PARTNERSHIPS TO IMPROVE THE QUALITY OF REPORTABLE DISEASE DATA FOR TRIBAL NATIONS IN WASHINGTON STATE

2023 TRIBAL PUBLIC HEALTH EMERGENCY PREPAREDNESS CONFERENCE

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Linkages to address misclassification of AI/AN people

Linkages with the Washington Disease Reporting System
  - Background
  - Findings

Strengths, Limitation, and Conclusions

Questions and Answers
“Closing [economic and health disparity] gaps and addressing program and policy issues is complicated by the invisibility of American Indians and Alaska Natives in their own land.

It is not clear if invisibility results from lack of data or if lack of data leads to invisibility.”

-Michelle Connolly (Blackfeet/Cree) et al, 2019, Statistical Journal of the IAOS 35(1)
AI/AN MISCLASSIFICATION

Misclassification is the incorrect recording of a person’s race in a data or surveillance system.

In the Northwest, AI/AN people are often misclassified as White.
Misclassification causes AI/AN people to be under-represented in health data, which leads to:

• Inaccurate AI/AN health data
• Artificially lowered disease burden
• Too few AI/AN cases to calculate stable disease rates and trends
• Incomplete health data for public health decision-making, emergency response, and advocacy
Since (before) 1999, NWTEC has been correcting misclassified AI/AN data through record linkages between the Northwest Tribal Registry and state health data systems.

We regularly link with:
• Birth and death records
• State Cancer Registries
• Hospital discharge data
• Communicable Disease data
• Other systems
AI/AN status data for NWTEC “Northwest Tribal Registry”

- AI/AN people seen at IHS, tribal, and urban health clinics in the Northwest
- Data obtained from the Indian Health Service with tribal approval through a resolution from NPAIHB
- Does not include any health data, just identifiers like name, address, date of birth, etc.

**LINKAGE METHODS OVERVIEW**

- Death certificates
- Hospital discharge
- Cancer registries
- Syndromic Surveillance (ESSENCE)
- STD/HIV/Communicable diseases, including COVID-19
- Childhood blood lead registry
- Birth certificates
- Trauma registries
- Violent Death Registry
Completed over 45 linkages

Linked with over 11 million records

Identified and corrected over 57,000 misclassified AI/AN records
MISCLASSIFICATION EFFECT ON MORTALITY RATES

Idaho Residents, 2013-2017

- Age-adjusted All-cause Mortality Rate: 10.4% increase
- Pre-linkage rate: 772.0 Rate per 100,000
- Post-linkage rate: 852.0 Rate per 100,000

Oregon Residents, 2014-2017

- Age-adjusted All-cause Mortality Rate: 10.9% increase
- Pre-linkage rate: 905.5 Rate per 100,000
- Post-linkage rate: 1003.9 Rate per 100,000
MISCLASSIFICATION EFFECT ON HOSPITALIZATION RATES

Age-adjusted All-cause Hospitalization Rate
Washington, 2016

AI/AN Pre-Link
6,991.0

45.7% increase

AI/AN Post-Link
10,186.7
CHRONIC HCV LINKAGE
(DIAGNOSES FROM 2007-2016)

- **Linkage Results**
  - Identified 1,594 misclassified AI/AN chronic HCV cases
  - Majority (86%) of misclassified records originally had missing/unknown race
  - Increased the total number of cases among AI/AN people by 122%
  - Increased the rate of chronic HCV diagnoses from 2007-2016 by 119%
Washington Disease Reporting System - purpose and uses

- An Electronic disease surveillance system used during outbreaks and public health emergencies to track cases.
- Conduct outbreak management and case investigation, and generate publicly reported case counts, hospitalizations and deaths.
**WDRS STRENGTHS AND LIMITATIONS**

**Strengths**

- Allow public health staff in Washington State to receive, enter, manage, process, track and analyze disease-related data.

**Limitations**

- The information in WDRS comes from various places
- Different places = different protocols

**Data quality issues**

- Data completeness of race and ethnicity information in WDRS
- Affects the usability of data for AI/AN communities in Washington
In 2018, NPAIHB and DOH conducted our first pilot linkages with Washington reportable conditions data. These linkages pre-dated the implementation of WDRS.

Fast forward to 2021: Recognizing that Covid-19 surveillance data was likely undercounting AI/AN cases in Washington State, NPAIHB and DOH began conversations about conducting regular linkages with Washington communicable disease data.
NPAIHB and DOH finalized a data sharing agreement and linkage protocol in early 2022.

DOH uses the linkage results to update race data collected in WDRS as follows:

- RACE = missing, blank, or “unknown“ → RACE = AI/AN
- RACE != missing, blank, or “unknown“ → AI/AN added to existing RACE
- Source hidden
We have linked:
- Washington COVID-19 cases from the 2020 through Q4 2022
- General Communicable Diseases cases available in WDRS
COVID-19 LINKAGE FINDINGS

- Linked with ~1.8 million confirmed and probable cases through the end of December 2022
- Identified 17,060 misclassified AI/AN cases

Correcting misclassification increased the number of AI/AN Covid-19 cases by 64%.

Source: Northwest Tribal Epidemiology Center, 2023 • Created with Datawrapper
Of the 17,060 misclassified records, **70.3%** had “Unknown” or missing data for the record’s race information, while **25.1%** were coded as White.
Linked with 25,954 confirmed and probable cases through the end of December 2022

Identified 189 misclassified AI/AN cases among 306 matched cases

Correcting misclassification increased the number of AI/AN GCD cases by 68%.

Of the 189 misclassified records, 42.9% had “Unknown” or missing data for the record’s race information, while 45.0% were coded as White.
GENERAL COMMUNICABLE DISEASES FINDINGS

Disease distribution of 306 matched cases

- Shigella toxin-producing Escherichia coli (STEC): 5%
- Seasonal Influenza: 5%
- Cryptosporidiosis: 3%
- Campylobacteriosis: 35%
- Salmonellosis: 11%
- Shigellosis: 8%
- Giardiasis: 6%
- Pertussis: 6%
- Hepatitis A: 7%
- Other: 13%
STRENGTHS AND LIMITATIONS OF WDRS DATA LINKAGES

Strengths
- Improved data for Tribes, Washington State, and TECs in our region (Northwest TEC and UIHI)
- Stronger partnerships between NWTEC and DOH for improving data quality and sharing

Limitations
- Linkages currently limited to specific modules of WDRS (Covid-19 and General Communicable Diseases)
- Linkages with the Northwest Tribal Registry may not identify all misclassified AI/AN cases
- Quarterly linkages result in a lag in updates and corrections to the race field
CONCLUSION AND PLANS FOR FUTURES

- Linkages are a powerful tool for increasing the visibility of AI/AN people in non-Tribal data systems.
- Improved AI/AN data can be to more accurately describe and monitor disease burden in AI/AN communities, assist in outbreak and emergency response, and ensure allocation of resources to Tribal and urban Indian communities.
- Hope to expand linkages to other WDRS modules, including HIV, STIs, HCV, and other conditions.
WASHINGTON DOH

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- Please contact DOHAgencyCOVID19DQEpis@doh.wa.gov for more information about this work.

NWTEC

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- Partners at Washington DOH
- For more information about our linkages and other data support for Northwest Tribes, please contact: sjoshi@npaihb.org