Misclassification of American Indians & Alaska Natives in Washington's chronic Hepatitis C surveillance system

MONIKA DAMRON

SUJATA JOSHI

SOYEON LIPPMAN

AI/AN Racial Misclassification

AI/AN are frequently misclassified in surveillance and administrative data systems

- Published studies have found misclassification rates between 30%-70%[1,2,3]

Compared with other race groups, AI/AN have lowest levels of agreement (~60%) between self-reported race and race assigned in medical records[4]

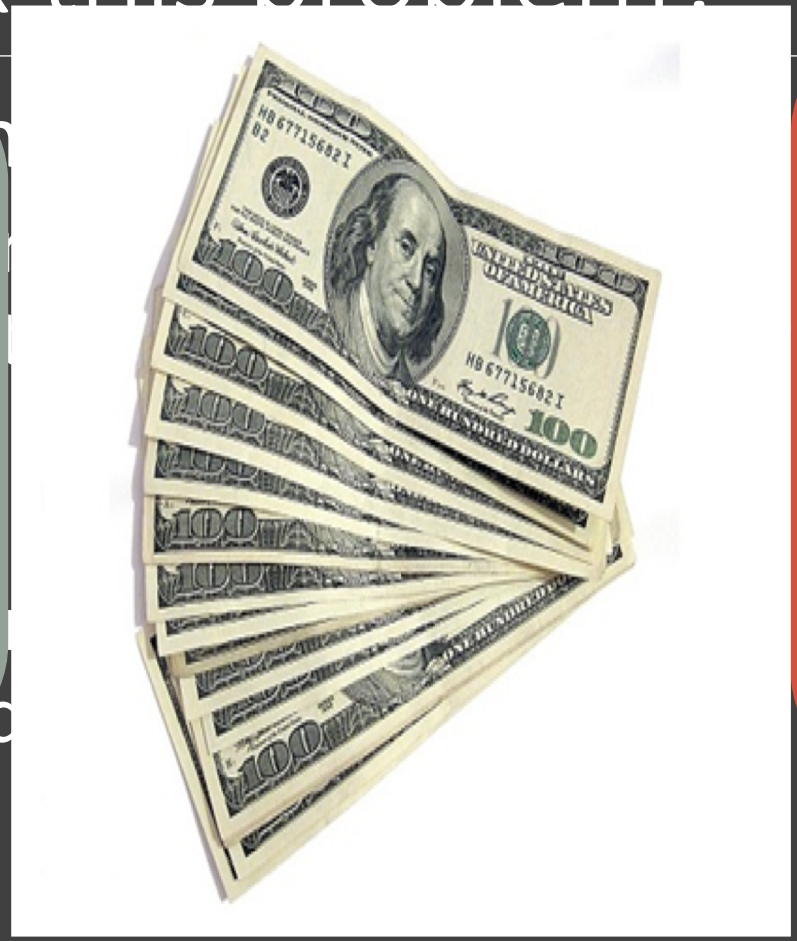
1. Hoopes M., E. Vinson, and K. Lopez. 2012. "Regional Differences and Tribal Use of American Indian/Alaska Native Cancer Data in the Pacific Northwest." Journal of Cancer Education 27(1): 73-79.
2. Johnson, J.C., A.S. Soliman, D. Tadgerson, G.E. Copeland, D.A. Seefeld, N.L. Pingatore, R. Haverkate, M. Banerjee, and M.A. Roubidoux. 2009. "Tribal Linkage and Race Data Quality for American Indians in a State Cancer Registry." American Journal of Preventive Medicine 36(6): 549-554.
3. Boehrmer, U., Kressin, N.R., Berlowitz, D.R., Christiansen, C.L., Kazis, L.E., and Jones, J.A. 2002. "Self-Reported vs. Administrative Race/Ethnicity Data and Study Results." American Journal of Public Health 92(9): 1471-1473.
4. Kressin, N.R., B. Chang, A. Hendrcks, and L.E. Kazis. 2003. "Agreement between Administrative Data and Patients' Self-Reports of Race/Ethnicity." American Journal of Public Health 93(10): 1734-1739.

Why does this matter?

