska
  - Southern Plains
  - Pacific Coast
  - East
  - Southwest
  - US
- Race recode that incorporates IHSLink
- PRCDA county flag
- Includes data for 1999-2021 dx years
- AI/AN Data Briefs
  - https://www.cdc.gov/cancer/uscs/about/data-briefs/index.htm

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CDC Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

USCS U.S. Cancer Statistics

United States Cancer Statistics: Data Visualizations
The official federal statistics on cancer incidence and deaths, produced by the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI).

Methods to improve AI/AN cancer data	USCS Data Viz*	USCS Data Viz – AI/AN Incidence Analytic Database module**
1) IHS Linkage	Yes	Yes
2) Restrict to PRCDA counties	No	Yes
3) Restrict to non-Hispanic AI/AN	No	Yes

* https://gis.cdc.gov/Cancer/USCS/#/AtAGlance/ - State- and county-specific data for non-Hispanic American Indian and Alaska Native persons are not presented for states that opted not to present these data: Illinois, Kansas, New Jersey, New York, and North Dakota.
** https://gis.cdc.gov/Cancer/USCS/#/AIAN/ - data for all states included.

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All American Indian/Alaska Native cancer data is accurate.

True 0%

False 0%

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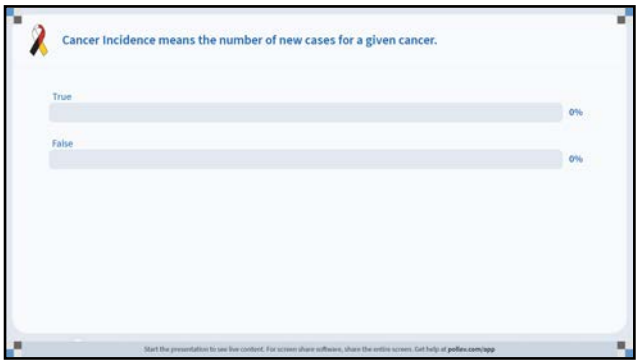

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USCS Data Visualization Tool –
AI/AN restricted to PRCDA only

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United States Cancer Statistics: Data Visualizations
American Indian and Alaska Native, Non-Hispanic restricted to PRCDA only
Rate of New Cancers in American Indian and Alaska Native, Non-Hispanic*
Click to get direct link if you want to copy webpage with your selections
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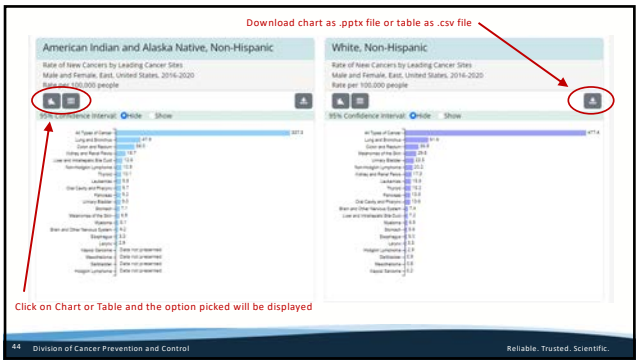
Download chart as .pptx file or table as .csv file
American Indian and Alaska Native, Non-Hispanic
White, Non-Hispanic
Click on Chart or Table and the option picked will be displayed
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American Indian and Alaska Native, Non-Hispanic, United States, 2016-2020
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USCS
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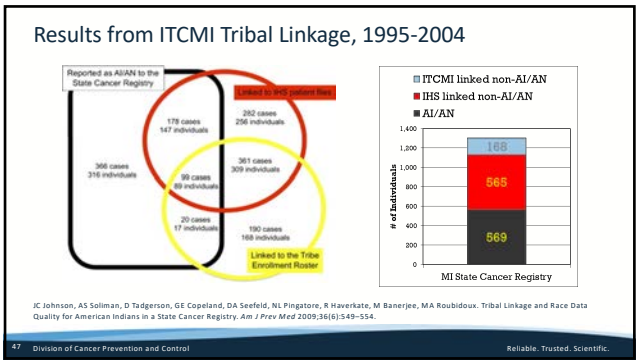
Results from ITCMI Tribal Linkage, 1995-2004
Reported as AI/AN to the State Cancer Registry
178 cases
147 individuals
282 cases
256 individuals
366 cases
316 individuals
361 cases
309 individuals
99 cases
89 individuals
20 cases
17 individuals
190 cases
168 individuals
Linked to the Tribe Enrollment Roster
ITCMI linked non-AI/AN
IHS linked non-AI/AN
AI/AN
# of Individuals
168
565
569
MI State Cancer Registry
JC Johnson, AS Soliman, D Tadgerson, GE Copeland, DA Seefeld, NL Pingatore, R Haverkate, M Banerjee, MA Roubidoux. Tribal Linkage and Race Data Quality for American Indians in a State Cancer Registry. Am J Prev Med 2009;36(6):549–554.
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Data Dissemination Strategies

