Cancer and Mortality Surveillance for American Indian and Alaska Native Populations

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Epidemiologist

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Navajo Nation

- Approximately 27,000 square miles
- Larger than 10 of the 50 states in the US (about the size of West Virginia)
- Population density: 7.2 persons per sq mile
- Race
  - 96% Navajo or other American Indian
  - 4% White
AI/AN Population

- **2010 Census**
  - 5.2 million – AI/AN in combination with other races
  - 2.9 million – AI/AN only
  - 57% of the AI/AN population resides in urban areas

<table>
<thead>
<tr>
<th></th>
<th>AI/AN</th>
<th>U.S. All Races</th>
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</thead>
<tbody>
<tr>
<td><strong>Median Age</strong></td>
<td>29 yrs</td>
<td>37.2 yrs</td>
</tr>
<tr>
<td><strong>Median Income</strong></td>
<td>$25,850</td>
<td>$32,150</td>
</tr>
<tr>
<td><strong>2000</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Median Income</strong></td>
<td>$25,850</td>
<td>$32,150</td>
</tr>
<tr>
<td><strong>2000</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Poverty Rate</strong></td>
<td>28.8%</td>
<td>15.5%</td>
</tr>
<tr>
<td><strong>High School</strong></td>
<td>70.9%</td>
<td>80.4%</td>
</tr>
<tr>
<td><strong>2000</strong></td>
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</table>
Map of INDIAN COUNTRY

Source: Dean Seneca, OSTLTS, CDC
AI/AN

- Are eligible to participate in all public, private, and state health programs available to the general population
- Have treaty rights to federal health care services though the Department of Health and Human Services

Source: http://www.ihs.gov/PublicAffairs/IHSBrochure/BasisHlthSvc
s.asp
Indian Health Service (IHS)

- Provides a comprehensive health service delivery system for approximately 2.2 million AI/AN who belong to 566 federally recognized tribes in 35 states.
- Principal federal health care provider and health advocate for Indian people.

- *Its Goal*... to assure that comprehensive, culturally acceptable personal and public health services are available and accessible to American Indian and Alaska Native people.
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)
Results from IHS Linkage: NPCR & SEER

- Use “improved” data to report cancer burden of AI/AN
  - Cancer Supplement: An Update on Cancer in American Indians and Alaska Natives, 1999-2004
  - AJPH AI/AN Mortality Supplement, 1990-2009
    - [http://ajph.aphapublications.org/toc/ajph/104/S3](http://ajph.aphapublications.org/toc/ajph/104/S3)
Alaska
Hawaii
Pacific Coast
Southern Plains
Southwest

AI/AN Cancer Supplement, 1999-2004

Northern Plains

State

Included
Excluded

CHSDA* County

*Contract Health Service Delivery Areas
Number of individuals identified by IHS linkage for 2006 data submission

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<tr>
<th>Region</th>
<th>Pre-link</th>
<th>Post-link</th>
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<tr>
<td>East</td>
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<td>1,129</td>
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<tr>
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</table>
AI/AN cancer rates for all sites by IHS region, compared to US NHW, both sexes, 1999-2004

Rate per 100,000

- Alaska: Pre-link 511.0, Post-link 538.1
- East: Pre-link 141.1, Post-link 286.1
- Northern Plains: Pre-link 358.3, Post-link 201.6
- Southern Plains: Pre-link 492.6, Post-link 160.8
- Pacific Coast: Pre-link 204.0, Post-link 232.9
- Southwest: Pre-link 475.9
- US NHW: Pre-link 511.0
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

- **Red**: Linkage completed
- **Data rec’d – linkage in progress**: Data recorded, linkage in progress
- **Interest expressed – data not rec’d**: Interest expressed, data not recorded
- **Not participating**
Linkage of death records from State VS with administrative records from the Indian Health Service (1990-2003)
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.

NOTE: AIAN is American Indian or Alaska Native; API is Asian or Pacific Islander.
SOURCE: National Longitudinal Mortality Study.
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 AI/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

AI/AN Mortality Database (AMD: 1990-2009)
Al/AN mortality rates per 100,000 for All Causes, both sexes, CHSDA counties, 1999-2009

Pre-link
Post-link

- Northern Plains
- Alaska
- Southern Plains
- Southwest
- Pacific Coast
- East
- US NHW
Life Expectancy at Birth by Sex in CHSDA Counties