- Small numbers get even smaller
  - Difficult to maintain patient confidentiality
  - Statistical instability
- Inaccurate data → inaccurate statistics
  - Difficult to establish baselines, track changes, and measure disparities

How do we fix this problem?

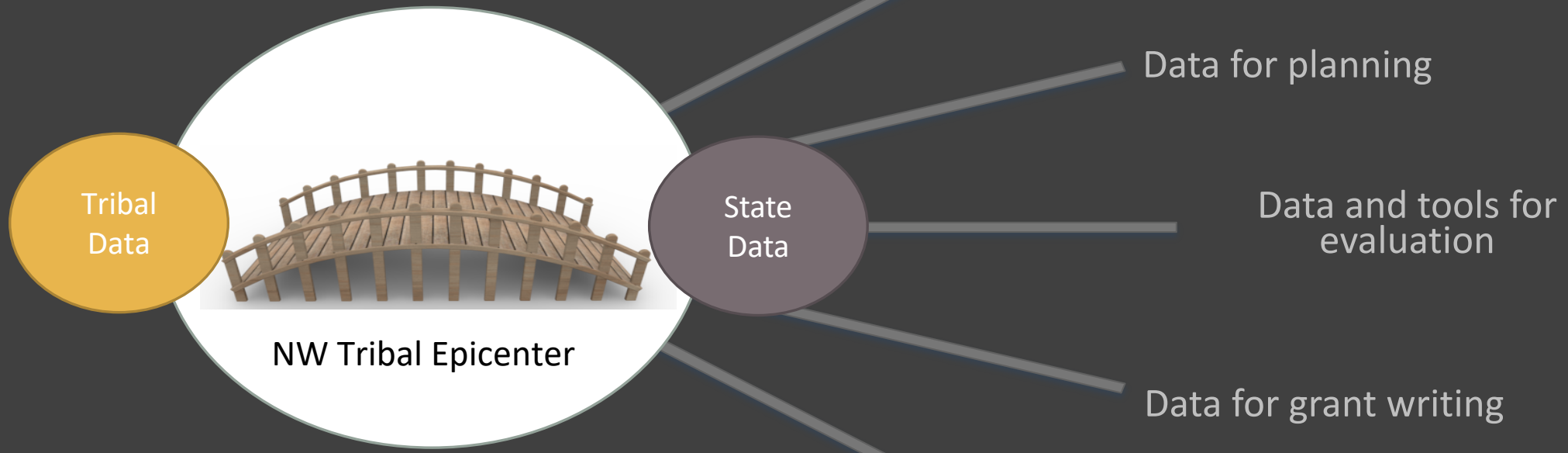
Advocacy and Political Will



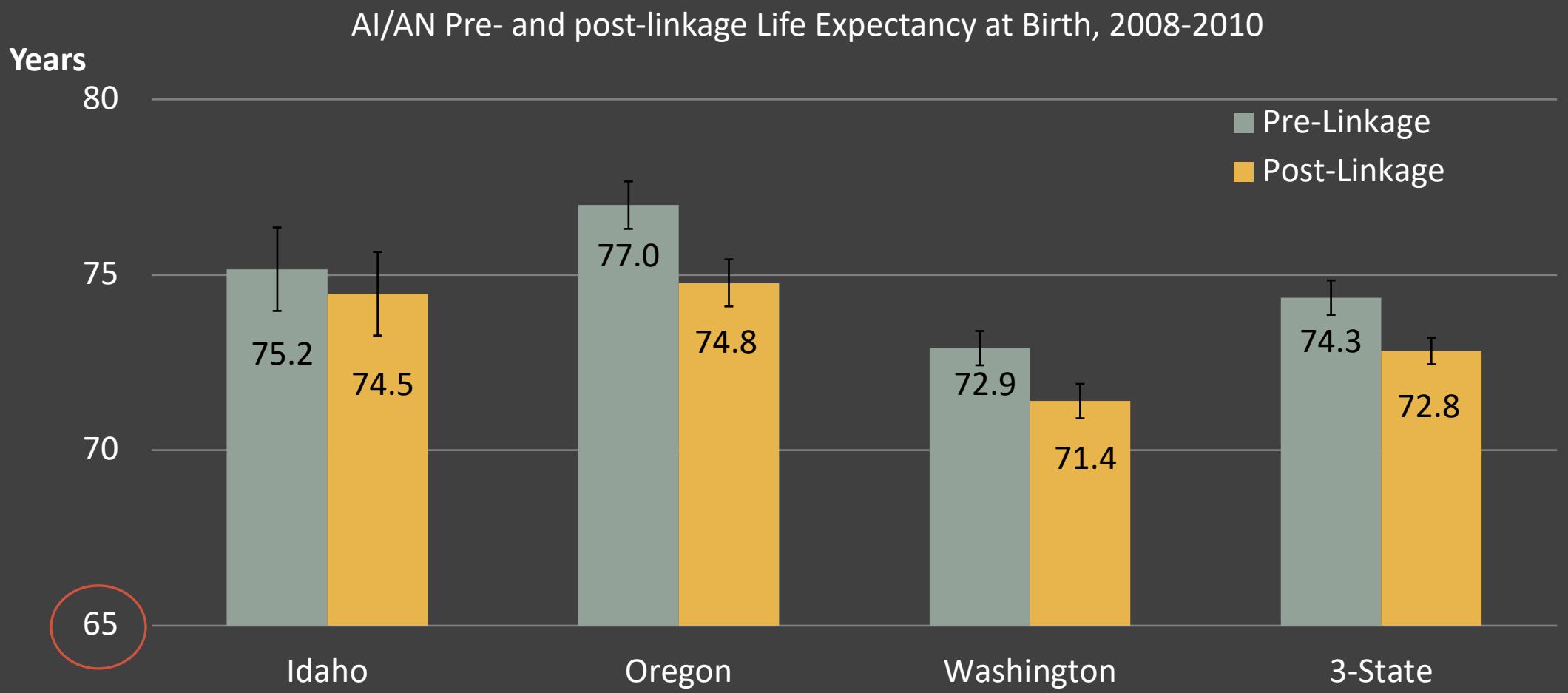
Time and Commitment

Downstream Solution

