Addressing Racial Misclassification for American Indians and Alaska Natives

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Purpose

- Importance of data

- What is racial misclassification

- Impacts of racial misclassification

- How it happens

- How do we address it?

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Nations

- Tribal Sovereignty
  - American Indian tribes are independent nations and have authority to govern themselves

  - Policy agreements via treaties carried out between tribes and the U.S. federal government
    - Only tribes that signed treaties with the federal government were given federal recognition
    - These treaties offered access to health care and education

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Tribal Epidemiology Center

- One of 12 Tribal Epicenters across the US

- Funded by the Indian Health Service (IHS)

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Northwest Tribal Epidemiology Center (NWTEC)

- Housed within the Northwest Portland Area Indian Health Board (NPAIHB)

- Our organization provides epidemiological and public health support for the 43 federally recognized tribes in our three-state region: Idaho, Oregon, and Washington (~300,000 AI/AN)

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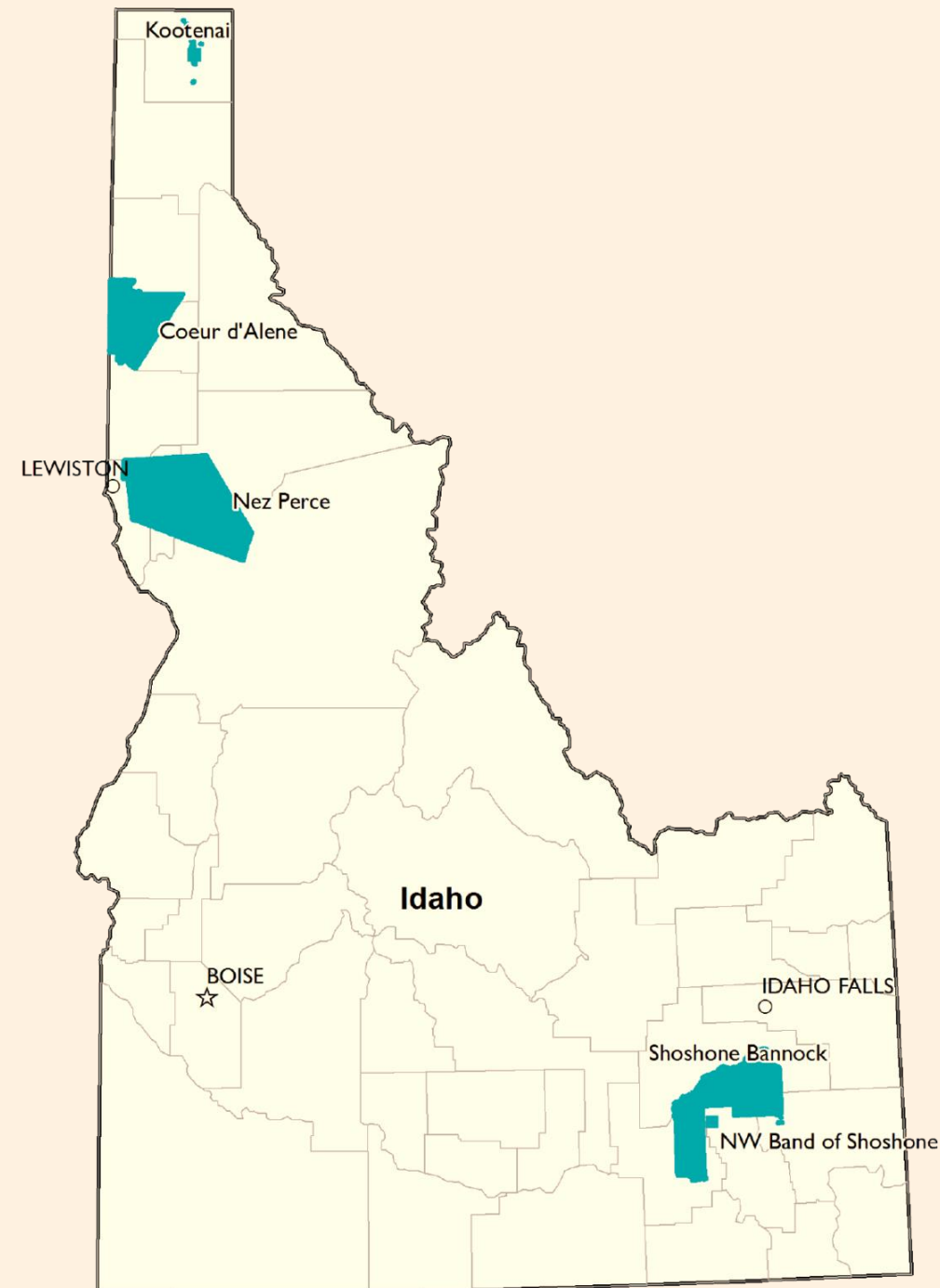*Indian Leadership for Indian Health*

Idaho

- There are 5 federally recognized tribes in Idaho
  - Coeur d'Alene
  - Kootenai
  - Nez Perce
  - NW Band of Shoshone
  - Shoshone Bannock

There are approximately 51,991 AI/AN living in the state of Idaho.

NWTEC—How do we use data?

Our organization provides epidemiological and public health support for the tribes in our three-state region:

- Assist communities in implementing disease surveillance systems and identifying health status priorities.

Identify and establish priorities

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NWTEC—How do we use data?

Our organization provides epidemiological and public health support for the tribes in our three-state region:

- Provide health specific data and community health profiles for Tribal communities.

Apply for funding

Develop policies, advocate, and educate

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NWTEC—How do we use data?

Our organization provides epidemiological and public health support for the tribes in our three-state region:

- Conduct tribal health research and program evaluation.

Select and implement interventions

Evaluate programs and progress toward goals

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NWTEC—How do we use data?

Our organization provides epidemiological and public health support for the tribes in our three-state region:

- Partner with tribal, state, and federal agencies to improve the quality and accuracy of AI/AN health data.

