Urban Indian Health Institute

A Division of the Seattle Indian Health Board

DATA EQUITY WEBINAR SERIES

DECOLONIZING DATA PRACTICES THROUGH INDIGENOUS EVALUATION APPROACHES

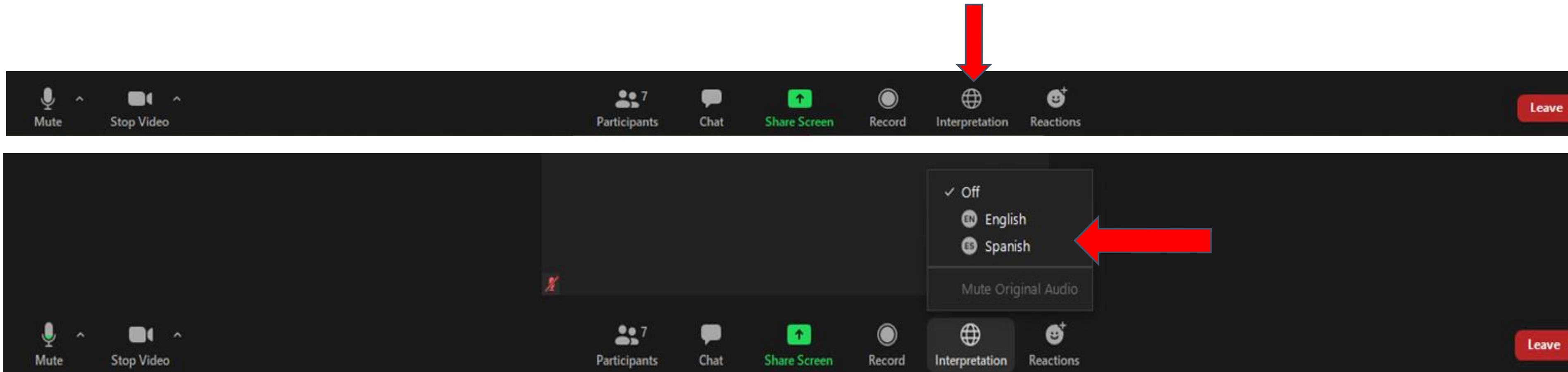
NOVEMBER 14, 2022

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 prefiere escuchar en español, seleccione el icono de interpretación que parece a 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.

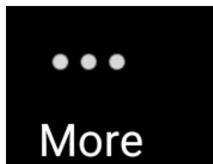


Raise Hand, & Reactions

Levantar Mano y Reacciones

ZOOM APP ON PHONE OR TABLET

APLICACIÓN DE ZOOM POR TELÉFONO O TABLETA



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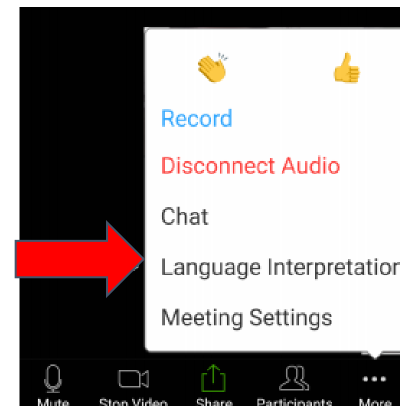
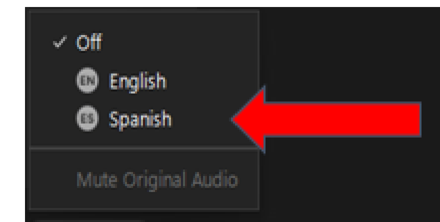
SELECCIONE LOS TRES PUNTITOS





SELECT YOUR LANGUAGE

SELECCIONE SU LENGUAJE

This presentation is being recorded

Recording

Tools located on the bar at the bottom of your screen

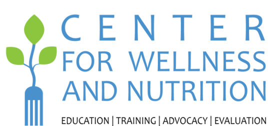
Access resources and send messages within the meeting

Read live transcriptions/ closed captions

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.