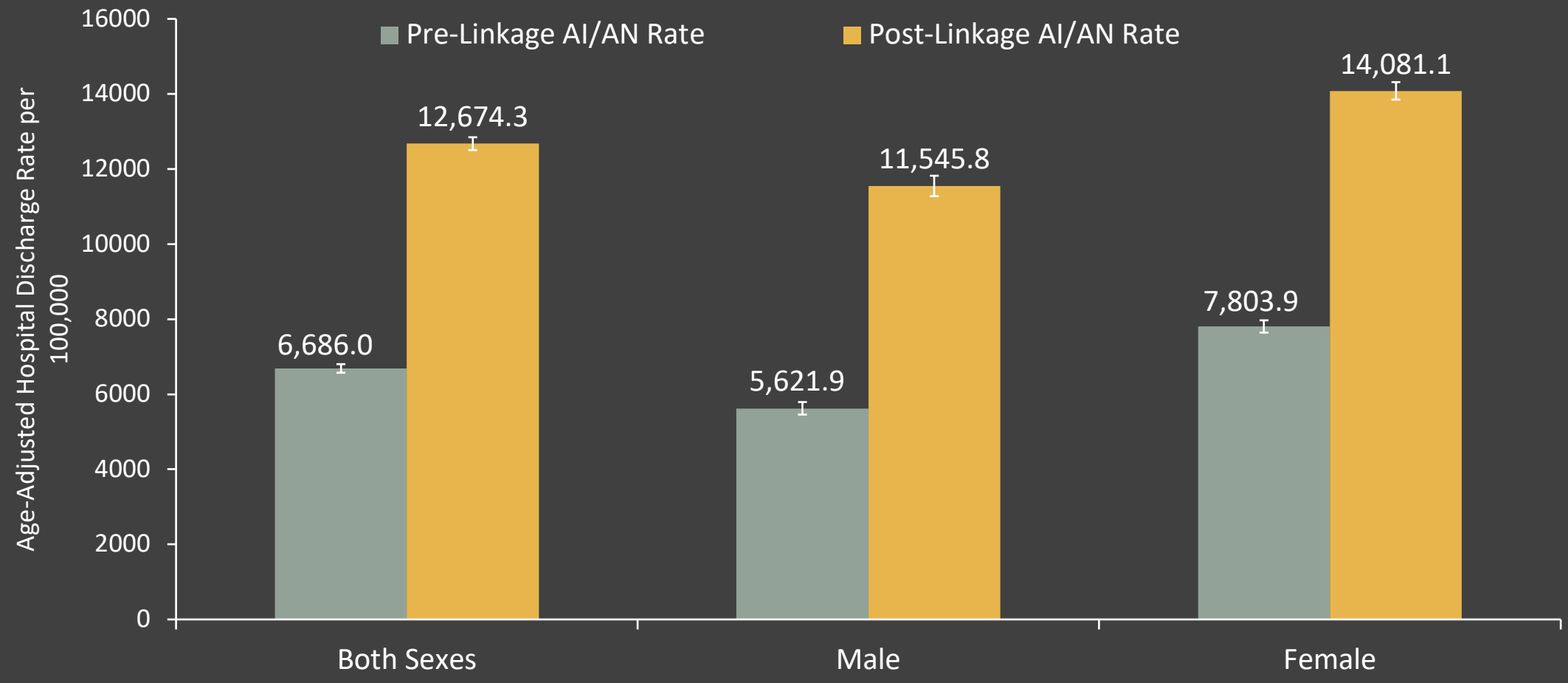
Linkages to correct misclassification



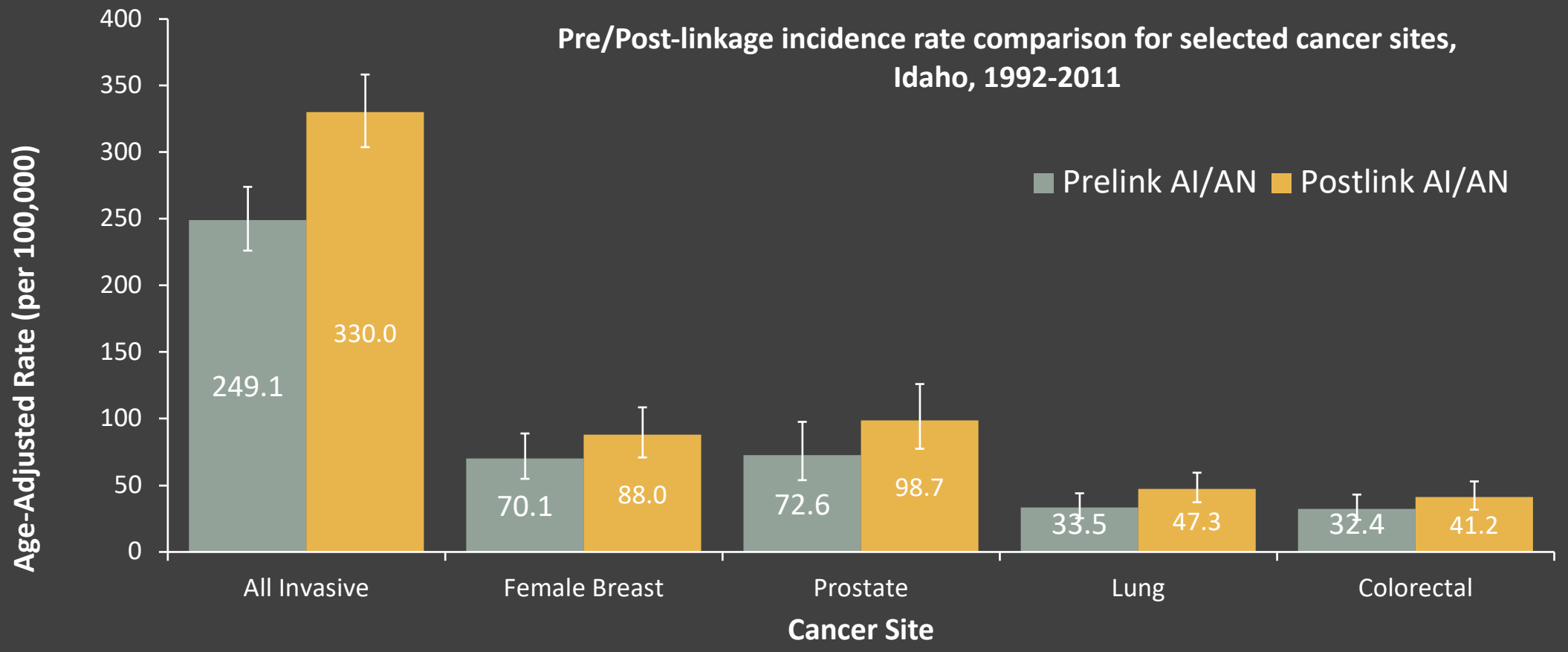
Linkage correction revealed true AI/AN Life Expectancy 1.4 years lower