Partner for improved health outcomes

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Data Challenges among AI/AN Populations

- Small numbers
  - AI/AN often put into "other" category
  - Unreliable or unstable statistical estimates
  - Racial misclassification contributes to this
- Inaccessible data
  - Data is often siloed amongst various entities
- Data collection
  - Race data is not always collected

American Indian/Alaska Native alone or in combination make up **2.9% of the US population**
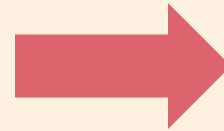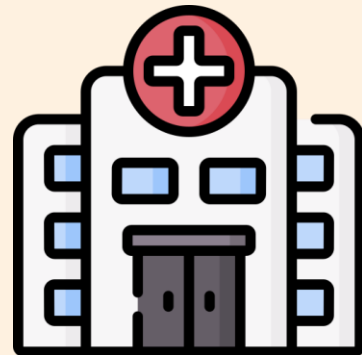
American Indian/Alaska Native alone make up **1.1% of the US population**

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What is racial misclassification?

Racial misclassification occurs when there is an incorrect recording of a person's race within a data or surveillance system
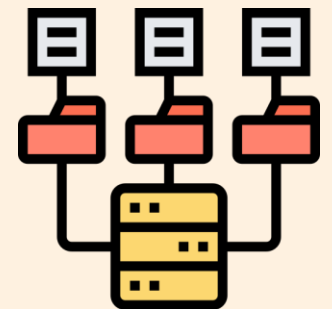
John D, 33yr old male, AI/AN

John D, 33yr old male, WHITE

Hospital discharge data

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How does it happen?

- Provider, medical staff or funeral director guessed the person's race
  - Spanish surname, appearance
- Race was misclassified on a medical document and copied to other places
- Form doesn't have AI/AN as a race option or it only allows the selection of one race
- Race is not collected at all
- The person or family does not know their AI/AN status or wish to disclose it

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Racial Misclassification

How common is misclassification of AI/AN? Very common!

- AI/AN populations are more likely to be racially misclassified than any other racial group in cancer registry datasets and medical records

- Published studies have found misclassification rates anywhere between 30-70%

- National death certificate study found 35,657 AI/AN (20%) were misclassified on their death certificates from 1990 – 2009

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Impacts of racial misclassification

AI/AN are left out of key health reports, disease rates, or public health surveillance

- Underrepresentation of AI/AN in the data leads to:
  - Inaccurate or incomplete AI/AN health data
  - Artificially lowered disease burdens
  - Cannot determine if specific health programs are needed in particular areas
  - Too few AI/AN to calculate stable disease rates and trends

Tribal leaders and public health officials cannot make informed decisions

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How can we address misclassification?
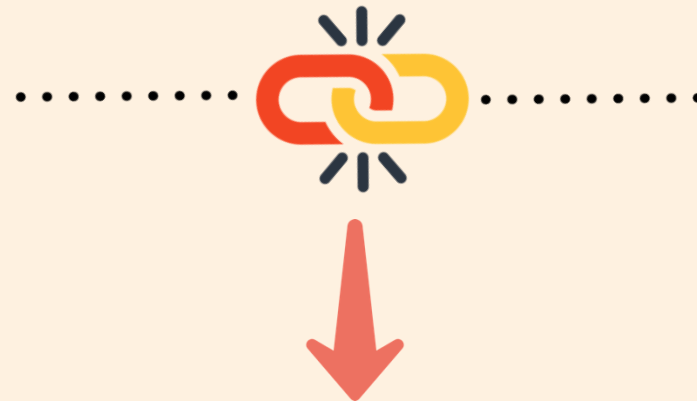
Fix it after it happens

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Data linkage to address misclassification

Health Data
- Death Certificates
- Hospital discharge
- Cancer registries
- Syndromic Surveillance
- EMS
- STD/HIV/Communicable disease
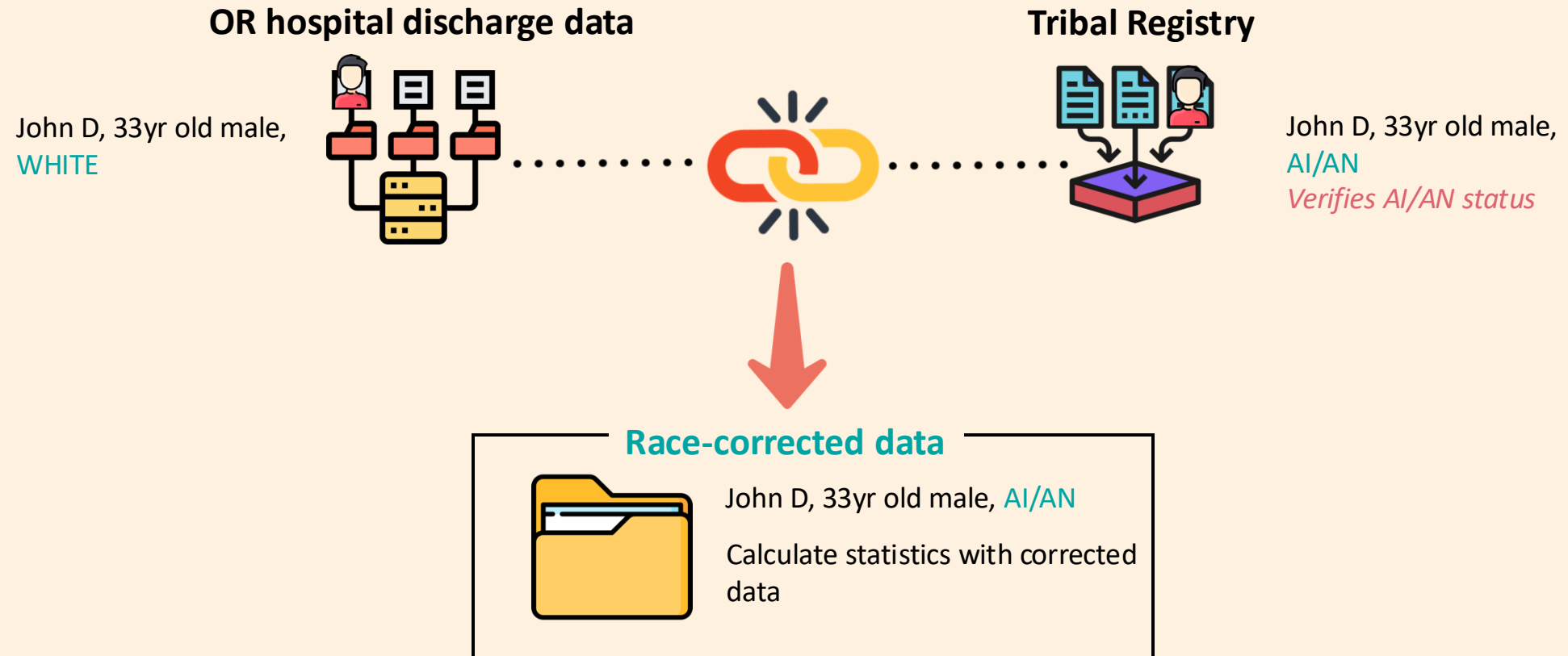- Birth certificates
- Etc

