DATA EQUITY WEBINAR SERIES

DECOLONIZING DATA PRACTICES THROUGH INDIGENOUS EVALUATION APPROACHES

NOVEMBER 14, 2022
English
If you are a monolingual English speaker, please select the world-like interpretation icon at the bottom of the screen, then select English. If you are using zoom via a telephone/tablet, you will select the three dots to see more options, followed by interpretation and then English.

Español
Si solo habla/o prefieres escuchar en español, seleccione el icono de interpretación que parece un mundo en la parte inferior de la pantalla, luego seleccione español y no olvide silenciar el audio original. Si está usando Zoom en un teléfono o tableta, seleccionará los tres puntos para ver más opciones, seguido por interpretación y después español.
This presentation is being recorded

Recording

Tools located on the bar at the bottom of your screen

Chat
Access resources and send messages within the meeting

Live Transcript
Read live transcriptions/closed captions

Q&A
Enter questions for the presenters, and read their responses.
About Us

The Center for Wellness and Nutrition (CWN), a program of the Public Health Institute, is a national leader in developing campaigns, programs, and partnerships to promote wellness and equitable practices in the most vulnerable communities in California and across the country.
Data and Health Equity: Using Open-Source Data and Mapping to Understand Rural Community and Special Population Needs

December 12th

1PM (Pacific)
2PM (Mountain)
3PM (Central)
4PM (Eastern)
CONTEXT AND FOCUS FOR TODAY

Historically, policies and systems in this country have been deeply rooted in racism resulting in the stark inequities we see today.

Achieving health equity and racial justice with the communities we serve requires that we are intentional about data practices and strategies, especially those that transform data into action.

Today's Webinar will:

• Focus on the need for better data to help address the SDOH impacting Indigenous communities;
• Share the challenges associated with data collection practices;
• Provide steps to take to improve data collection to accurately and ethically represent all community members.
INDIGENOUS LAND ACKNOWLEDGMENT
Rosalina James, PhD
Public Health Associate Officer
WHO IS URBAN INDIAN HEALTH INSTITUTE

- Parent Organization est. 1970
- Seattle Indian Health Board
  - Grounded in Trad. Medicine
  - Federally Qualified Health Center (FQHC)
- 1 of 12 Tribal Epidemiology Centers
- Serves Urban AI/AN since 200
- 62 Urban AI/AN Based Organizations
WHO IS URBAN INDIAN HEALTH INSTITUTE, CONT.
TRIBAL EPIDEMIOLOGY CENTERS

• Established via Indian Health Care improvement Act (IHCIA)

• Four TECs were started in 1996, now 12 TECs

• TECs function independently, but also as part of a national network
PUBLIC HEALTH AUTHORITY

• 2010 Affordable Care Act permanently reauthorized the IHCIA

• TECs given “Public Health Authority” status

• Health and Human Services directed to provide TECs access to HHS data systems and protected health information
URBAN INDIAN HEALTH INSTITUTE

• Established in 2000 as a division of the Seattle Indian Health Board

• Mission to support the health and well-being of urban Indian communities through information, scientific inquiry, and technology

• Unique features
  • National scope
  • Integrated into a primary care clinic
British General Jeffrey Amherst advocated the use of smallpox to disaffected tribes of Native Americans in order to eradicate them.

Express policy of the U.S. government to sterilize Native women, often without informed consent or through coercion.

Gila River cut off from the Pima Indians and rerouted to farmers upstream.

Alcohol study with the Inupiat people that did not obtain proper consent and leaked the sensational "findings" before consulting the community.

Study conducted with the Havasupai Tribe; their DNA was to be collected for a study on type 2 diabetes. It was then used for research that was not in the consent process or stated research goals.

1763
1960s-1970s
1970
2000s
HISTORY OF MISTREATMENT - MISTRUST

Abusive health systems – 1970’s forced sterilization
Tribes confront painful legacy of Indian boarding schools

Marsha King, Seattle Times, Feb 3, 2008

The damage from that early abuse, loneliness and lack of love is being seen as a major factor in ills that plague tribes today, passed from one generation to the next and manifesting in high rates of poverty, substance abuse, domestic violence, depression and suicide

“I got to know that strap...Everybody knew what that strap was for, hanging inside the door.”
– Genevieve Williams, Tulalip

“I used to stand in the window and cry.”  – Fran James, Lummi
HISTORY OF MISTREATMENT - MISTRUST

Exploitation by biomedical research

- Bioprospecting, denigration of culture, forced assimilation
- Havasupai and Nuu-chah-nulth samples used for research that was unauthorized by the tribes
- Helicopter research – take blood/info, never learn outcomes, no tangible benefit
Mistrust of academic research due to historical and current trauma inflicted in the name of “knowledge for the greater good”

- Increasing involvement in/control over research process
- Time to act on health and social factors
FROM THE HEADLINES

Arizona State Board of Regents settlement with Havasupai Tribe

Consent form covered “medical and behavioral” research, but recruiters discussed only diabetes research on schizophrenia, inbreeding, and migration.