Washington AI/AN hospitalization rate (both sexes) increased by 90%



Idaho AI/AN cancer incidence rate increased by 32 %



Hepatitis C

Hepatitis C Virus (HCV)

- Blood-borne virus, most commonly spread through sharing needles/injection equipment
- Causes inflammation of the liver, which if left untreated can lead to liver cancer, liver transplants, and/or premature death
- Most common blood-borne condition in the U.S.
- HCV causes more deaths than all other reportable communicable diseases combined
- American Indians have the highest rates of new HCV infections of all race/ethnicity groups

Barriers to Hepatitis C Surveillance

- Acute and chronic HCV infections are reportable conditions in Washington State
- Chronic HCV infections are often underreported
  - Patients often don't recognize symptoms or get tested
  - Symptoms may develop many years after infection
  - Case definitions for chronic HCV have changed over time
  - Local Health Jurisdictions have limited funding for screening and surveillance
- Some higher risk populations (homeless, military, institutionalized individuals) may not be included in survey estimates of chronic HCV infections
- Demographic information (i.e., race/ethnicity data) is often missing for reported cases

Partnership with Washington DOH

- Had previously conducted linkages with Washington vital records, hospital discharge, trauma and cancer registries
- Proposed and obtained approval to conduct linkages with Washington DOH communicable disease surveillance systems
- Worked with Washington DOH's tribal epidemiologist (Dr. Soyeon Lippman) to obtain approvals, obtain data, and complete linkage work
- This work supports both agencies' goals to provide improved health data to Washington Tribes.