Race-corrected data

AI/AN Status Data
Northwest Tribal Registry
- Patient registration data from AI/AN seen at IHS or tribal health clinics in the Northwest
- Does not include AI/AN who never sought care at a tribal/IHS clinic
- This is not tribal enrollment data

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Data linkage to address misclassification

OR hospital discharge data

Tribal Registry

John D, 33yr old male, WHITE

John D, 33yr old male, AI/AN
Verifies AI/AN status

Race-corrected data

John D, 33yr old male, AI/AN

Calculate statistics with corrected data

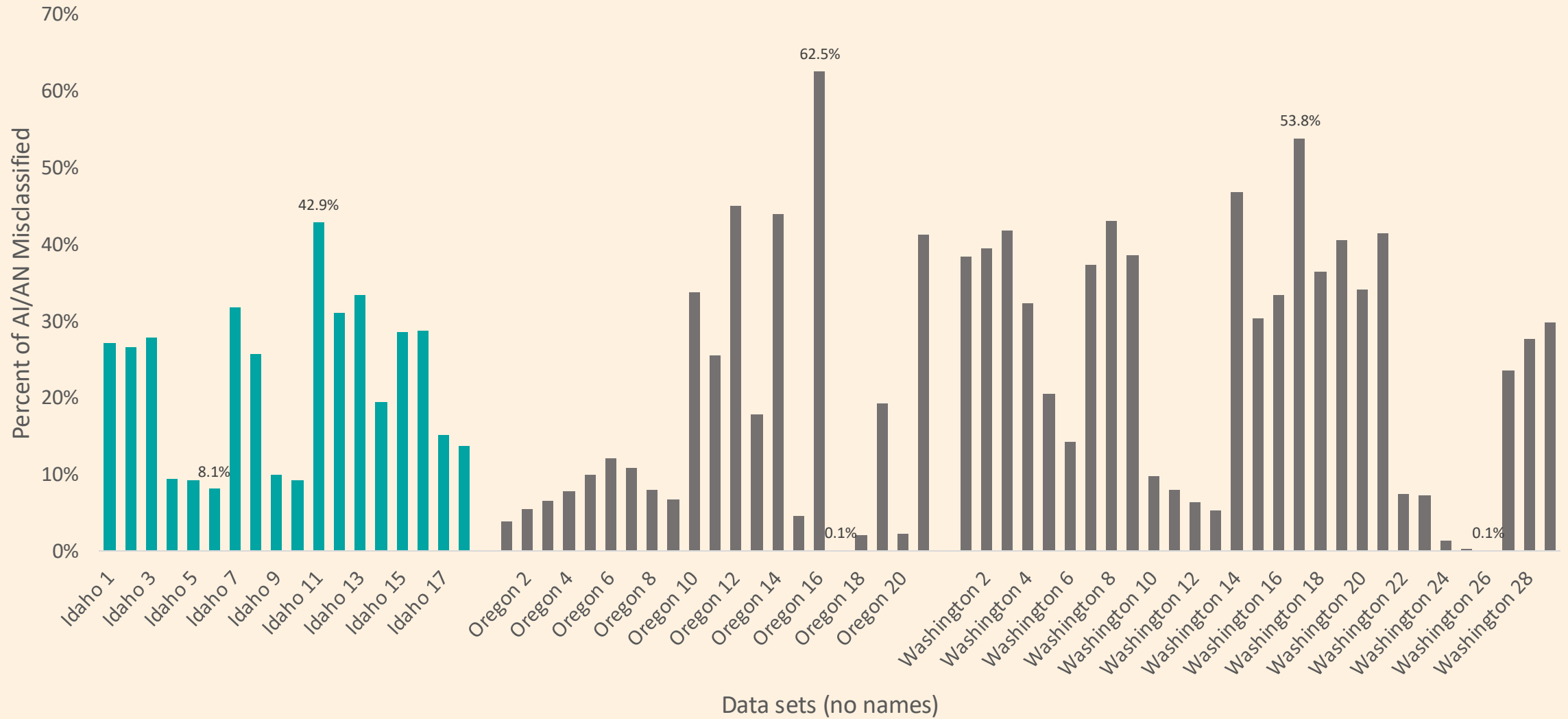NORTHWEST PORTLAND AREA INDIAN HEALTH BOARD
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NPAIHB Data Linkages

- Since 2018 NPAIHB has linked with 29 different databases in the Northwest
  - Linked with 14.6 million records
  - Identified and corrected over 64,321 misclassified AI/AN records
- Misclassification of AI/AN varied across databases
  - Some had only ~1% or fewer misclassified while others had over 60% of their AI/AN misclassified as another race