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Cancer among the Navajo

https://nec.navajo-nsn.gov/Portals/0/Reports/NavajoCancerReport%2013Nov2023.pdf

- Report produced in response to professional & community concerns that cancer may be increasing among the Navajo
- 3rd report recently completed
  - 2014-2018
- Data sources:
  - Arizona Cancer Registry
  - New Mexico Tumor Registry
  - USCS AI/AN Incidence Analytic DB
  - US Mortality Data

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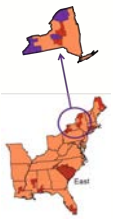
Cancer among the Haudenosaunee (People of the Longhouse)

- Utilize national datasets (USCS AIAD and USCS AMD) to provide an accurate picture of health disparities for all enrolled and non-enrolled members of the Haudenosaunee
- Provide data for modifying interventions and health systems
- Analysis restricted to counties that comprise the following territories:
  - Allegany
  - Cattaraugus
  - Oil Springs
  - Oneida Indian Nation
  - Onondaga
  - St. Regis Mohawk
  - Tonawanda
  - Tuscarora
- Previous publication:
  - Haring RC, Jim MA, Erwin D, Kaur J, Henry WAE, Haring ML, Seneca DS. Mortality disparities: A Comparison with the Haudenosaunee in New York State. *Cancer Health Disparities*. 2018 ;2:e1-e20
- Upcoming Publication
  - Breast and Prostate Cancer Incidence
- Collaborator- Roswell Park Comprehensive Cancer Center: Center for Indigenous Health Research



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USCS Data Briefs

Publications That Use U.S. Cancer Statistics Data | CDC
https://www.cdc.gov/cancer/uscs/about/publications.htm

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AI/AN Cancer Data 101

- Webinar for Tribal Epi Centers
- Topics covered:
  - IHS-NPCR/SEER Linkage
    - Race recode
    - Cancer site groupings
    - Cancer data sources
  - AI/AN Cancer Incidence
  - IHS-NDI Linkage
    - Update

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Manuscripts (planned and in-process)

https://www.cdc.gov/cancer/uscs/about/publications.htm

- Kidney cancer (accepted by not published yet)
- USCS AI/AN Mortality Database
  - Leading causes of death, 2020
    - IHS Region
    - IHS Area
    - Urban
  - COVID-19, 2020
    - IHS Region
    - IHS Area
    - Urban

https://nccd.cdc.gov/DCPC_SCS/index.aspx#!/results?titleMatches=American%20Indian&titleMatchType=exact&sort=publicationYear&dir=true

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Supplements

- IHS-NDI linkage and IHS-NPCR/SEER linkage (cancer papers)
- https://ajph.aphapublications.org/toc/ajph/104/S3

- IHS-NPCR/SEER Linkage
- https://acsjournals.onlinelibrary.wiley.com/doi/full/10.1002/cncr.23729

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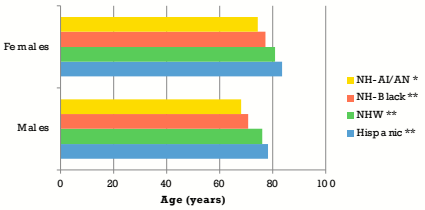
Life expectancy at birth by sex in CHSDA counties, 2007-2009



* 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.