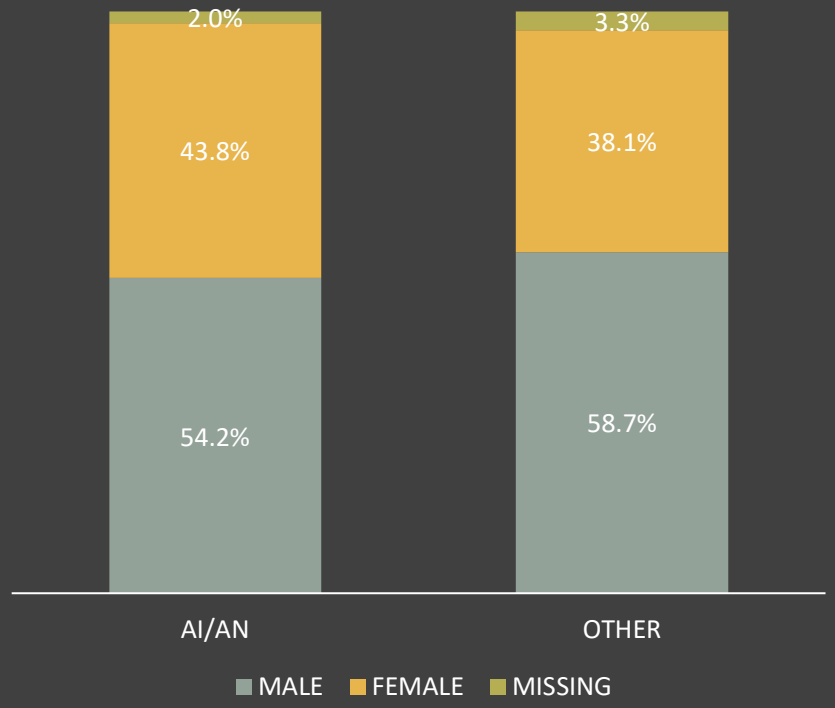
Methods

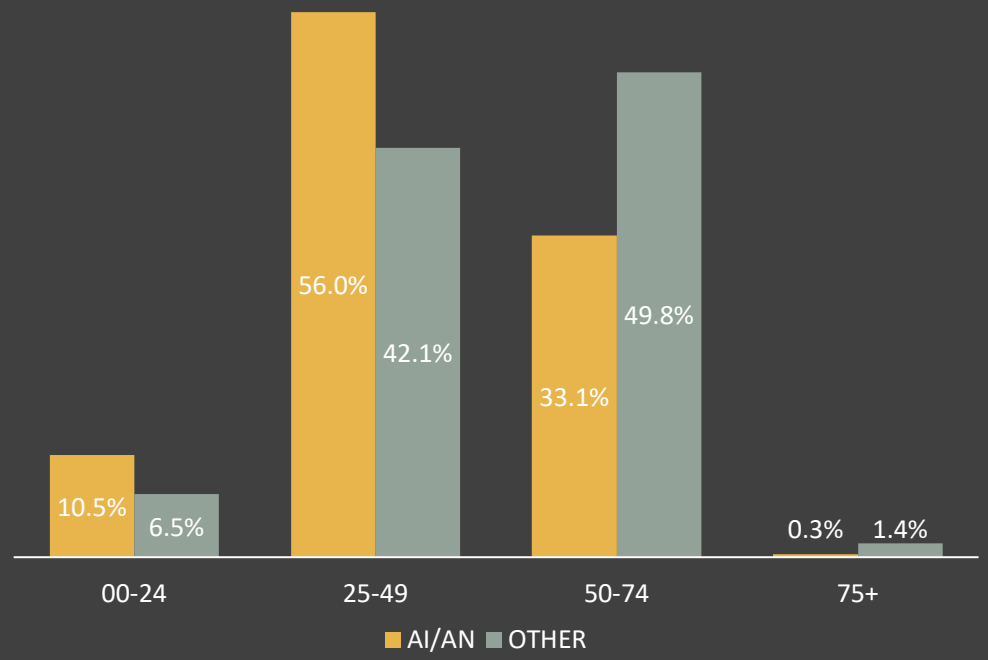
- Linked the Northwest Tribal Registry (NTR) with Washington's Chronic Hepatitis C database in LinkPlus v. 2.0
  - NTR: 212,785 records
  - Washington Chronic HCV database: 58,715 records from 2007-2016
- Cleaned and prepared post-linkage dataset for analysis in SAS
- Hepatitis C Case – defined as records with confirmed or probable HCV
- Compared AI/AN cases to non-AI/AN cases (Other)
- Rates age-adjusted to the U.S. 2000 Standard Population, rates calculated using the NCHS bridged race estimates as population denominators