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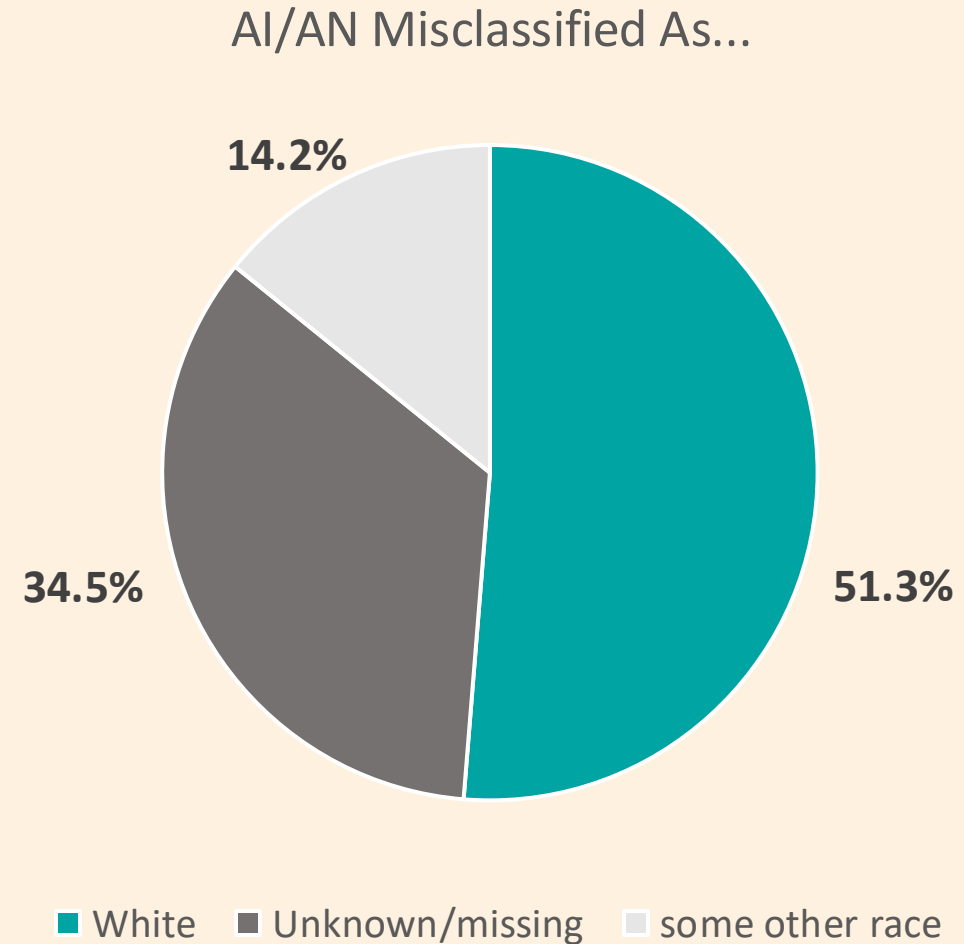INDIAN HEALTH BOARD
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AI/AN Misclassified in NPAIHB Linkages, By State (2018-2024)

What are AI/AN being misclassified as in the Northwest?

- Mostly as 'white'
- A lot of 'unknown' and 'missing'

AI/AN Misclassified As...

14.2%

34.5%

51.3%

■ White ■ Unknown/missing ■ some other race

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2008-2022 Death Certificate Data (OR, WA, and ID)
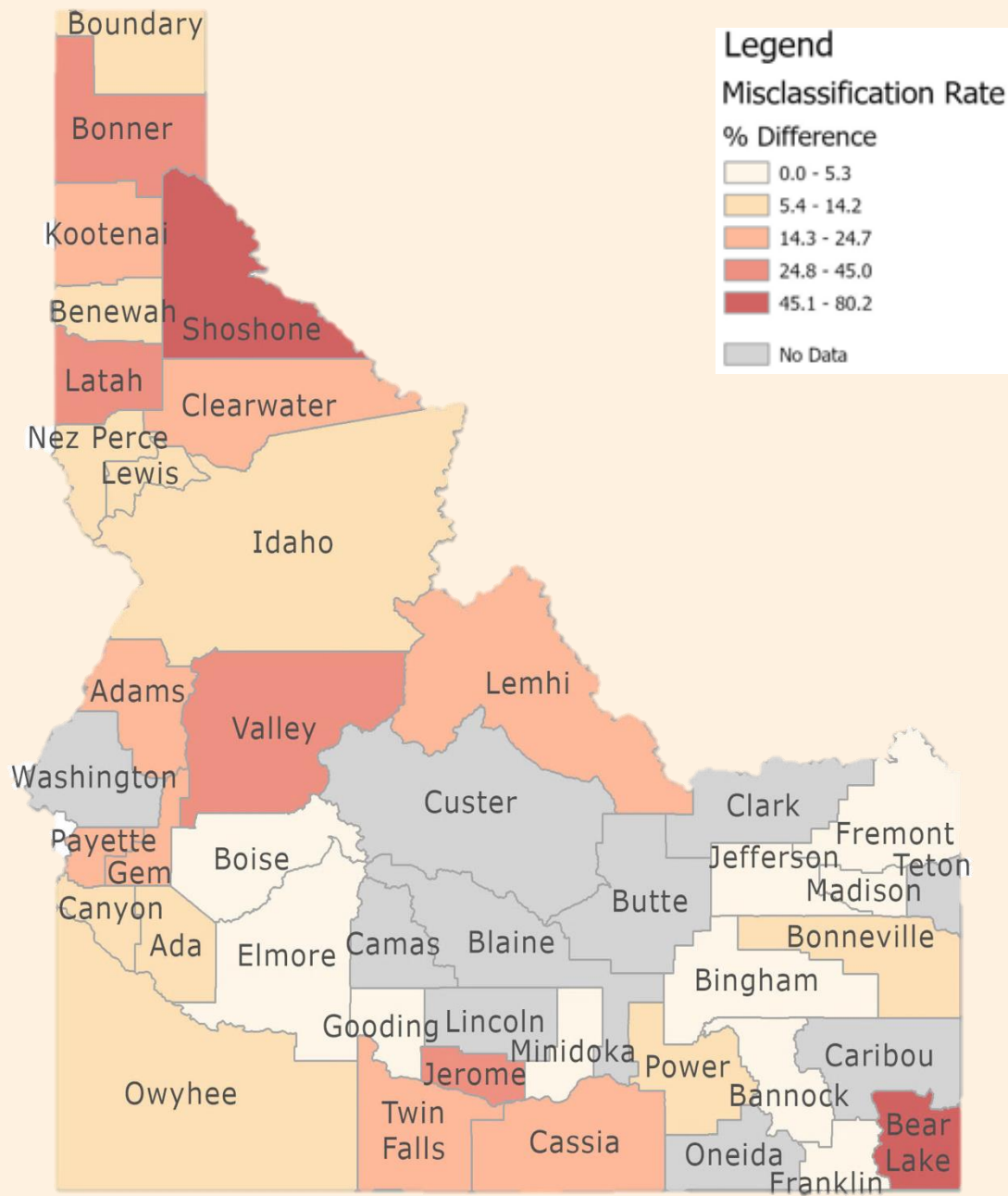
- Total AI/ANs misclassified in entire dataset = 2,741

