

# 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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NORTHWEST PORTLAND AREA  
INDIAN HEALTH BOARD  
*Indian Leadership for Indian Health*

# PRESENTATION OUTLINE

- Linkages to address misclassification of AI/AN people
- Linkages with the Washington Disease Reporting System
  - Background
  - Findings
- Strengths, Limitation, and Conclusions
- Questions and Answers

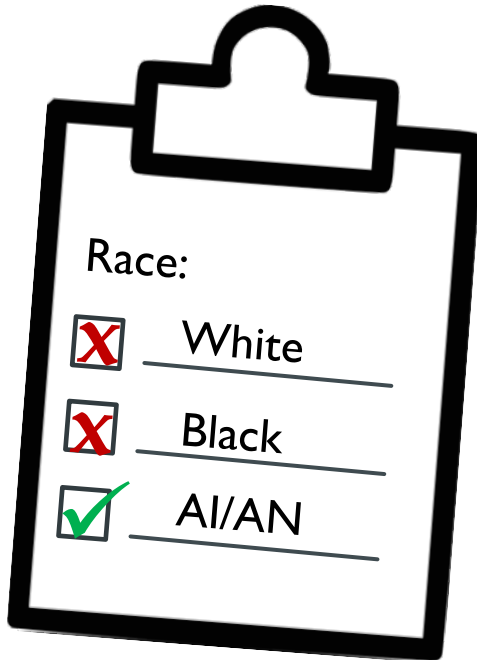
## VISIBILITY THROUGH DATA

“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.