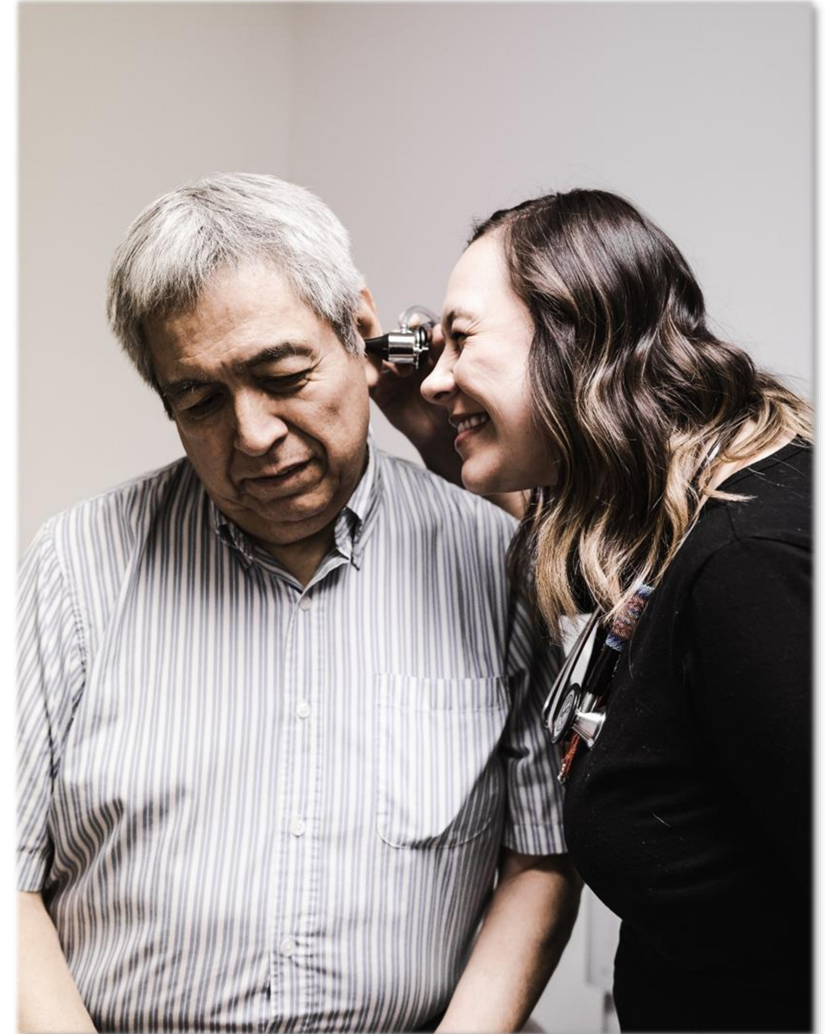
- Today's Webinar will:
- Focus on the need for better data to help address the SDOH impacting Indigenous communities;
- Share the challenges associated with data collection practices;
- Provide steps to take to improve data collection to accurately and ethically represent all community members.

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



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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

TIMELINE

1763

British General Jeffrey Amherst advocated the use of smallpox to disaffected tribes of Native Americans in order to eradicate them.

Late 1800s

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

1960s-1970s

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

1970

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

2000s

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.

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DECOLONIZE
DATA

HISTORY OF MISTREATMENT - MISTRUST

Abusive health systems – 1970's forced sterilization

Tribes confront painful legacy of Indian boarding schools

"I used to stand in the window and cry." – Fran James, Lummi

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

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

HISTORY OF MISTREATMENT - MISTRUST

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

Ewan Callaway, NY Times, 27 April 2010

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

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

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

A LACK OF DATA

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

CHALLENGES OF WESTERNIZED SYSTEMS

Biological-Epidemiological Model	How to Address
• 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	• Conduct mixed-methods research • Report strength-based and positive outcomes • Acknowledge that Indigenous practices and methods are true science TOO.