Findings

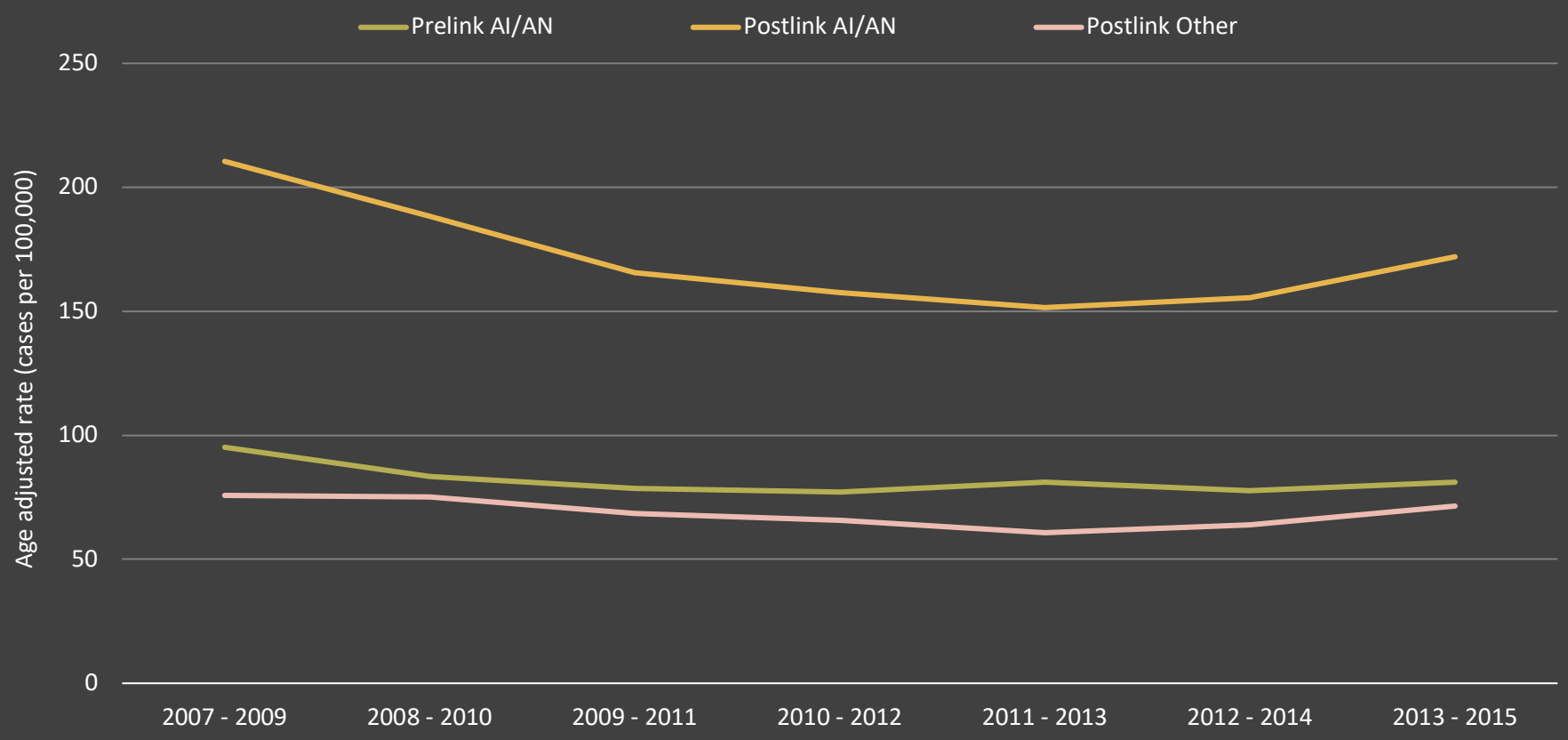
Majority of all records (67%) were missing race information

Linkage identified 1,499 misclassified AI/AN HCV cases





Rates


Prelink AI/AN
Postlink AI/AN
Postlink Other
Age adjusted rate (cases per 100,000)
250
200
150
100
50
0
2007 - 2009
2008 - 2010
2009 - 2011
2010 - 2012
2011 - 2013
2012 - 2014
2013 - 2015

Conclusions

Majority of records in Washington's HCV database were missing race/ethnicity information

- Makes it difficult to identify burden within specific populations and disparities between groups
- Difficult to measure extent of AI/AN misclassification in this dataset

AI/AN chronic HCV cases were different (more likely to be female and in younger age groups) than the general population

- Implications for outreach, screening, and prevention interventions

Discussion

- How do we interpret these findings, given that the majority of records were missing race information?
- Do you trust these data? Would you use these data?
- Is it worthwhile doing linkages in these cases?
- What are strategies we could suggest to Washington DOH for:
  - Improving race/ethnicity data collection in this system?
  - Generally providing better information to tribes and urban Indian population for Hepatitis C?
    - I.E., are bad data better than no data?

Contact

Monika Damron

mdamron@npaihb.org

Sujata Joshi

sjoshi@npaihb.org

Soyeon Lippman

Soyeon.Lippman@doh.wa.gov

Acknowledgements

Thank you to:

The Tribes of Washington, patients, and families

Dr. Thomas Weiser, Sarah Hatcher, and Jessica Leston

This presentation was supported by Cooperative Agreement Number NU58DP006385-01, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.