Ewan Callaway, NY Times, 27 April 2010
CUTTER INCIDENT

1955: Cutter Laboratories
- Defective vaccine
- 200+ children paralysis, death

Led to regulation of vaccines
Safety record. Preventable infectious diseases: Measles, whooping cough, HPV, flu
AI/AN DATA CHALLENGES

Racial misclassification

Biomedical-epidemiological model

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

Variability in collection, analysis, and presentation of data

High rates of missing data

Suppression of small numbers

Small population

Collapsing racial data into ‘other’

Lack of cultural relevance
**A LACK OF DATA**

<table>
<thead>
<tr>
<th>Small Population</th>
<th>How to Address</th>
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</thead>
<tbody>
<tr>
<td>• 5.5 million American Indians and Alaska Natives (AI/AN) in the United States</td>
<td>• Have a standard, accepted and inclusive definition of AI/AN</td>
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<tr>
<td>• Stratification for health outcomes, demographics, geography, etc. further reduce sample size</td>
<td>• Aggregate data across time or geography</td>
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<tr>
<td></td>
<td>• Use weighted sampling</td>
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<tr>
<td></td>
<td>• Limit stratification in analysis</td>
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<tr>
<td></td>
<td>• Understand “not statistically significant” does not mean a true difference does not exist</td>
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# A LACK OF DATA

<table>
<thead>
<tr>
<th>Limited Sources</th>
<th>How to Address</th>
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<tbody>
<tr>
<td>• Data sets that do not contain both race/ethnicity data and geographic data at the level needed</td>
<td>• Mandate the collection of race and ethnicity in health data</td>
</tr>
<tr>
<td>• Public health departments only provide data on a state-level, additionally certain reports may omit AI/AN</td>
<td>• Limit stratification in analysis to restrict reduction of sample size</td>
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<tr>
<td>• Difficult to identify variability in population health linked to geographic context</td>
<td>• Consider creating a supplemental report specific to AI/AN</td>
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## CHALLENGES OF WESTERNIZED SYSTEMS

<table>
<thead>
<tr>
<th>Biological-Epidemiological Model</th>
<th>How to Address</th>
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</thead>
<tbody>
<tr>
<td>• Guides federally funded research paradigm</td>
<td>• Conduct mixed-methods research</td>
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<tr>
<td>• Requires researchers to justify studies by using evidence-based practices and westernized</td>
<td>• Report strength-based and positive outcomes</td>
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<tr>
<td>paradigms</td>
<td>• Acknowledge that Indigenous practices and methods are true science TOO.</td>
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<tr>
<td>• Often results in approaches insufficient to understand health status and wellbeing of</td>
<td></td>
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<tr>
<td>Indigenous communities</td>
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**PUBLIC HEALTH INSTITUTE**

** CENTER FOR WELLNESS AND NUTRITION

** Urban Indian Health Institute

A Division of the Seattle Indian Health Board
### CHALLENGES OF WESTERNIZED SYSTEMS

<table>
<thead>
<tr>
<th>Lack of Cultural Relevance</th>
<th>How to Address</th>
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</thead>
<tbody>
<tr>
<td>• Most data collection tools are not culturally-adapted</td>
<td>• Place indigenous voices and knowledge at the center</td>
</tr>
<tr>
<td>• Tools lack questions that hold resonance for native communities</td>
<td>• Data collection tools and surveys must be culturally adapted</td>
</tr>
<tr>
<td>• Results are inadequate to fully inform policy and programs in native communities</td>
<td>• Use model of Indigenous health equity</td>
</tr>
</tbody>
</table>
# INVISIBILITY AND ERASURE

<table>
<thead>
<tr>
<th>Collapsing Racial Data into “Other”</th>
<th>How to Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Racial groups with small numbers collapsed into “other” catch-all groups</td>
<td>• Avoid reporting data and findings as ‘multi-racial’ and ‘other’</td>
</tr>
<tr>
<td>• Reporting of multi-racial identified individuals as a single homogenized “multi-racial” category</td>
<td>• Consider oversampling the AI/AN population</td>
</tr>
<tr>
<td>• Common in dissemination and analysis of data sets</td>
<td>• Have a standard, accepted and inclusive definition of AI/AN</td>
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<tr>
<td></td>
<td>• Allow for AI/AN to self-identify, if possible</td>
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<td></td>
<td>• Allow for AI/AN to identify as multiple races</td>
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</tbody>
</table>
## INVISIBILITY AND ERASURE

<table>
<thead>
<tr>
<th>Suppression of Small Numbers</th>
<th>How to Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>• A standard epidemiologic practice</td>
<td>• Limit stratification in analysis to restrict reduction of sample size</td>
</tr>
<tr>
<td>• Done out of concern for protected health information</td>
<td>• Aggregate data across time or geography</td>
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<tr>
<td>• Done because small samples often yield statistically insignificant results</td>
<td>• Oversample the AI/AN population</td>
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<tr>
<td>• Harmful when applied without question or consideration of alternate strategies</td>
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</tbody>
</table>

- Limit stratification in analysis to restrict reduction of sample size
- Aggregate data across time or geography
- Oversample the AI/AN population
## Incomplete Systems of Data