# AI/AN MISCLASSIFICATION

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



# RECORD LINKAGES

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

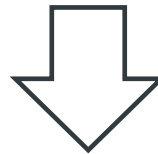


# LINKAGE METHODS OVERVIEW

## 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.

Northwest  
Tribal  
Registry



Corrected  
Data

Health  
data

- 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

# LINKAGES: 2018-2023



Completed over 45 linkages

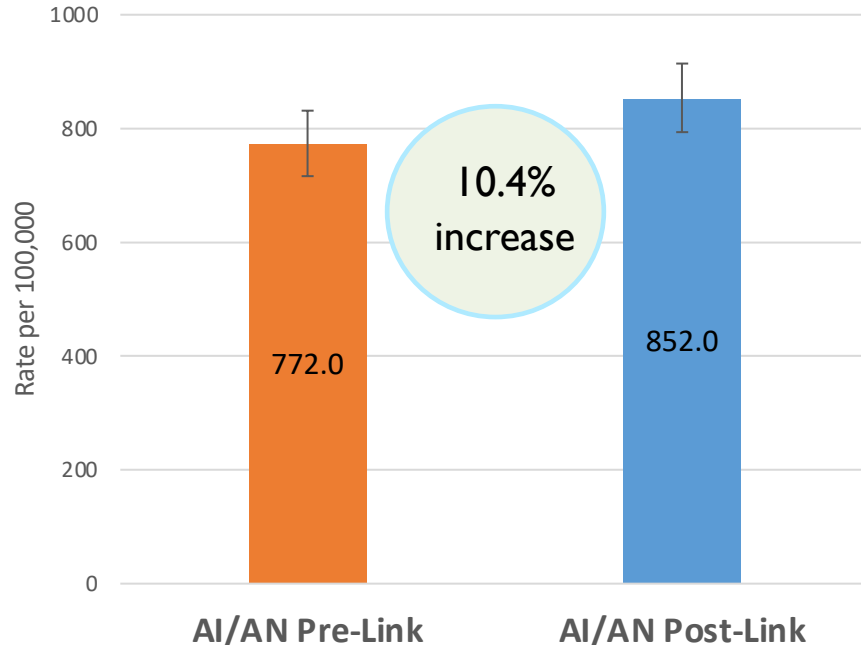
Linked with over 11 million records

Identified and corrected over 57,000 misclassified AI/AN records

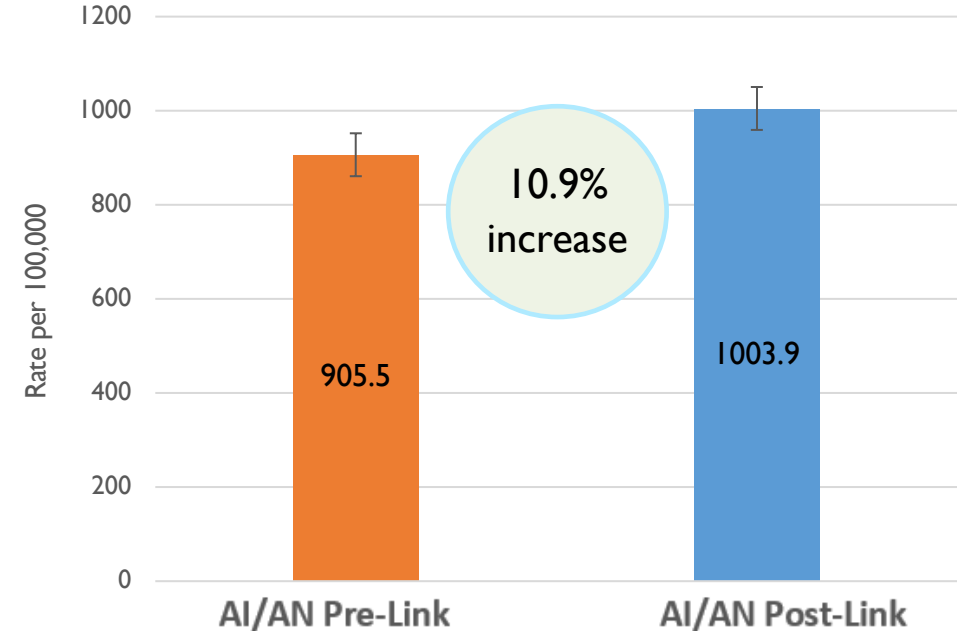
# MISCLASSIFICATION EFFECT ON MORTALITY RATES



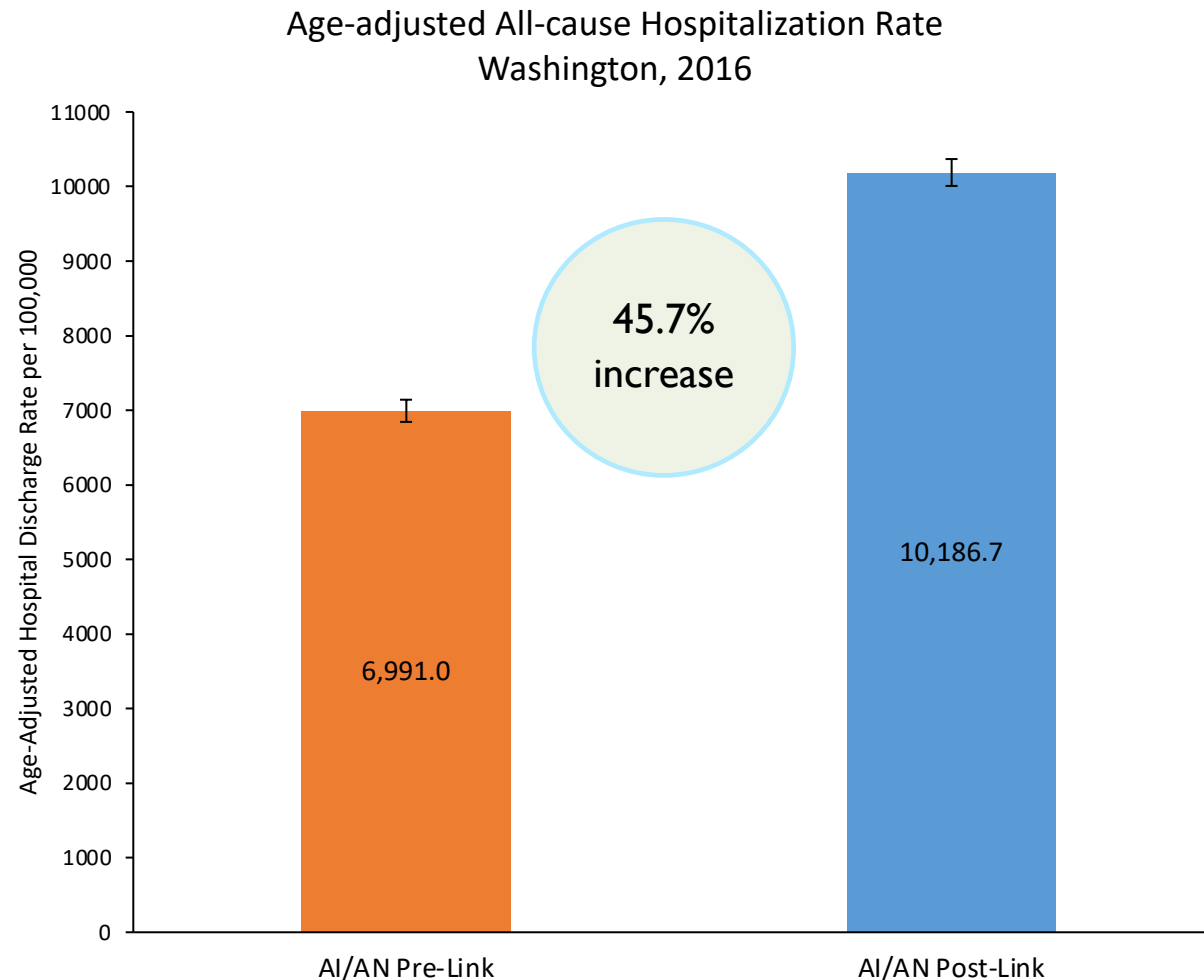
Age-adjusted All-cause Mortality Rate  
Idaho Residents, 2013-2017



