



Who Counts? Racial Misclassification and American Indians/Alaska Natives

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**Urban Indian
Health Institute**
A Division of the Seattle Indian Health Board



Let us begin in a good way...



Agenda

Indigenous Data Sovereignty

**Urban Indian Health
Institute**

Data Challenges

Data Misclassification

**Reclaiming Health &
Wellness**



A group of people are seated at a table in a restaurant or cafe. The scene is dimly lit, with warm ambient lighting. In the foreground, three people are visible from behind, seated at a table. They are wearing patterned clothing. The background shows other tables and chairs, and a large window or glass partition. A green banner is overlaid at the top of the image, containing the title text.

Indigenous Data Sovereignty

The right to govern the collection, ownership and application of one's own data

Warrants Outstanding Contingent Fund

April 1	Warrants Paid	119	81	Wts. Outstanding	984060
" 30-07	To Balance Per last		888	"	985830
May 31-07	Warrants Paid		9699	"	196991
" 31-07	Warrants Outstanding		372	"	188887
June 30	Warrants Paid	129	286032	"	100864
June 30-07	Warrants Outstanding		289957	"	289752
July 31-07	Warrants Outstanding			"	286032
" "	Warrants Outstanding			"	97165
Aug 31-07	Wts. Outstanding		4138375	"	383197
Sept 30-07	Wts. Outstanding		4138375	"	238617
Oct 31	Wts. Outstanding		5123135	"	98656
Nov. 30	Wts. Paid		5123135	"	337273
"	Wts. Outstanding		6072575	"	310108
Dec 31	Wts. Outstanding	163	5148578	"	103729
Jan 31	Wts. Outstanding	168	2737220	"	413837
Feb 29	Wts. Outstanding	174	788560	"	413837
Mar 31	Wts. Outstanding	178	1472575	"	984760
"	Wts. Outstanding		2256005	"	512313
"	Wts. Outstanding		3693980	"	512313
"	Wts. Outstanding		1660435	"	949446
"	Wts. Outstanding		1537935	"	607257
"	Wts. Outstanding		98360	"	607257
"	Wts. Outstanding		925160	"	945170
"	Wts. Outstanding		119310	"	701774
"	Wts. Outstanding			"	696694
"	Wts. Outstanding			"	918692
"	Wts. Outstanding			"	788564
"	Wts. Outstanding			"	273712
"	Wts. Outstanding			"	956860
"	Wts. Outstanding			"	369398
"	Wts. Outstanding			"	225600
"	Wts. Outstanding			"	94235
"	Wts. Outstanding			"	19836
"	Wts. Outstanding			"	153793
"	Wts. Outstanding			"	12555

**DECOLONIZE
DATA**



REPION
 2019/10

The Urban Indian Health Institute

- One of 12 IHS Tribal Epidemiology Centers (TECs), and a division of the Seattle Indian Health Board



