Who Counts? Racial Misclassification and American Indians/Alaska Natives

Adrian E. Dominguez, Scientific Director

June 14, 2019
Let us begin in a good way...
Agenda

Indigenous Data Sovereignty

Urban Indian Health Institute

Data Challenges

Data Misclassification

Reclaiming Health & Wellness
Indigenous Data Sovereignty

The right to govern the collection, ownership and application of one’s own data
The Urban Indian Health Institute

- One of 12 IHS Tribal Epidemiology Centers (TECs), and a division of the Seattle Indian Health Board
- Serves urban American Indians and Alaska Natives (AI/AN) since 2000
- UIHI serves to improve the health of AI/AN by:
  - Identifying & understanding health disparities and resiliency
  - Strengthening public health capacity
  - Disease surveillance and disease prevention
  - Health promotion and disease prevention grounded in indigenous methodologies
Tribal Epidemiology Centers

Urban Indian Health Institute

Northwest

Rocky Mountain

Northern Plains

Great Lakes

Oklahoma Area

United South & Eastern Tribes

Alaska

Inter-Tribal Council Of Arizona, Inc.

California

Navajo

Albuquerque Area Southwest
The Urban Indian Health Network
Decolonizing Data

- Indigenous Methodologies
- Indigenous Epidemiology
- Indigenous Research
- Cultural Rigor
Decolonizing Research
5.2 million
American Indians and Alaska Natives alone or in combination with other races

78%
of American Indians and Alaska Natives live off reservation

71%
of American Indians and Alaska Native live in urban areas

22%
of American Indians and Alaska Natives live on reservations

2010 U.S. Census; U.S. Census Bureau
AI/AN Data Challenges

Racial misclassification

Biomedical-epidemiological model

Limited sources that collect both race (AI/AN) and geography (urban)

Collapsing racial data into ‘other’

Variability in collection, analysis, and presentation of data

High rates of missing data

Suppression of small numbers

Lack of cultural relevance
<table>
<thead>
<tr>
<th>Small Population</th>
<th>Limited Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.2 million American Indians and Alaska Natives (AI/AN) in the United States</td>
<td>Limited data sets contain both race/ethnicity data and geographic data</td>
</tr>
<tr>
<td>Stratification for health outcomes, demographics, geography, etc. further reduce sample size</td>
<td>Public health departments only provide data on a state-level</td>
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<tr>
<td></td>
<td>Difficult to identify variability in population health linked to geographic context</td>
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</table>
Challenges of Westernized Systems

**Biological-Epidemiological Model**
- Guides federally funded research paradigm
- Requires researchers to justify studies by using evidence-based practices and westernized paradigms
- Often results in approaches insufficient to understand health status and wellbeing of indigenous communities

**Lack of Cultural Relevance**
- Most data collection tools are not culturally-adapted
- Tools lack questions that hold resonance for native communities
- Results inadequate to fully inform policy and programs in native communities
Collapsing Racial Data into “Other”

- Racial groups with small numbers collapsed into “other” catch-all groups
- Common in dissemination of data sets
- Reporting of multi-racial identified individuals as a single homogenized “multi-racial” category

Suppression of Small Numbers

- A standard epidemiologic practice
- Done out of concern for protected health information
- Done because small samples often yield statistically insignificant results
- Harmful when applied without question or consideration of alternate strategies
Variability in Data Governance and Presentation

- Range of practices for data collection, analysis and presentation
- Need for greater transparency and documentation about methodological choices
- More exploration of implications

High Rates of Missing Data

- Race/ethnicity data is often missing
- Health-related fields are often missing or incorrectly coded
- Data is excluded from analysis
Misclassification masks the actual AI/AN population size:

- Tribe formerly ‘recognized’
- Use of Spanish surnames to determine race
- Self-identification with multiple races
- Changes to tribal enrollment policies
- ‘AI/AN’ not a response category in surveys or records
- Inconsistent definition of AI/AN
- Imprecise definition of AI/AN
- Changing self-identification
- Tribe not federally recognized
- Racism
- Subjective observation of data collector
Correcting for Racial Misclassification

- Conduct specific research on AI/AN population/community
- Support linkage projects
- Report limitations of work

Improving Data & Enhancing Access - Northwest (IDEA-NW)
- UIHI collaboration with Northwest Portland Area Indian Health Board
- Compares public health datasets with tribal enrollment lists
- Identifies cases of racial misclassification and adjusts counts
## Linkage Project – Washington State