Age-adjusted All-cause Mortality Rate  
Oregon Residents, 2014-2017



# MISCLASSIFICATION EFFECT ON HOSPITALIZATION RATES

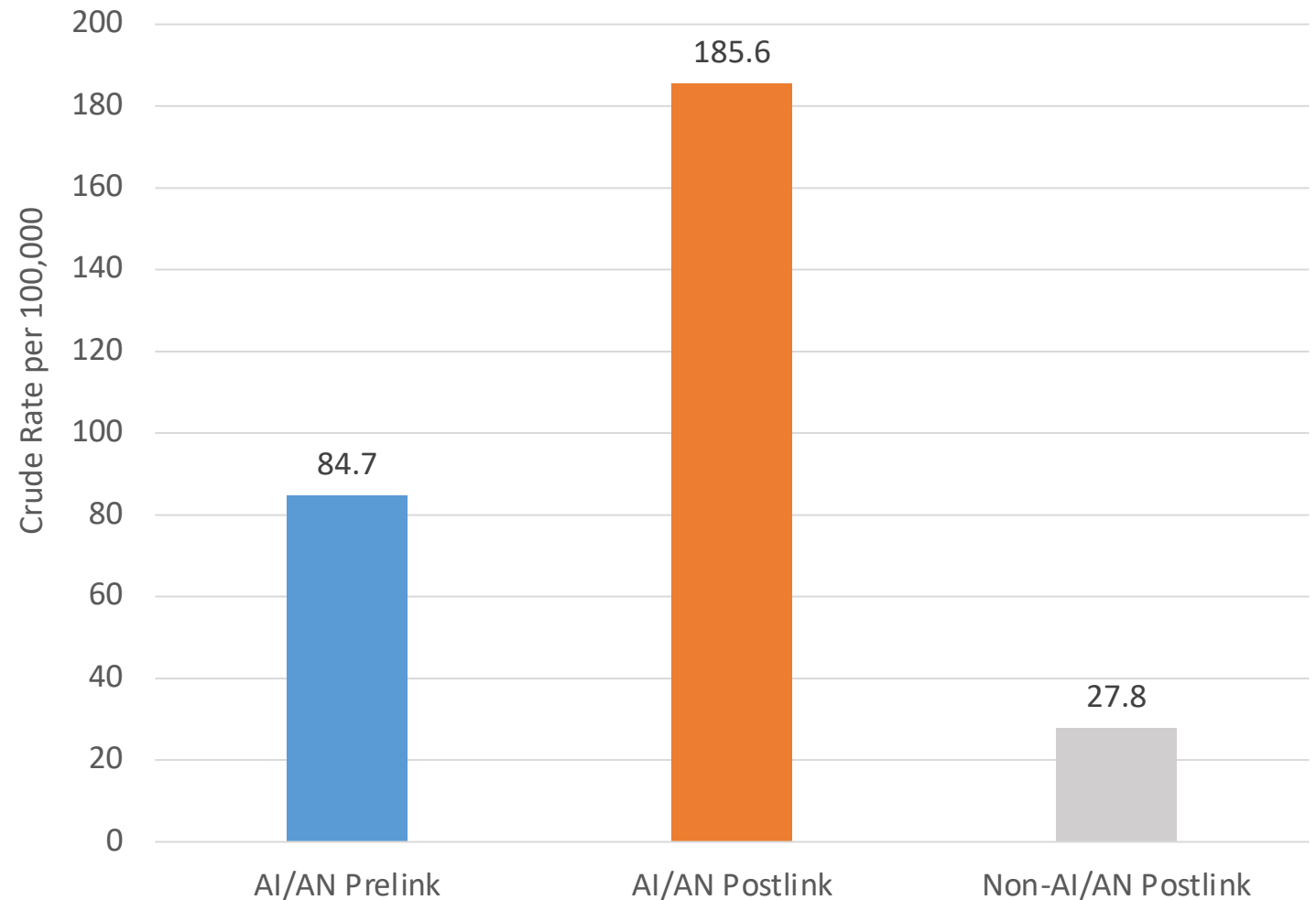


## CHRONIC HCV LINKAGE (DIAGNOSES FROM 2007-2016)

### ■ 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%

Pre- and Post-link Rates for Chronic HCV Diagnoses,  
Washington State 2007-2016



# WDRS BACKGROUND

- 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

## BACKGROUND AND METHODS USED FOR WDRS LINKAGES

- 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.