**Urban Indian
Health Institute**

A Division of the Seattle Indian Health Board

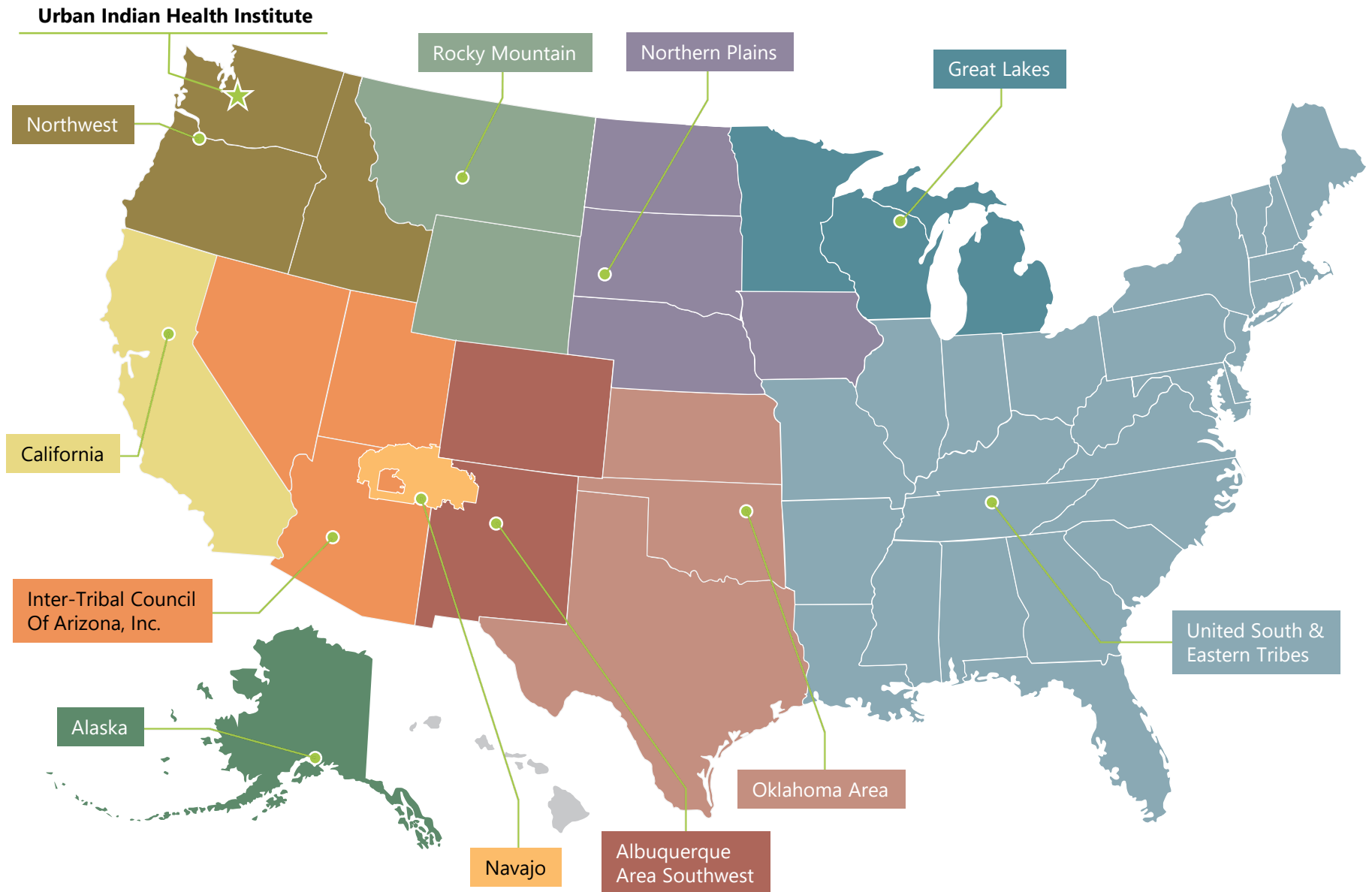
- Serves urban American Indians and Alaska Natives (AI/AN) since 2000



Seattle Indian Health Board
For the Love of Native People

- UIHI serves to improve the health of AI/AN by:
 - Identifying & understanding health disparities and resiliency
 - Strengthening public health capacity
 - Disease surveillance and disease prevention
 - Health promotion and disease prevention grounded in indigenous methodologies

Tribal Epidemiology Centers





Decolonizing Data

- Indigenous Methodologies
- Indigenous Epidemiology
- Indigenous Research
 - Cultural Rigor

Decolonizing Research



American Indians/Alaska Natives



**5.2
million**

American
Indians and
Alaska Natives
alone or in
combination
with other
races

78%

of American Indians and
Alaska Natives live off
reservation

71%

of American Indians and
Alaska Native live in
urban areas

22%

of American Indians and
Alaska Natives live on
reservations

Source: Continuity and Change: Demographics, Socioeconomic, and Housing Conditions of American Indians and Alaska Natives; U.S. Department of Housing and Urban Development, Office of Development and Research; January 2014.
2010 U.S. Census; U.S. Census Bureau

AI/AN Data Challenges

Racial misclassification

Small population

Biomedical-epidemiological model

Limited sources that collect both race (AI/AN) and geography (urban)

Collapsing racial data into 'other'