  - Washington = 1,514

  - Oregon = 948

  - Idaho = 279

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How prevalent is misclassification?

- Varies by data set/data system

- Studies found patterns connected to geographic region
    - Lower rates of misclassification in areas with higher population of AI/AN

- In the state of Idaho, racial misclassification in death certificate data varies by county.
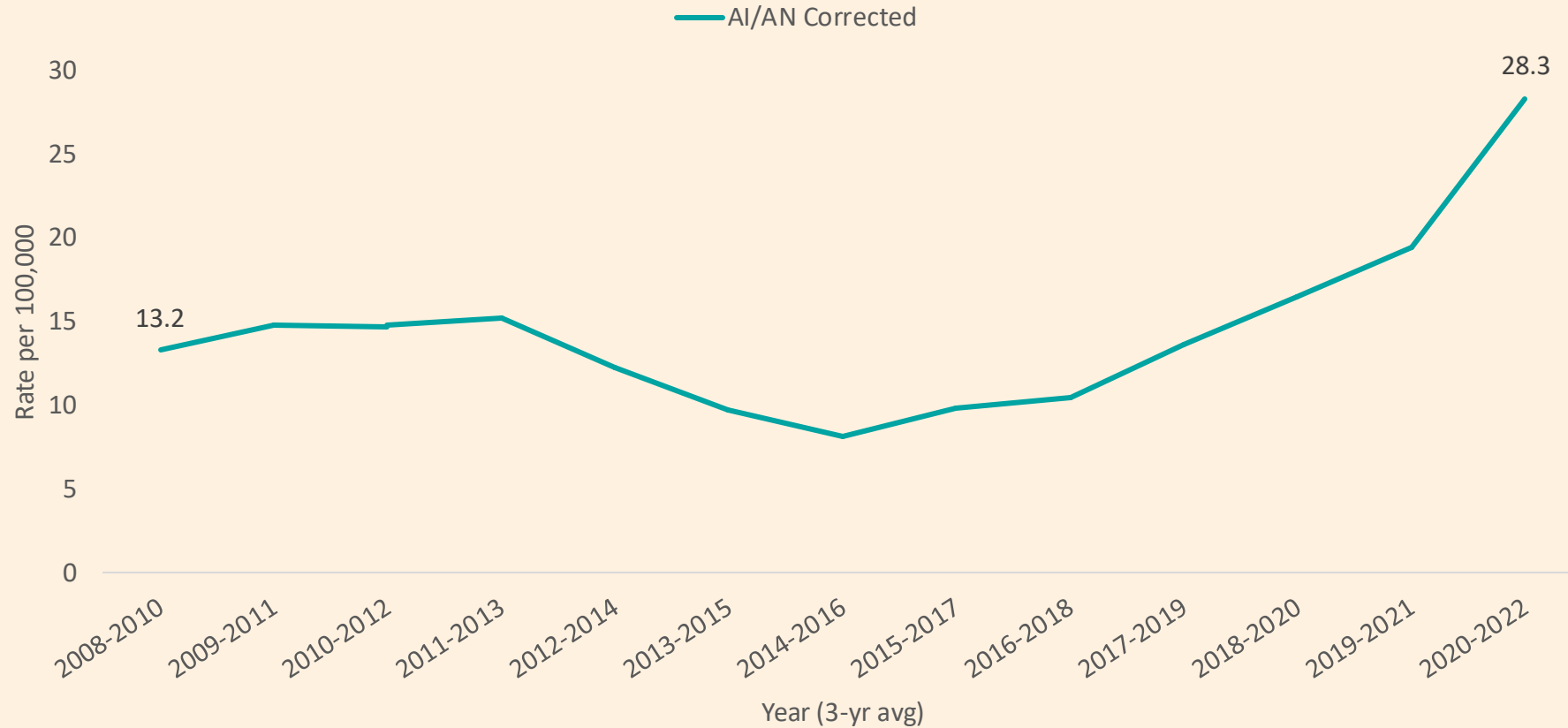
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Legend

Misclassification Rate

% Difference

- 0.0 - 5.3
- 5.4 - 14.2
- 14.3 - 24.7
- 24.8 - 45.0
- 45.1 - 80.2

No Data

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Idaho Misclassification Statistics