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Top 10 cancer causes of cancer death for AI/AN Males by IHS Region: CHSDA, 1999-2009

#	Northern Plains	Alaska	Southern Plains	Southwest	Pacific Coast	East	US
-	All cancers 1.51*	All cancers 1.44*	All cancers 1.31*	All cancers 0.79*	All cancers 1.05	All cancers 0.83*	All cancers 1.11*
1	Lung (1) 1.71*	Lung (1) 1.43*	Lung (1) 1.22*	Lung (1) 0.34*	Lung (1) 0.98	Lung (1) 0.82*	Lung (1) 1.01
2	Colorectal (3) 1.84*	Colorectal (2) 2.12*	Colorectal (2) 1.48*	Prostate (2) 0.83*	Colorectal (3) 1.41*	Colorectal (3) 0.87	Colorectal (3) 1.26*
3	Prostate (2) 1.55*	Stomach (11) 4.43*	Prostate (3) 1.30*	Colorectal (3) 0.66*	Prostate (2) 0.98	Prostate (2) 0.98	Prostate (2) 1.09*
4	Liver (10) 2.75*	Pancreas (4) 1.72*	Kidney (8) 2.11*	Stomach (14) 4.31*	Liver (9) 2.11*	Liver (8) 1.38	Liver (8) 2.12*
5	Kidney (8) 2.08*	Prostate (3) 0.93	Liver (9) 2.18*	Liver (8) 2.19*	Pancreas (4) 1.02	Stomach (11) 1.50	Kidney (10) 1.92*
6	Pancreas (4) 0.94	Liver (7) 2.12*	Pancreas (4) 0.95	Kidney (10) 2.33*	Esophagus (6) 1.15	Pancreas (4) 0.50*	Pancreas (4) 0.96
7	Esophagus (6) 1.23	Esophagus (6) 1.66*	Esophagus (6) 1.44*	Pancreas (4) 1.01	Kidney (10) 1.23	Kidney (9) 1.13	Stomach (14) 2.49*
8	Stomach (13) 2.44*	Kidney (10) 1.58*	NHL (5) 1.20	NHL (5) 0.66*	NHL (5) 0.79	Urinary Bladder (2) 0.86	Esophagus (6) 1.06
9	NHL (5) 0.96	[illegible]	Stomach (14) 1.92*	Esophagus (6) 0.76*	Stomach (14) 1.57*	Esophagus (6) 0.58*	NHL (5) 0.82*
10	AML (11) 0.93	NHL (5) 0.46*	Brain (10) 0.93	Myeloma (12) 1.38*	Brain (8) 0.69*	NHL (5) 0.45*	Brain (9) 0.63*

* Statistically significant

White MC, Espey DK, Swan J, Wiggins CL, Eheman C, Kaur JS. Disparities in Cancer Mortality and Incidence Among American Indians and Alaska Natives in the United States. *Am J Public Health*. 2014;104:S377-S387.

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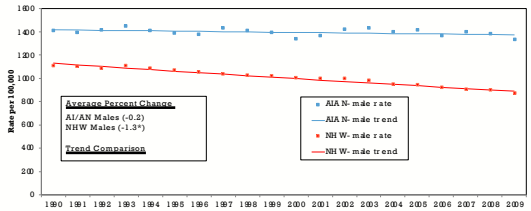
Annual age-adjusted all cause death rates for AI/AN and NHW, Males, CHSDA counties, Joinpoint trend lines, 1990-2009



*Annual Percent Change in rates during 1990-2009 is significant at alpha=0.05

†Difference in Average Annual Percent Change between AI/AN and NHW during last 10 years (2000-2009) is significant at alpha=0.05

White MC, Espey DK, Swan J, Wiggins CL, Eheman C, Kaur JS. Disparities in Cancer Mortality and Incidence Among American Indians and Alaska Natives in the United States. *Am J Public Health*. 2014;104:S377-S387.

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Top 10 cancer causes of cancer death for AI/AN Females by IHS Region: CHSDA, 1999-2009

