Improving Cancer Surveillance and Mortality Data for AI/AN Populations

Melissa A. Jim, MPH (Diné)
Epidemiologist, Cancer Surveillance Branch
Assigned to IHS Division of Epidemiology and Disease Prevention

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Background

- Race misclassification of AI/AN occurs in cancer surveillance and vital statistics databases.

- Varies by state.

- Decreasing misclassification can improve accuracy of health indicators and program planning/resource allocation.
NPCR and SEER

* National Program of Cancer Registries (CDC)
† Surveillance, Epidemiology, and End Results Program (NCI)
Indian Health Service (IHS) Linkage

- Identify AI/AN cases misclassified as non-Native
- Link administrative records from IHS with records from central cancer registries (NPCR and SEER)
- Results are captured in “IHS Link” variable that is part of the NAACCR layout
IHS Linkage

- Link every 5 years
- Link every year
IHS Linkage

- Use “improved” data to report cancer burden of AI/AN
  - Cancer Supplement: An Update on Cancer in American Indians and Alaska Natives, 1999-2004
Alaska
Hawaii
Pacific Coast
Northern Plains
Southern Plains
Southwest
East

State
Included
Excluded
CHSDA* County
Included
Excluded

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

- **Alaska**: 70
- **East**: 1,380 (Pre-link: 1,340, Post-link: 40)
- **Northern Plains**: 1,129 (Pre-link: 1,100, Post-link: 29)
- **Southern Plains**: 3,310 (Pre-link: 3,250, Post-link: 60)
- **Pacific Coast**: 2,402 (Pre-link: 2,350, Post-link: 52)
- **Southwest**: 423 (Pre-link: 420, Post-link: 3)
AI/AN cancer rates per 100,000 for All Sites, both sexes, compared to US NHW rate, 1999-2004

- Alaska: Pre-link 511.0, Post-link 538.1
- East: Pre-link 286.1, Post-link 141.1
- Northern Plains: Pre-link 358.3, Post-link 201.6
- Southern Plains: Pre-link 492.6, Post-link 160.8
- Pacific Coast: Pre-link 312.7, Post-link 204.0
- Southwest: Pre-link 232.9, Post-link 160.8
- US NHW: Pre-link 475.9
AI/AN cancer rates per 100,000 for All Sites, both sexes, compared to US NHW rate, 2003-2008

Northern Plains  Alaska  Southern Plains  Pacific Coast  East  Southwest  NHW
Limitations

- IHS only covers 57% of the AI/AN population

- Linkage between a state cancer registry and a Bemidji Area Tribe
  - 1995-2004 diagnosis years
    - IHS identified 614 individuals that were not identified as AI/AN by the registry
    - Bemidji Area Tribe identified 242 individuals that were not identified as AI/AN by the registry OR by linkage with IHS
National Death Index (NDI)-IHS Linkage

- Link records from the National Death Index (NDI) with the Indian Health Service
  - NDI is the central index of death record information on file in state VS offices
  - Established as a resource to aid investigators with mortality ascertainment activities

- Identify AI/AN deaths misclassified as non-Native
- Use “improved” data to report cancer mortality of AI/AN
Cancer Among the Navajo

- Report was produced in response to professional & community concerns that cancer may be increasing among the Navajo

- Tribal-specific cancer report
  - Navajo Nation Tribal Epi Center
    - Dornell Pete, MPH
  - IHS Navajo Area
    - Carmelita Sorrelman, MPH
    - Susie John, MD
  - New Mexico Tumor Registry (SEER)
    - Chuck Wiggins, PhD
  - Arizona Cancer Registry (NPCR)
  - CDC Division of Cancer Prevention and Control
    - Melissa Jim, MPH
Tribal Linkages

- Inter Tribal Council of Michigan (ITCMI)

- Interested in linking tribal enrollment data with the Michigan Cancer Surveillance System to produce tribal cancer summaries

- Provide training to ITCMI employees to build capacity to pursue tribal data linkages
Conclusion

- Racial misclassification can be addressed by data linkages
- Provide better data for cancer control programs
Melissa A. Jim, MPH
Epidemiologist
Cancer Surveillance Branch
CDC Division of Cancer Prevention and Control
c/o IHS Division of Epidemiology and Disease Prevention
5300 Homestead Road NE
Albuquerque, NM 87110
mjim@cdc.gov or melissa.jim@ihs.gov
505-248-4451