Record linkages to improve AI/AN cancer data in the Northwest

Improving Data & Enhancing Access (IDEA-NW) Project
Northwest Tribal EpiCenter

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Public data sources do not always report statistics for AI/AN specifically

- Region- or tribe-specific data can be harder to come by

When AI/AN data are available, often incomplete or skewed due to racial misclassification

- In general, AI/AN misclassified as another race (in NW, usually White), rather than the other way around
- AI/AN racially misclassified more frequently than other races
- Net result: Surveillance data underestimated for AI/AN
NW Tribal Registry =
Portland Area IHS registration file +
Seattle Indian Health Board +
(Partnering tribes’ enrollment)

- LinkPlus software (CDC)
- Race field examined for all matched cases
  - If coded as something other than AI/AN, considered racially misclassified
- Misclassified AI/AN cases reported back to cancer registry for correction
Approach

State cancer registry

De-identified data for analysis

Improved race data reported back to state

Tribal & urban partners

Local-level data disseminated to tribes

8/17/2011
Northwest Portland Area Indian Health Board
## Misclassification results

### Misclassification identified through 2010 cancer linkages (dx years 2008-2009)

<table>
<thead>
<tr>
<th>CDRI</th>
<th>OSCaR</th>
<th>WSCR</th>
</tr>
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<tbody>
<tr>
<td>% of newly matched cases coded as non-AIAN</td>
<td>35.3%</td>
<td>24.2%</td>
</tr>
</tbody>
</table>

- 77.4% coded as White
- 18.6% had unknown or missing race
- Cancer incidence rates significantly underestimated if not corrected

8/17/2011
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Impact of record linkage on AI/AN invasive cancer rates, 2002-2006

* Significantly greater than pre-linkage rate
† 2002-2005
• Urban AI/AN more likely to be misclassified
  ▪ Proximity from reservation
  ▪ Lower levels of AI/AN ancestry
• Seattle Indian Health Board
  ▪ Multi-service community health center targeting urban AI/AN, largely King County residents
  ▪ Race is self-reported, not required to be AI/AN for services
  ▪ Urban Indian Health Institute
### Characteristics of misclassified AI/AN cases by cancer registry

<table>
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<tbody>
<tr>
<td>n(%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total misclassified</td>
<td>303</td>
<td>578</td>
</tr>
<tr>
<td>Race 1 as coded</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>272 (89.8)</td>
<td>489 (84.6)</td>
</tr>
<tr>
<td>Black</td>
<td>5 (1.7)</td>
<td>15 (2.6)</td>
</tr>
<tr>
<td>Unknown</td>
<td>15 (5.0)</td>
<td>60 (10.4)</td>
</tr>
<tr>
<td>All others combined</td>
<td>11 (3.6)</td>
<td>14 (2.4)</td>
</tr>
<tr>
<td>Linkage source</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NTR alone</td>
<td>189 (62.4)</td>
<td>352 (60.9)</td>
</tr>
<tr>
<td>SIHB alone</td>
<td>104 (34.3)</td>
<td>203 (35.1)</td>
</tr>
<tr>
<td>Both</td>
<td>10 (3.3)</td>
<td>23 (4.0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>135 (44.6)</td>
<td>189 (32.7)</td>
</tr>
<tr>
<td>Female</td>
<td>168 (55.5)</td>
<td>389 (67.3)</td>
</tr>
</tbody>
</table>

*Note: AI/AN = American Indian/Alaska Native, NTR = Northwest Tribal Registry, SIHB = Seattle Indian Health Board, SEER = Surveillance Epidemiology and End Results*
**Results: UIHI partnership**

**Age-Adjusted Incidence Rates, AI/AN all cancer sites, 2002-2007**

excluding non-urinary bladder *in situ* cases

![Bar chart showing incidence rates for different populations](chart.png)

- **Incidence rate (per 100,000)** with 95% confidence intervals

**Population**

- Washington†
- 13 SEER counties
- King
- Pierce
- Snohomish

†2002-2005 only

*Significantly greater than pre-linkage rate
Tribal partnerships

- Opportunities for tribe-specific projects using enrollment or clinical registration data
  - 2 completed/in progress
  - Support data for large grant
  - A handful of other tribes have expressed interest

- Northwest Tribal Comprehensive Cancer Program
Products

- State and area-wide cancer fact sheets
- Tribal cancer profiles
  - Data analyzed at CHSDA level
  - More meaningful for some tribes than for others
- Local-level data used for:
  - Grant applications/reporting
  - Program planning
  - Health assessment
  - Response to observed cancer anomalies
- Comprehensive regional report (in progress)
- Published manuscripts
Data linkage resources

• Other EpiCenters, states looking for info on “where to start”

• Effort with CSTE Tribal Epidemiology Subcommittee
  ▪ Workshop on state-EpiCenter data sharing issues & opportunities (6/2010)

• Collection of resources developed, hosted on CSTE and NPAIHB websites
  http://www.npaihb.org/epicenter/project/linkage_resources_toolkit
Limitations

- Small numbers, unstable rate estimates
- NTR under-represents some important sub-populations
  - Urban AI/AN
- NTR can’t identify all tribe- or community-members
  - Overlapping service delivery areas make local-level reporting difficult
  - Tribe-specific projects using enrollment data address this gap
Acknowledgments

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• Urban Indian Health Institute

• Eric Vinson, Kerri Lopez, Dr. Tom Becker