#	Northern Plains	Alaska	Southern Plains	Southwest	Pacific Coast	East	US
-	All cancers 1.60*	All cancers 1.50*	All cancers 1.36*	All cancers 0.84*	All cancers 1.18*	All cancers 0.88*	All cancers 1.17*
1	Lung (1) 2.11*	Lung (1) 1.38*	Lung (1) 1.34*	Breast (2) 0.64*	Lung (1) 1.18*	Lung (1) 0.83*	Lung (1) 1.06*
2	Breast (2) 1.13	Breast (2) 1.26*	Breast (2) 1.18*	Lung (1) 0.28*	Breast (2) 0.88	Breast (2) 0.71*	Breast (2) 0.92*
3	Colorectal (3) 1.53*	Colorectal (3) 2.43*	Colorectal (3) 1.64*	Colorectal (3) 0.72*	Colorectal (3) 1.38*	Colorectal (3) 1.30*	Colorectal (3) 1.31*
4	Pancreas (4) 1.14	Stomach (17) 7.11*	Pancreas (4) 1.27*	Ovary (5) 1.10	Pancreas (5) 1.23*	Pancreas (4) 0.93	Pancreas (4) 1.08
5	Cervix (20) 4.15*	Pancreas (4) 1.06	Ovary (5) 1.15	Pancreas (4) 1.02	Ovary (4) 1.01	Ovary (5) 0.61*	Ovary (5) 0.98
6	Ovary (5) 0.92	Liver (10) 3.14*	NHL (6) 1.40*	Liver (9) 3.14*	Liver (10) 2.84*	Liver (10) 1.67	Liver (10) 2.84*
7	Liver (12) 3.25*	Ovary (5) 1.08	Liver (11) 2.54*	Stomach (15) 3.61*	NHL (6) 1.21	Kidney (13) 1.56	NHL (6) 1.07
8	Stomach (16) 3.28*	[illegible]	Kidney (9) 1.81*	Kidney (11) 2.36*	[illegible] 1.57*	Cervix (19) 1.69	Stomach (14) 2.77*
9	Kidney (9) 2.04*	Kidney (12) 1.91	Cervix (13) 1.58*	NHL (6) 0.91	Stomach (16) 2.47*	[illegible] 1.42*	Kidney (12) 2.02*
10	NHL (6) 1.11	NHL (6) 0.70	[illegible] 1.42*	Cervix (17) 2.05*	Kidney (12) 1.78*	Myeloma (9) 1.42*	Cervix (19) 2.11*

* Statistically significant

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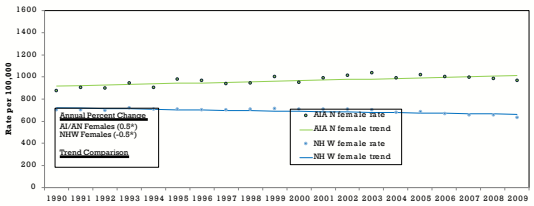
Annual age-adjusted all cause death rates for AI/AN and NHW, Females, CHSDA counties, Joinpoint trend lines, 1990-2009



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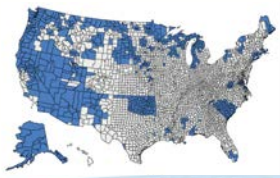
Conclusion

- Racial misclassification can be addressed through data linkages to provide better data
- Limitation
  - IHS only covers 53.5% of the AI/AN population



- Tribal linkages

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Thank you!
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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.

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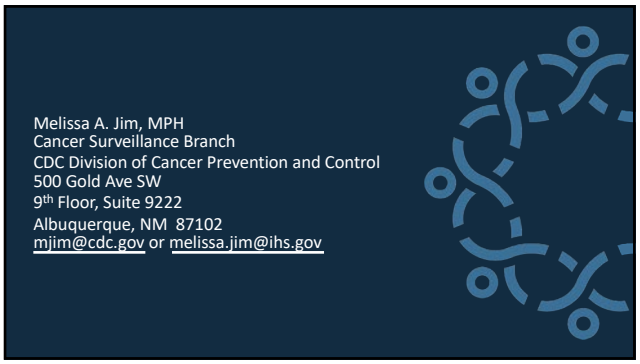
Melissa A. Jim, MPH
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500 Gold Ave SW
9th Floor, Suite 9222
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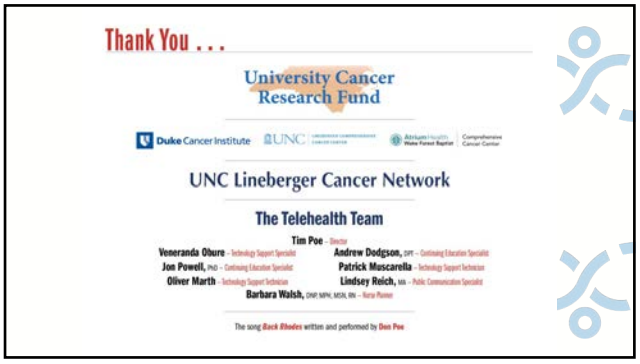
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The song Back Rhodes written and performed by Don Poe

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Questions/Comments?
Nobody has responded yet.
Hang tight! Responses are coming in.

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