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<tr>
<th>Age (years)</th>
<th>NH-AI/AN*</th>
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<th>Hispanic**</th>
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<td>20</td>
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<td>60</td>
<td>68.0</td>
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<td>80</td>
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<td><strong>All causes 1.67</strong>*</td>
<td><strong>All causes 1.42</strong>*</td>
<td><strong>All causes 1.35</strong>*</td>
<td><strong>All causes 1.33</strong>*</td>
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<td><strong>All causes 1.46</strong>*</td>
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<td>Heart disease (1) 1.58*</td>
<td>Cancer (1) 1.44*</td>
<td>Heart disease (1) 1.33*</td>
<td>UI (4) 2.83*</td>
<td>Heart disease (1) 1.23*</td>
<td>Heart disease (1) 0.90*</td>
<td>Heart disease (1) 1.22*</td>
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<tr>
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<td>UI (3) 2.52*</td>
<td>Cancer (2) 1.31*</td>
<td>Heart disease (1) 0.94*</td>
<td>Cancer (2) 1.05</td>
<td>Cancer (2) 0.83*</td>
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<tr>
<td>3</td>
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<td>Heart disease (2) 1.29*</td>
<td>UI (4) 1.73*</td>
<td>Cancer (2) 0.79*</td>
<td>UI (4) 2.03*</td>
<td>UI (4) 1.39*</td>
<td>UI (4) 2.54*</td>
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<td>4</td>
<td>Diabetes (6) 4.18*</td>
<td>Suicide (4) 2.34*</td>
<td>Diabetes (6) 3.01*</td>
<td>CLD (10) 4.74*</td>
<td>CLD (10) 3.33*</td>
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<td>Diabetes (8) 3.91*</td>
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<td>Stroke (5) 1.13</td>
<td>CLD (11) 3.88*</td>
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<tr>
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<td>Suicide (7) 1.98*</td>
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<td>Suicide (5) 1.25*</td>
<td>Suicide (6) 1.08*</td>
<td>Diabetes (6) 2.43*</td>
<td>CLD (11) 2.38*</td>
<td>Suicide (7) 1.49*</td>
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<tr>
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<td>CLRD (11) 2.87*</td>
<td>Homicide (18) 4.51*</td>
<td>Stroke (5) 1.14*</td>
<td>CLRD (3) 0.69*</td>
<td>CLRD (3) 1.09*</td>
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<tr>
<td>8</td>
<td>Stroke (5) 1.30*</td>
<td>Flu/Pneumo (11) 3.10*</td>
<td>Stroke (8) 1.25*</td>
<td>Flu/Pneumo (7) 2.41*</td>
<td>Suicide (8) 1.19*</td>
<td>Kidney disease (9) 1.27</td>
<td>Stroke (5) 1.20*</td>
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<tr>
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<td>Homicide (21) 9.79*</td>
<td>Diabetes (7) 1.07</td>
<td>Homicide (7) 1.42*</td>
<td>Stroke (5) 1.06</td>
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<td>Homicide (21) 4.85*</td>
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<td>Flu/Pneumo (8) 2.19*</td>
<td>CLD (8) 1.28</td>
<td>Kidney disease (10) 1.93*</td>
<td>Kidney disease (11) 2.01*</td>
<td>Flu/Pneumo (9) 1.26*</td>
<td>Flu/Pneumo (7) 1.09</td>
<td>Flu/Pneumo (8) 1.90*</td>
</tr>
</tbody>
</table>

* Statistically significant

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

Average Percent Change
AI/AN Males (-0.2)
NHW Males (-1.3*)