Idaho AI/AN Drug Overdose Death Rate, 2008-2022

—— AI/AN Corrected

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Idaho Misclassification Statistics
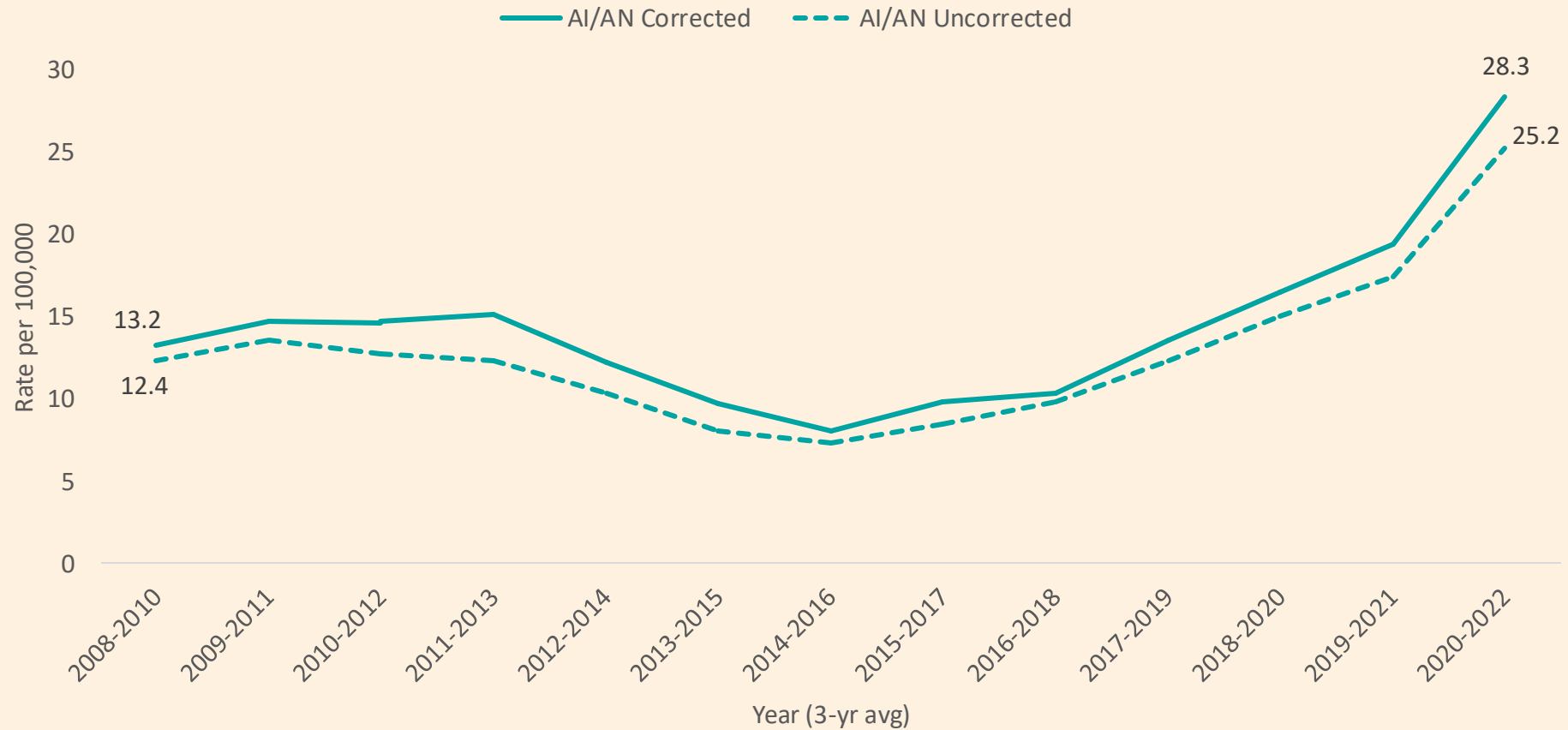
Idaho AI/AN Drug Overdose Death Rate, 2008-2022

—— AI/AN Corrected   - - - AI/AN Uncorrected

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Idaho Misclassification Statistics

Idaho AI/AN Drug Overdose Death Rate, 2008-2022

— AI/AN Corrected   --- AI/AN Uncorrected

23% increase

13.2
12.4
28.3
25.2

Rate per 100,000

Year (3-yr avg)