### Variability in Data Governance and Presentation

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

### How to Address

- Collaborate with AI/AN populations and communities
- Report limitations of work
- Consider using a more inclusive definition of AI/AN
- Be transparent about methodology
### INCOMPLETE SYSTEMS OF DATA

**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

**How to Address**

- Regular assessment of the data collection process to identify problems and initiate quality improvement activities
- Mandate the collection of race and ethnicity in health data
- Staff should be trained in best practices to collect race and ethnicity data
MISCLASSIFICATION: COMMON CAUSES & FACTORS

Misclassification masks the actual AI/AN population size:

- Tribe formerly ‘recognized’
- Use of Spanish surnames to determine race
- Self-identification with multiple races
- Changes to tribal enrollment policies
- ‘AI/AN’ not a response category in surveys or records
- Inconsistent definition of AI/AN
- Imprecise definition of AI/AN
- Subjective observation of data collector
- Tribe not federally recognized
- Changing self-identification
- Racism
MISCLASSIFICATION: COMMON CAUSES & FACTORS

Millions Of People Are Missing From CDC COVID Data As States Fail To Report Cases

September 1, 2021 4:20 PM ET Heard on All Things Considered
MISCLASSIFICATION: COMMON CAUSES & FACTORS

Share Of Total COVID-19 Cases

PUBLIC HEALTH INSTITUTE
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Urban Indian Health Institute
A Division of the Seattle Indian Health Board
UIHI COVID-19 RESOURCE MAP

Click on resource icons to display a pop-up containing details about each resource.

Click on transit stops to display a pop-up containing links to transit schedules.
Use the Screening tool to draw an area of interest
Create a report displaying the map and a list the resources in that area
Print report
A client arrived at our clinic seeking supplies such as a tent and hygiene bag. He had not been able to shower for a while and had no way to get food, as he only knew about one hot meal center in the area. He also did not have a phone and did not know the area well, so landmarks and street names were not much help. I asked him where he was staying, he said downtown. I was able to print a map of all the hygiene stations and food banks in a few mile radius of where he was staying. That way he did not have to keep returning to find food resources, he could just have a list with him at all times that had all the details he needed and a map showing him how to get there.
A relative came in to SIHB asking about access to a shelter and had mentioned that he was going to be moving to an encampment further south with a friend. He had expressed he was worried about where to find food once he was up there or how to shower. I told him about the map and printed it out with routes highlighted for him on how to access. After he had moved he later came back in for a walk in to see about housing and we were able to get him into clean and sober housing. I personally feel that he was only comfortable coming back for assistance with housing due to the rapport from giving the hygiene kit and map as assistance. No strings-attached, immediate help can be hard to come by for the homeless community.
# EMPOWERMENT IS PREVENTION

<table>
<thead>
<tr>
<th>Guiding Youth Principles</th>
<th>Activities</th>
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<tbody>
<tr>
<td>• Building resiliency</td>
<td>• Youth Gathering of Native Americans</td>
</tr>
<tr>
<td>• Promoting cultural connectivity &amp; wellness</td>
<td>• Kiis Youth Council</td>
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<tr>
<td>• Mentorship – leadership development</td>
<td>• Question, Persuade, Refer Trainings</td>
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<tr>
<td>• Promoting positive development</td>
<td>• Urban Indian Underage Usage:</td>
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<tr>
<td>• Reduce stigma about:</td>
<td>• Research &amp; Ed. Campaign</td>
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<tr>
<td>• Mental health and substance misuse</td>
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Building Resiliency with Native People

**Impacts**
- Address chronic disease by:
  - Education development
  - Prevention initiatives
  - Management support
  - Technical Assistance

**Build Capacity**
- Public Health Infrastructure
- Indigenous-based:
  - Methods
  - Frameworks
  - Evaluation

**5 Year Initiative**

*Building Resiliency and Action to Nurture Community Health*
Serving Relatives Across UIOs

**Substance Abuse & Suicide Prevention**

24 Funded UIOs

21 Programs → 4 Purpose Areas:

1. Community Needs Assessment & Strategic Planning
2. Suicide Prevention – Intervention – Postvention
3. Substance Use Prevention, Treatment & Aftercare

**Domestic Violence Prevention**

14 Programs → 2 Purpose Areas:

1. DVP, Advocacy, Coordinated Community Responses
2. Forensic Healthcare Services
Indigenizing Data:
Knowledge → Sovereignty → Wellness
Dr. Rose James
PUBLIC HEALTH ASSOCIATE OFFICER
Urban Indian Health Institute

Contact Information
Email: rosej@uihi.org or info@uihi.org
WEBINAR SERIES
OVERVIEW

Save-the-Date for the last webinar of the series:

- **Monday, December 12 at 1 PM PST** - Data and Health Equity: Using Open-Source Data and Mapping to Understand Rural Community and Special Population Needs
Thank You

Follow us on Twitter - Take part in our interactive events! @phi_wellness

Connect to like-minded partners by joining us on LinkedIn
linkedin.com/company/center-for-wellness-and-nutrition

Have a question? Write to us at info@wellness.phi.org
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