Variability in collection, analysis, and presentation of data

High rates of missing data

Suppression of small numbers

Lack of cultural relevance



A Lack of Data

Small Population

- 5.2 million American Indians and Alaska Natives (AI/AN) in the United States
- Stratification for health outcomes, demographics, geography, etc. further reduce sample size

Limited Sources

- Limited data sets contain both race/ethnicity data and geographic data
- Public health departments only provide data on a state-level
- Difficult to identify variability in population health linked to geographic context



Challenges of Westernized Systems

Biological-Epidemiological Model

- Guides federally funded research paradigm
- Requires researchers to justify studies by using evidence-based practices and westernized paradigms
- Often results in approaches insufficient to understand health status and wellbeing of indigenous communities

Lack of Cultural Relevance

- Most data collection tools are not culturally-adapted
- Tools lack questions that hold resonance for native communities
- Results inadequate to fully inform policy and programs in native communities



Invisibility and Erasure

Collapsing Racial Data into “Other”

- Racial groups with small numbers collapsed into “other” catch-all groups
- Common in dissemination of data sets
- Reporting of multi-racial identified individuals as a single homogenized “multi-racial” category

Suppression of Small Numbers

- A standard epidemiologic practice
- Done out of concern for protected health information
- Done because small samples often yield statistically insignificant results
- Harmful when applied without question or consideration of alternate strategies



Incomplete Systems of Data

Variability in Data Governance and Presentation

- Range of practices for data collection, analysis and presentation
- Need for greater transparency and documentation about methodological choices
- More exploration of implications

High Rates of Missing Data

- Race/ethnicity data is often missing
- Health-related fields are often missing or incorrectly coded
- Data is excluded from analysis

Misclassification: Common Causes & Factors

Misclassification masks the actual AI/AN population size:



Correcting for Racial Misclassification

- Conduct specific research on AI/AN population/community
- Support linkage projects
- Report limitations of work

Improving Data & Enhancing Access - Northwest (IDEA-NW)

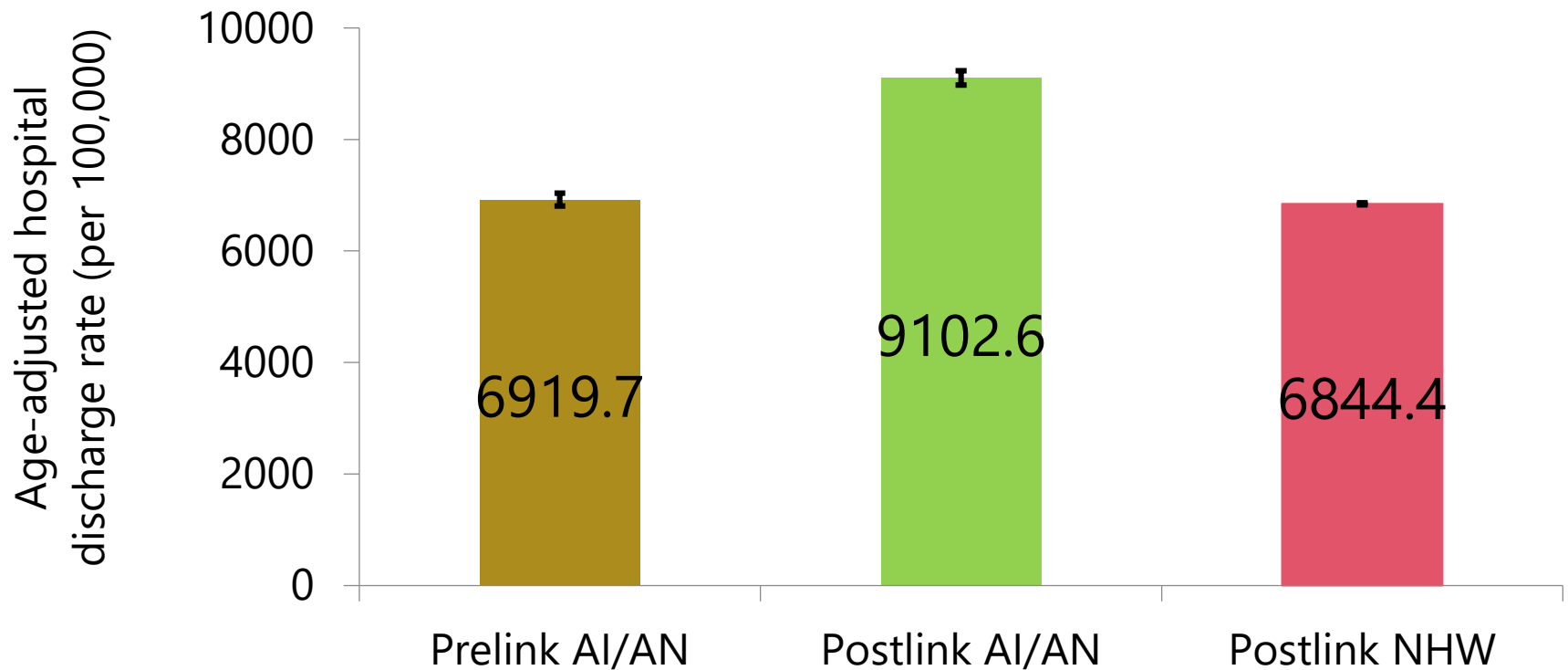
- UIHI collaboration with Northwest Portland Area Indian Health Board
- Compares public health datasets with tribal enrollment lists
- Identifies cases of racial misclassification and adjusts counts