Trend Comparison
Not parallel†

*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

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<tbody>
<tr>
<td>1</td>
<td>Cancer (2) 1.60*</td>
<td>Cancer (1) 1.50*</td>
<td>Heart disease (1) 1.27*</td>
<td>Cancer (2) 0.84*</td>
<td>Cancer (1) 1.23*</td>
<td>Heart disease (1) 1.06</td>
<td>Cancer (2) 1.17*</td>
</tr>
<tr>
<td>2</td>
<td>Heart disease (1) 1.59*</td>
<td>Heart disease (2) 1.35*</td>
<td>Cancer (2) 1.36*</td>
<td>Heart disease (1) 0.88*</td>
<td>Heart disease (2) 1.05</td>
<td>Cancer (2) 0.81*</td>
<td>Heart disease (1) 1.22*</td>
</tr>
<tr>
<td>3</td>
<td>UI (6) 3.14*</td>
<td>UI (5) 2.62*</td>
<td>UI (6) 1.78*</td>
<td>UI (6) 2.11*</td>
<td>UI (4) 2.03*</td>
<td>Diabetes (8) 3.77*</td>
<td>UI (6) 2.43*</td>
</tr>
<tr>
<td>4</td>
<td>Diabetes (7) 5.11*</td>
<td>Stroke (3) 1.47*</td>
<td>Diabetes (8) 3.40*</td>
<td>Diabetes (8) 5.19*</td>
<td>Stroke (10) 3.33*</td>
<td>UI (6) 1.58*</td>
<td>Diabetes (8) 4.04*</td>
</tr>
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<td>CLD (13) 10.20*</td>
<td>CLRD (4) 1.58*</td>
<td>Stroke (3) 1.22*</td>
<td>CLD (12) 5.75*</td>
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<td>Stroke (3) 1.08</td>
<td>Stroke (3) 1.20*</td>
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<tr>
<td>6</td>
<td>CLRD (4) 1.92*</td>
<td>CLD (10) 4.36*</td>
<td>CLRD (4) 1.02</td>
<td>Flu/Pneumo (7) 2.38*</td>
<td>Diabetes (6) 2.43*</td>
<td>CLRD (4) 0.81*</td>
<td>CLD (12) 5.36*</td>
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<tr>
<td>7</td>
<td>Stroke (3) 1.31*</td>
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<td>Flu/Pneumo (7) 1.01</td>
<td>Septicemia (10) 2.38*</td>
<td></td>
</tr>
</tbody>
</table>

* Statistically significant

Annual age-adjusted all cause death rates for AI/AN and NHW, Females, 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

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<th>Pacific Coast</th>
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<tbody>
<tr>
<td>1</td>
<td>All cancers 1.51*</td>
<td>All cancers 1.44*</td>
<td>All cancers 1.31*</td>
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* Statistically significant


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<td>1.60*</td>
<td>All cancers</td>
<td>1.36*</td>
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<td>1.18*</td>
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<td>(1.38*)</td>
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<td>(0.83*)</td>
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<td>Breast (2)</td>
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* Statistically significant

IHS-NDI Linkage Results

- Can be shared with:
  - Cancer registries
    - Approved NDI supplemental confidentiality agreement for this project (Y9-0033)
    - NDI date of death will be added to MF3 file after IHS Linkage
  - State vital statistics offices
    - State vital registrars can request the death certificate number and year of death for decedents from their state that linked to IHS from the NCHS Division of Vital Statistics Director
    - Death certificate number, year of death, and state of death will be sent to the designee named by the state registrar
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.

Update on Cancer Among the Navajo, 2005-2013

- 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 (Diné)
  - ABQ Area SW Tribal Epi Center
    - Dornell Pete, MPH (Diné)
  - IHS Navajo Area
    - Christine Benally, MPH (Diné)
  - NM Department of Health
    - Sam Swift, MPH
  - New Mexico Tumor Registry (SEER)
    - Chuck Wiggins, PhD
  - Arizona Cancer Registry (NPCR)
    - Tim Flood, MD
    - Chris Newton, MPA
  - CDC DCPC
    - Melissa A. Jim, MPH (Diné)
Update on Cancer Among the Navajo Data Sources

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

- Mortality data
    - Very little difference so opted to use US Mortality data available via SEER*Stat – data is current
  - Navajo-proxy
    - Restrict analyses to 6 counties that comprise most of Navajo Nation
      - 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)
  - Dean S. Seneca, MPH, MCURP (Seneca)

- 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

- Goal
  - Utilize AMD (1990-2009) 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)

- AMD 1999-2009
- Analyses restricted to counties that comprise 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.

Tribal Linkages

- Inter-Tribal Council of Michigan (ITCMI)
  - Link tribal enrollment data with the Michigan Cancer Surveillance System to produce tribal cancer summaries
  - Linkage training to ITCMI employees/students to build capacity to pursue tribal data linkages

- 3 MI tribal linkages completed
  - 1995-2004 diagnosis years
    - Tribe A
  - 1995-2008 diagnosis years
    - Tribe B & Tribe C

- Tribal linkage expanded in June 2015 for Tribe A
  - Update cancer data to 2012
  - Live birth data
  - Death certificate data
Results from ITCMI Tribal Linkage, 1995-2004

[Diagram showing the number of individuals reported as AI/AN to the State Cancer Registry, linked to IHS patient files, and linked to the Tribe Enrollment Roster.]

- 178 cases, 147 individuals (ITCMI linked non-AI/AN)
- 282 cases, 256 individuals (IHS linked non-AI/AN)
- 99 cases, 89 individuals (AI/AN)
- 20 cases, 17 individuals (non-AI/AN)
- 190 cases, 168 individuals (AI/AN)

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