## BACKGROUND AND METHODS USED FOR WDRS LINKAGES

- 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

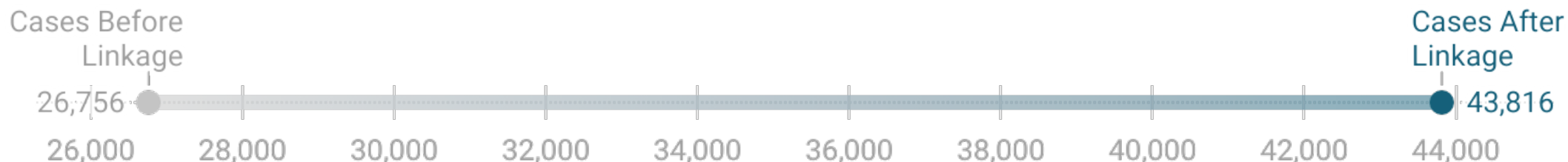
## WDRS LINKAGE FINDINGS

- 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

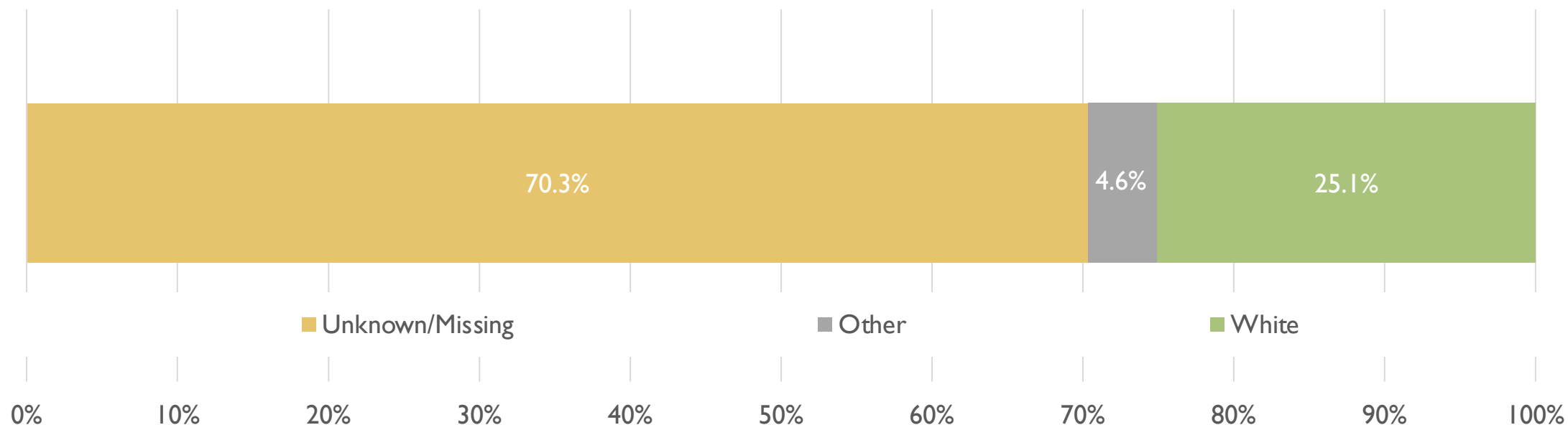
**Correcting misclassification increased the number of AI/AN Covid-19 cases by 64%.**



Source: Northwest Tribal Epidemiology Center, 2023 • Created with Datawrapper

# ORIGINAL RACE CODING FOR MISCLASSIFIED RECORDS

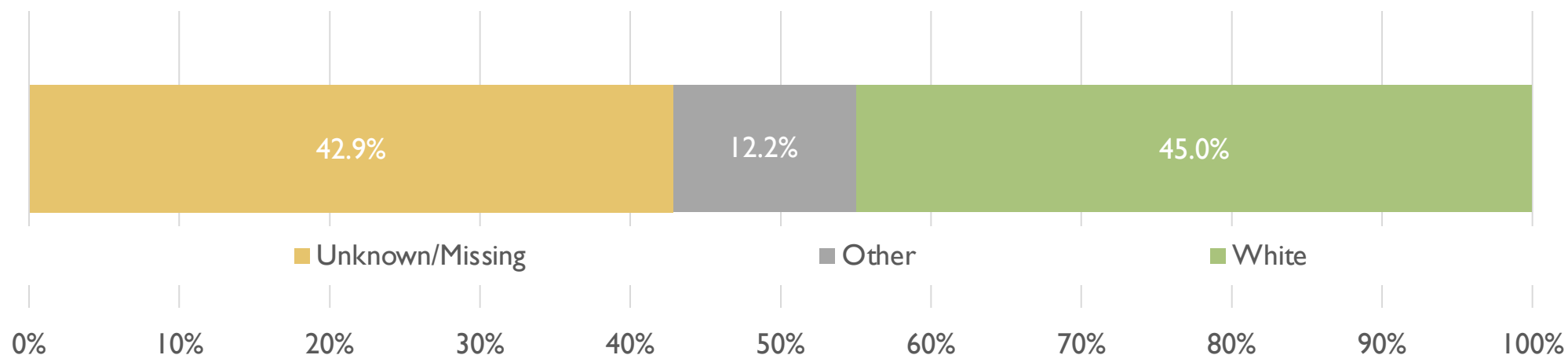
Of the 17,060 misclassified records, **70.3%** had “Unknown” or missing data for the record’s race information, while **25.1%** were coded as White.