Linkage Project – Washington State

Washington	Cases sent for linkage	Matches	Number (%) misclassified race among matches		AI/AN in database prior to linkage	AI/AN in database after linkage	% increased ascertainment of AI/AN	Number (%) of misclassified coded as White		Number (%) of misclassified with unknown or missing race		Misclassification on prevalence among all post-linkage AI/AN
CHARS, 2010	746,029	8,043	3,937	49.0%	9,794	12,268	25.3%	2,299	58.4%	1,380	35.1%	32.1%
CHARS, 2011	738,406	8,144	3,660	44.9%	10,812	13,290	22.9%	2,272	62.1%	1,110	30.3%	27.5%
Deaths, 2010	48,259	588	82	13.9%	971	1,053	8.4%	79	96.3%	0		7.8%
Trauma, 2005-2009	111,825	2,254	1,265	56.1%	1,778	3,043	71.1%	819	64.7%	241	19.1%	41.6%

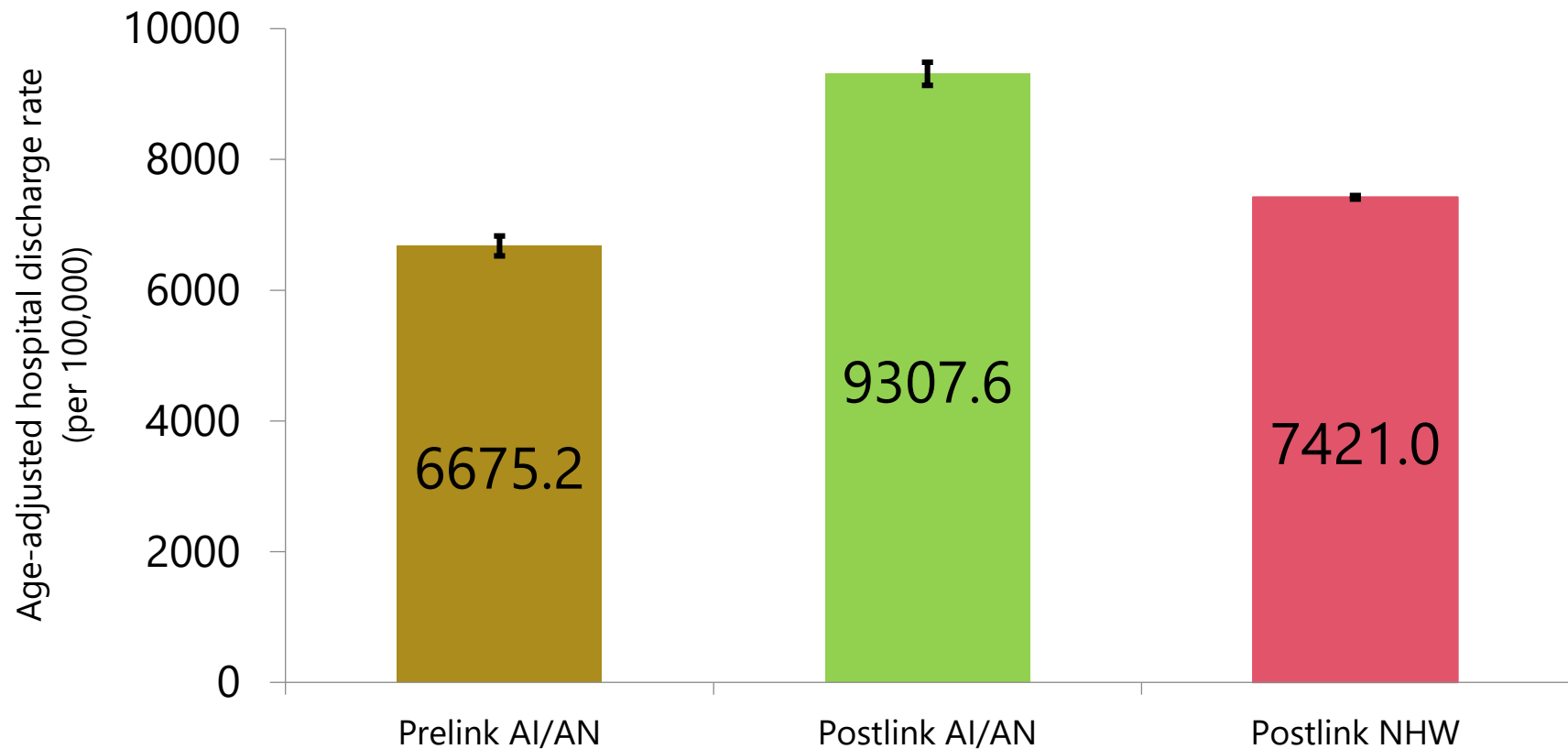
IDEA NW: Washington CHARS Linkage

Washington Comprehensive Hospital Abstract Reporting System (CHARS) Hospital Discharges, 2012-2013