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Idaho Misclassification Statistics
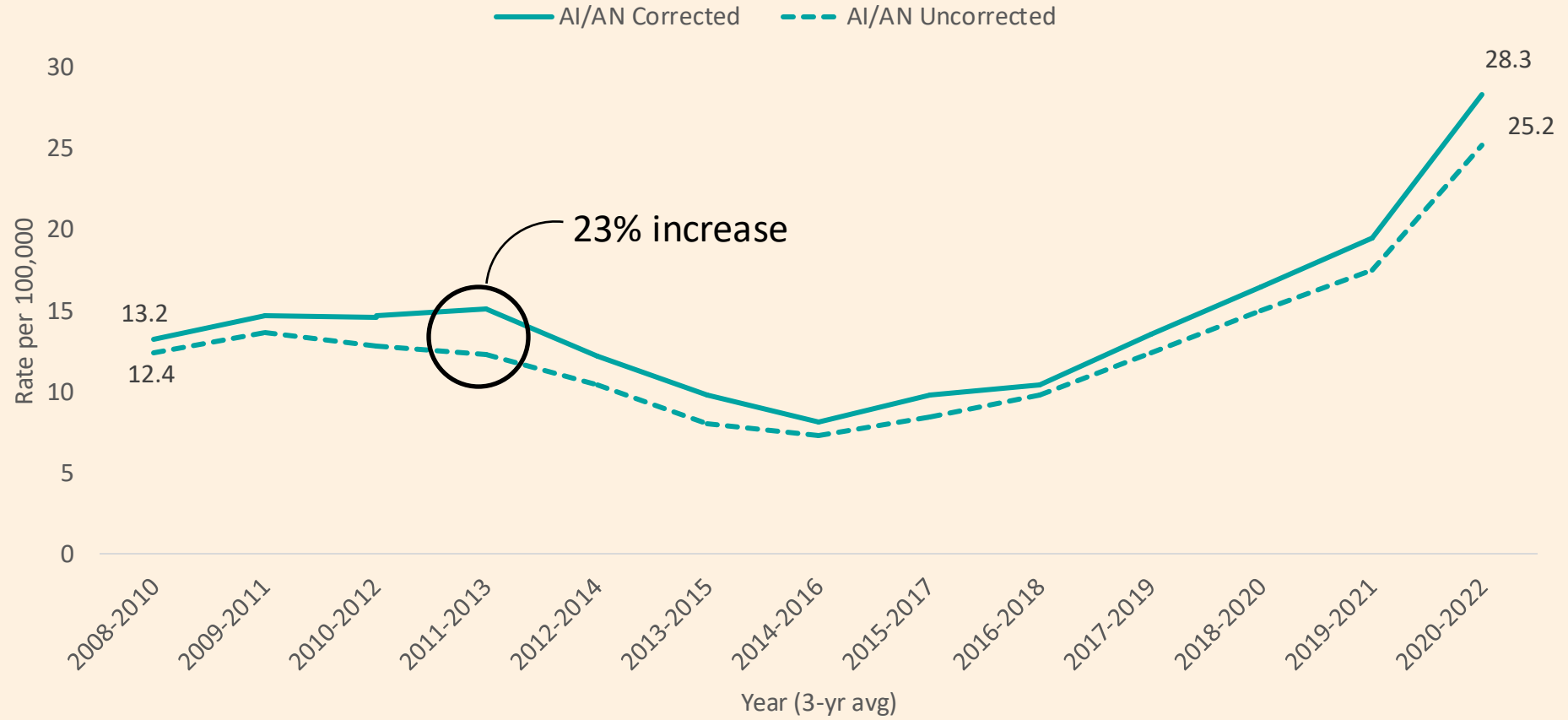

Idaho AI/AN Drug Overdose Death Rate, 2008-2022

—— AI/AN Corrected   - - - AI/AN Uncorrected

~12% increase throughout this period

13.2

12.4

Rate per 100,000

30
25
20
15
10
5
0

2008-2010 2009-2011 2010-2012 2011-2013 2012-2014 2013-2015 2014-2016 2015-2017 2016-2018 2017-2019 2018-2020 2019-2021 2020-2022
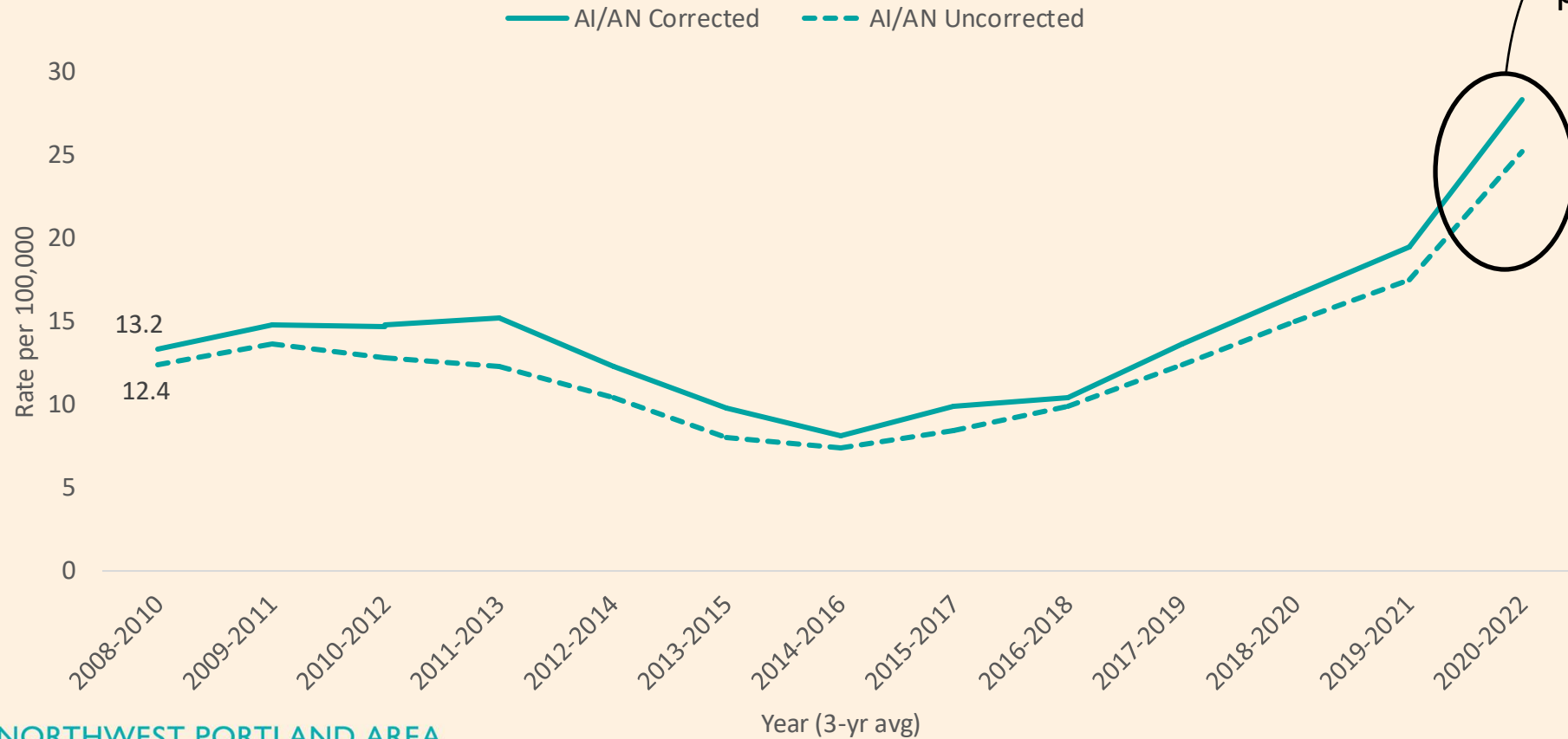
Year (3-yr avg)