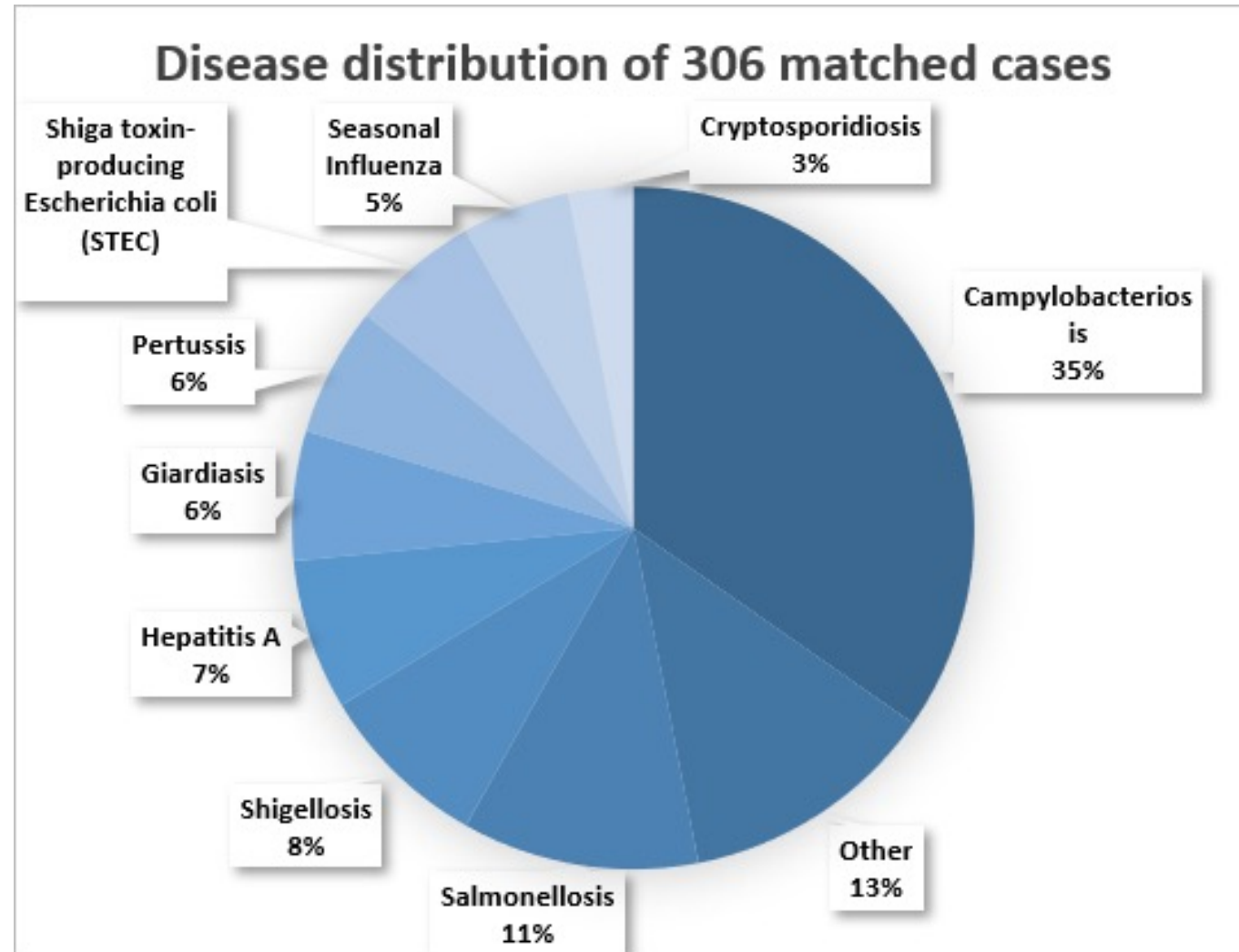
## GENERAL COMMUNICABLE DISEASES FINDINGS

- 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



# 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

# ACKNOWLEDGEMENTS

## Washington DOH

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  - Partners at NWTEC
  - Please contact [DOHAgencyCOVID19DQEpis@doh.wa.gov](mailto:DOHAgencyCOVID19DQEpis@doh.wa.gov) for more information about this work.

## NWTEC

- Thank you to:
  - The Tribes of Washington, patients, families, and Tribal leaders
  - Partners at Washington DOH
  - For more information about our linkages and other data support for Northwest Tribes, please contact: [sjoshi@npaihb.org](mailto:sjoshi@npaihb.org)