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<tr>
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<tbody>
<tr>
<td>Washington</td>
<td>Cases sent for linkage</td>
<td>Matches</td>
<td>Number (%) misclassified race among matches</td>
<td>AI/AN in database prior to linkage</td>
</tr>
<tr>
<td>CHAR, 2010</td>
<td>746,029</td>
<td>8,043</td>
<td>3,937</td>
<td>49.0%</td>
</tr>
<tr>
<td>CHAR, 2011</td>
<td>738,406</td>
<td>8,144</td>
<td>3,660</td>
<td>44.9%</td>
</tr>
<tr>
<td>Deaths, 2010</td>
<td>48,259</td>
<td>588</td>
<td>82</td>
<td>13.9%</td>
</tr>
<tr>
<td>Trauma, 2005-2009</td>
<td>111,825</td>
<td>2,254</td>
<td>1,265</td>
<td>56.1%</td>
</tr>
</tbody>
</table>

IDEA NW: Washington CHARS Linkage

Washington Comprehensive Hospital Abstract Reporting System (CHARS) Hospital Discharges, 2012-2013

Age-adjusted hospital discharge rate (per 100,000)

- Prelink AI/AN: 6919.7
- Postlink AI/AN: 9102.6
- Postlink NHW: 6844.4

Comprehensive Hospital Abstract Reporting System (CHARS) Hospital Discharges, Washington State, 2014:

IDEA NW: Washington Mortality Linkage

Washington State Mortality, 2014

Age-adjusted mortality rate (deaths per 100,000)

<table>
<thead>
<tr>
<th>Prelink AI/AN</th>
<th>Postlink AI/AN</th>
<th>Postlink NHW</th>
</tr>
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<tbody>
<tr>
<td>1046.9</td>
<td>1148.3</td>
<td>686.3</td>
</tr>
</tbody>
</table>

# IDEA NW: Washington Mortality Linkage

### Leading Causes of Death for Washington AI/AN, 2009-2013:

<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause of Death</th>
<th>Pre-linkage AI/AN</th>
<th>Post-linkage AI/AN</th>
<th>Change in # of Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Major Cardiovascular Diseases</td>
<td>1,148</td>
<td>1,261</td>
<td>+113</td>
</tr>
<tr>
<td>2</td>
<td>Malignant Neoplasms</td>
<td>902</td>
<td>980</td>
<td>+78</td>
</tr>
<tr>
<td>3</td>
<td>Unintentional Injury or Accident</td>
<td>543</td>
<td>580</td>
<td>+37</td>
</tr>
<tr>
<td>4</td>
<td>Chronic Liver Disease and Cirrhosis</td>
<td>250</td>
<td>275</td>
<td>+25</td>
</tr>
<tr>
<td>5</td>
<td>Chronic Lower Respiratory Diseases</td>
<td>231</td>
<td>260</td>
<td>+29</td>
</tr>
<tr>
<td>6</td>
<td>Diabetes Mellitus</td>
<td>206</td>
<td>224</td>
<td>+18</td>
</tr>
<tr>
<td>7</td>
<td>Suicide</td>
<td>147</td>
<td>166</td>
<td>+19</td>
</tr>
<tr>
<td>8</td>
<td>Alzheimer's Disease</td>
<td>98</td>
<td>111</td>
<td>+13</td>
</tr>
<tr>
<td>9</td>
<td>Influenza and Pneumonia</td>
<td>69</td>
<td>73</td>
<td>+4</td>
</tr>
<tr>
<td>10</td>
<td>Other Respiratory Diseases</td>
<td>68</td>
<td>73</td>
<td>+5</td>
</tr>
<tr>
<td><strong>Total Deaths</strong></td>
<td><strong>6,759</strong></td>
<td><strong>7,485</strong></td>
<td><strong>+726</strong></td>
<td></td>
</tr>
</tbody>
</table>

Epidemiologic Strategies to Increase Sample Size

- Aggregate data across time
- Use weighted sampling
- Oversample
- Limit stratification
- Use data from linkage projects
- Report limitations of work
Example program recommendations:

- Advocate for how data is collected
- Collect culturally relevant information
- Conduct mixed-methods research
- Recognize that “not statistically significant” does not mean a problem does not exist
- Report strength-based results
Reclaim narratives of indigenous health and well-being
Questions?
Resources

Tribal Nations & the United States: An Introduction (National Congress of American Indians)

Broken Promises: Continuing Federal Funding Shortfall for Native Americans (U.S. Commission on Civil Rights)

The American Indian and Alaska Native Population: 2010 Census Briefs (U.S. Census Bureau)


Urban Indian Health Data Dashboard (Urban Indian Health Institute)