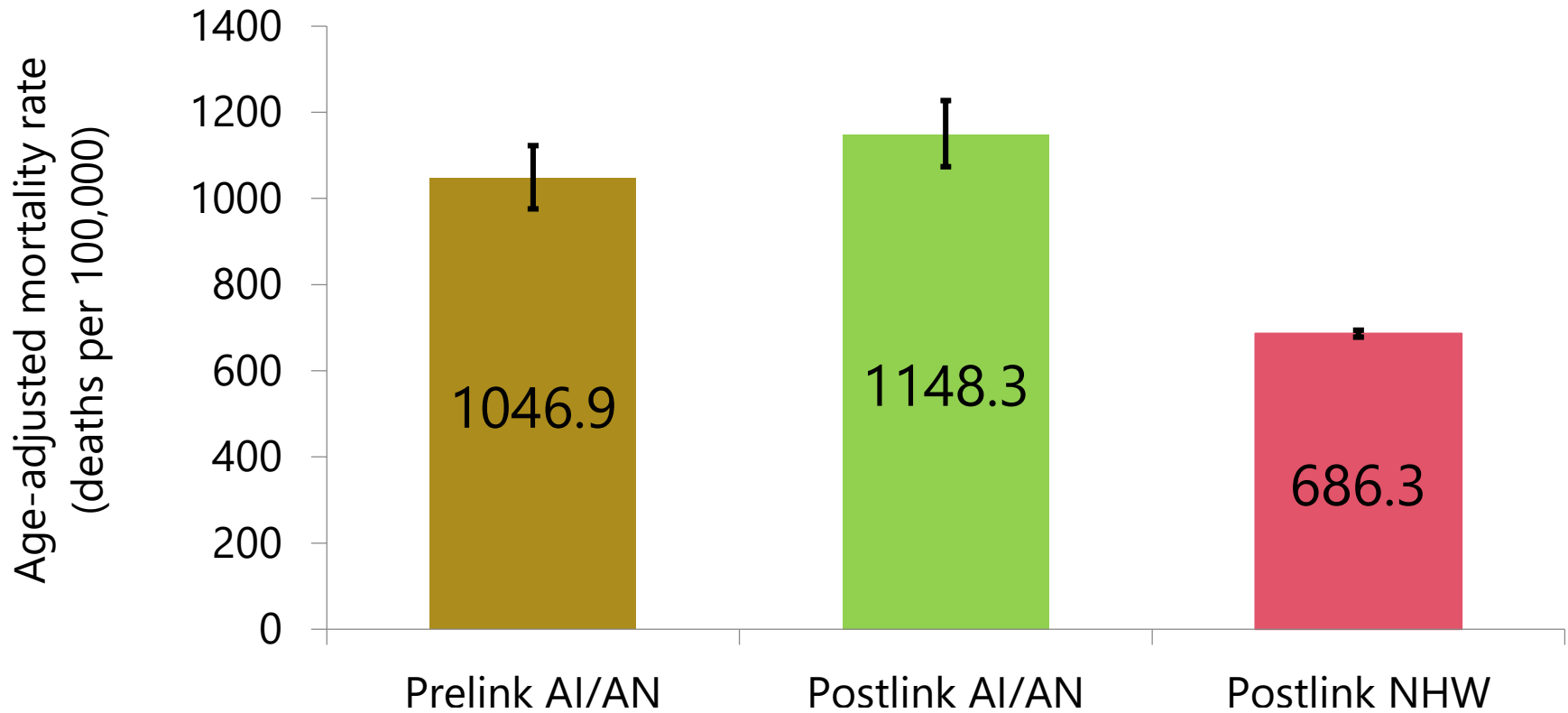
IDEA NW: Washington CHARS Linkage

Comprehensive Hospital Abstract Reporting System (CHARS) Hospital Discharges, Washington State, 2014:



IDEA NW: Washington Mortality Linkage

Washington State Mortality, 2014



IDEA NW: Washington Mortality Linkage

Leading Causes of Death for Washington AI/AN, 2009-2013:

Rank	Cause of Death	Pre-linkage AI/AN	Post-linkage AI/AN	Change in # of Deaths
1	Major Cardiovascular Diseases	1,148	1,261	+113
2	Malignant Neoplasms	902	980	+78
3	Unintentional Injury or Accident	543	580	+37
4	Chronic Liver Disease and Cirrhosis	250	275	+25
5	Chronic Lower Respiratory Diseases	231	260	+29
6	Diabetes Mellitus	206	224	+18
7	Suicide	147	166	+19
8	Alzheimer's Disease	98	111	+13
9	Influenza and Pneumonia	69	73	+4
10	Other Respiratory Diseases	68	73	+5
Total Deaths		6,759	7,485	+726



Epidemiologic Strategies to Increase Sample Size



- ✓ Aggregate data across time
- ✓ Use weighted sampling
- ✓ Oversample
- ✓ Limit stratification
- ✓ Use data from linkage projects
- ✓ Report limitations of work



Promoting Health Equity

Example program recommendations:

- ✓ Advocate for how data is collected
- ✓ Collect culturally relevant information
- ✓ Conduct mixed-methods research
- ✓ Recognize that “not statistically significant” does not mean a problem does not exist
- ✓ Report strength-based results



**Reclaim narratives of
indigenous health and
well-being**



Questions?



Resources

[Tribal Nations & the United States: An Introduction](#) (National Congress of American Indians)

[Broken Promises: Continuing Federal Funding Shortfall for Native Americans](#) (U.S. Commission on Civil Rights)

[The American Indian and Alaska Native Population: 2010 Census Briefs](#) (U.S. Census Bureau)

[Jim, M.A., et al \(2014\). Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area. *Am J Public Health*; 104 \(Suppl 3\): S295-302](#)

[James, R.J., et al \(2018\). Responsible Research with Urban Americans and Alaska Natives. *Am J Public Health*: 108 \(12\): 1613-1616](#)

[Urban Indian Health Data Dashboard](#) (Urban Indian Health Institute)

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