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Idaho Misclassification Statistics
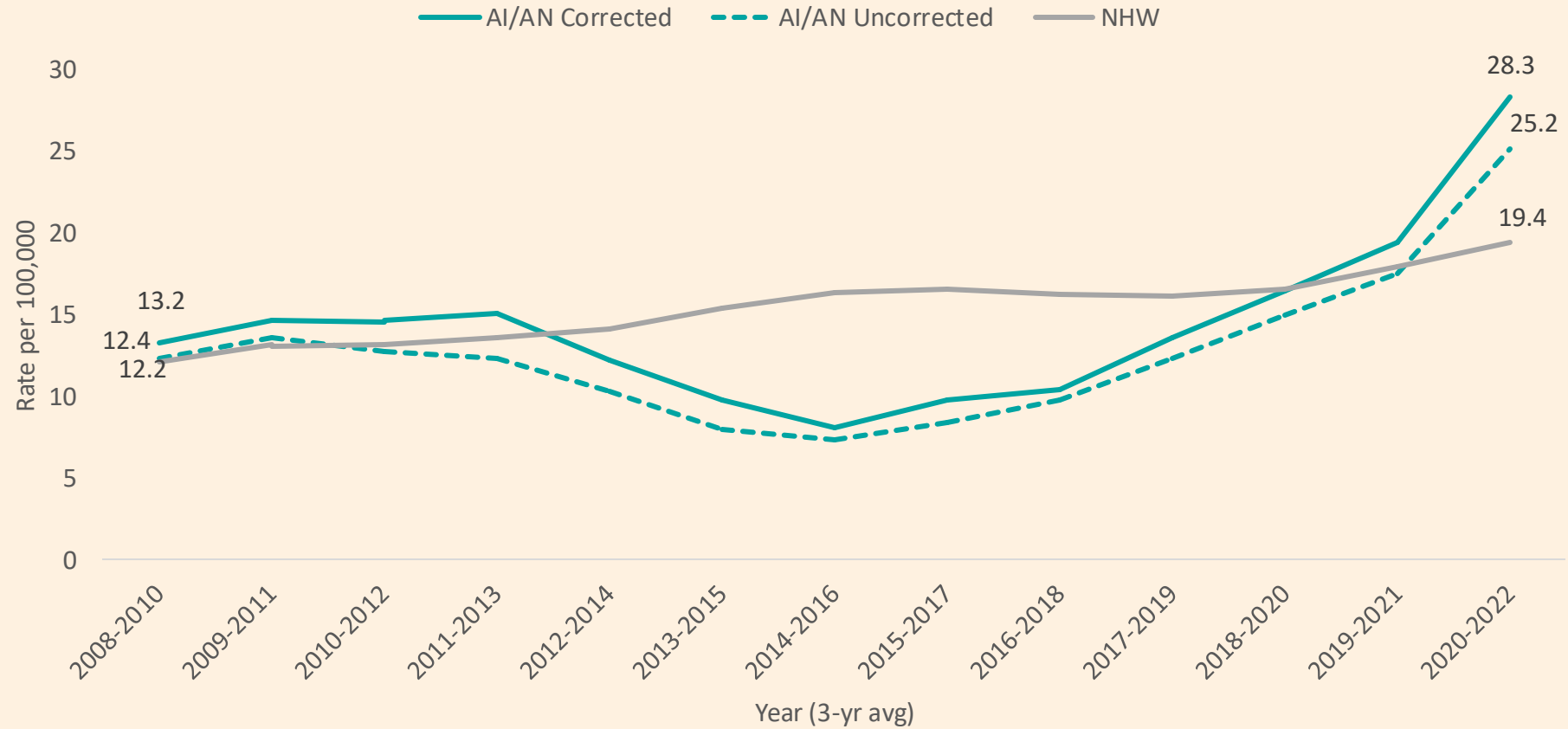

Idaho AI/AN Drug Overdose Death Rate, 2008-2022

— AI/AN Corrected   - - - AI/AN Uncorrected   — NHW

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What have data linkages accomplished?

- Increased the availability of accurate/complete data for tribal and AI/AN communities

- Improved representation of AI/AN in data systems

- State partnership opportunities have increased

How can we address misclassification?

Prevent it from happening

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Prevention

- Policy changes
  - Collect race in data systems that do not currently collect race
  - Use a more inclusive definition of AI/AN

- Training

- Data collection method changes
  - Always ask, never assume
  - Include AI/AN as a category on race collection forms
  - Allow space to enter tribal affiliation

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Best Practices

- Fill out **all** racial and ethnic identities as reported
- Never guess or assume– always verbally and directly ask about race, ethnicity, Hispanic origin
  - When someone identifies as AI/AN, do ask about Tribal affiliation and write it in, whenever possible
- Do always collect racial information yourself, if possible
- Be mindful of Tribal Nations in your area and urban Native populations or health centers

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Example Race and Ethnicity Prompts

- How would your family member have described their race?

- How would your family member have described their ethnicity?

- Was your family member enrolled in a Tribal Nation? If so, which one(s)? How do you spell it?

- Did your family member ever discuss Native American ancestry or Tribal membership?

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Resources

- [Best Practices for American Indian and Alaska Native Data Collection -- Urban Indian Health Institute (UIHI)](#)

- [Oklahoma Tribal Burial Resource Guide](#)

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Summary

- Racial misclassification of AI/AN is very common, but varies by state

- Misclassification heavily affects AI/AN statistics compared to others

- State and national reporting systems do not account for misclassification and may severely underestimate AI/AN statistics

- Misclassification rates can vary significantly by data set

- We can address misclassification by preventing and correcting!

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Questions?

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