CHALLENGES OF WESTERNIZED SYSTEMS

Lack of Cultural Relevance	How to Address
• Most data collection tools are not culturally-adapted • Tools lack questions that hold resonance for native communities • Results are inadequate to fully inform policy and programs in native communities	• Place indigenous voices and knowledge at the center • Data collection tools and surveys must be culturally adapted • Use model of Indigenous health equity

INVISIBILITY AND ERASURE

Collapsing Racial Data into "Other"	How to Address

• Racial groups with small numbers collapsed into "other" catch-all groups
• Reporting of multi-racial identified individuals as a single homogenized "multi-racial" category
• Common in dissemination and analysis of data sets
	• Avoid reporting data and findings as 'multi-racial' and 'other'
	• Consider oversampling the AI/AN population
	• Have a standard, accepted and inclusive definition of AI/AN
	    • Allow for AI/AN to self-identify, if possible
	    • Allow for AI/AN to identify as multiple races

INVISIBILITY AND ERASURE

Suppression of Small Numbers	How to Address
• 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	• 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	How to Address
• 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	• 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	How to Address
• Race/ethnicity data is often missing • Health-related fields are often missing or incorrectly coded • Data is excluded from analysis	• 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

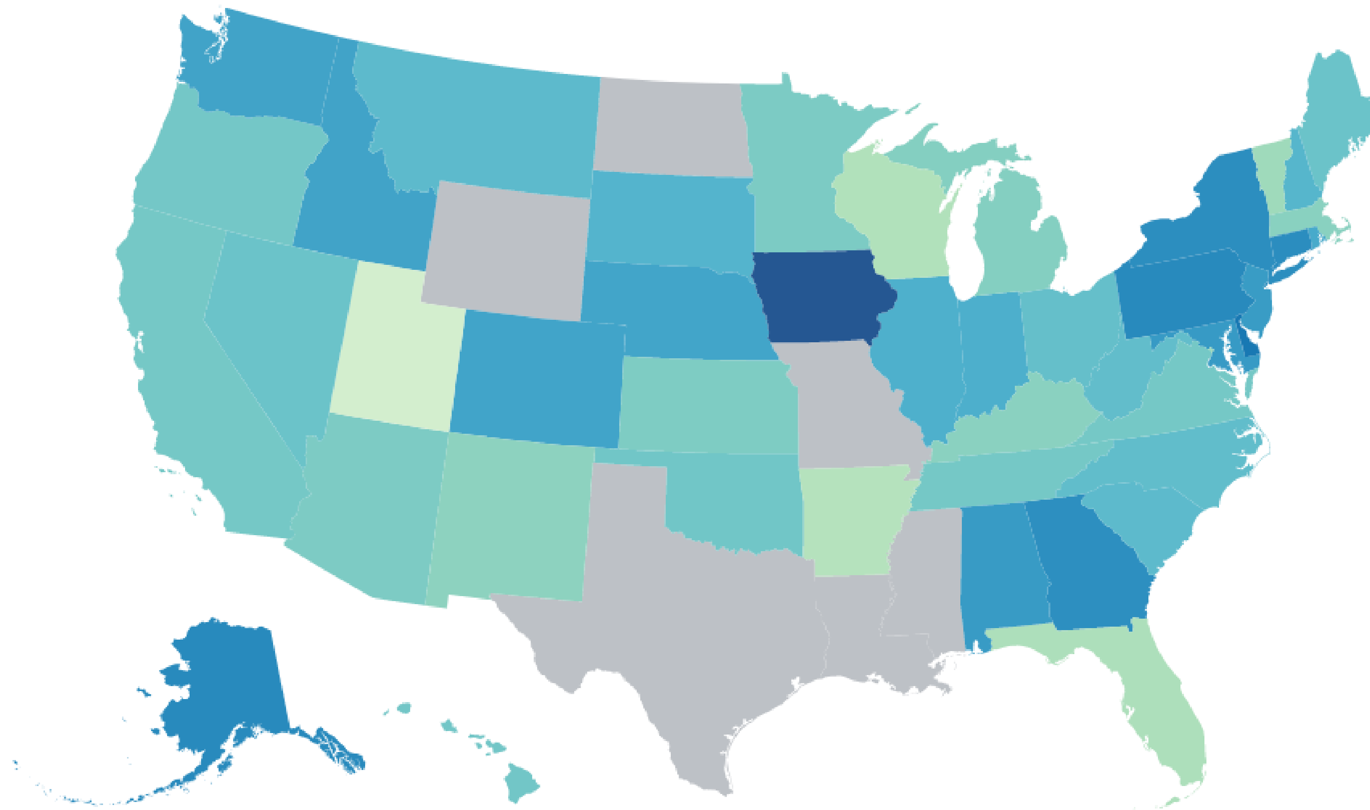
Misclassification masks the actual AI/AN population size:

MISCLASSIFICATION: COMMON CAUSES & FACTORS

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

September 1, 20214:20 PM ET Heard on All Things Considered

MISCLASSIFICATION: COMMON CAUSES & FACTORS



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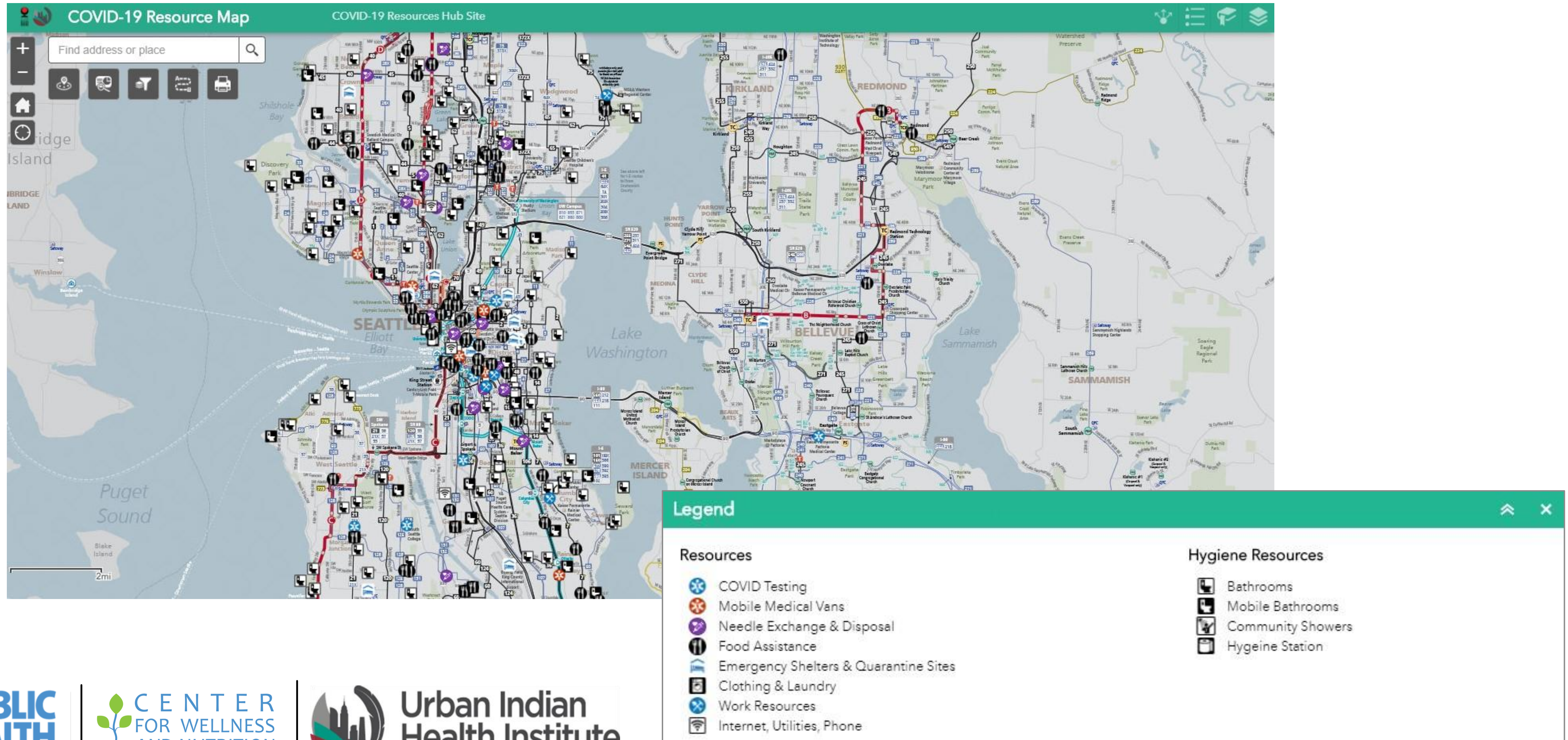
DECOLONIZE DATA

UIHI COVID-19 RESOURCE MAP



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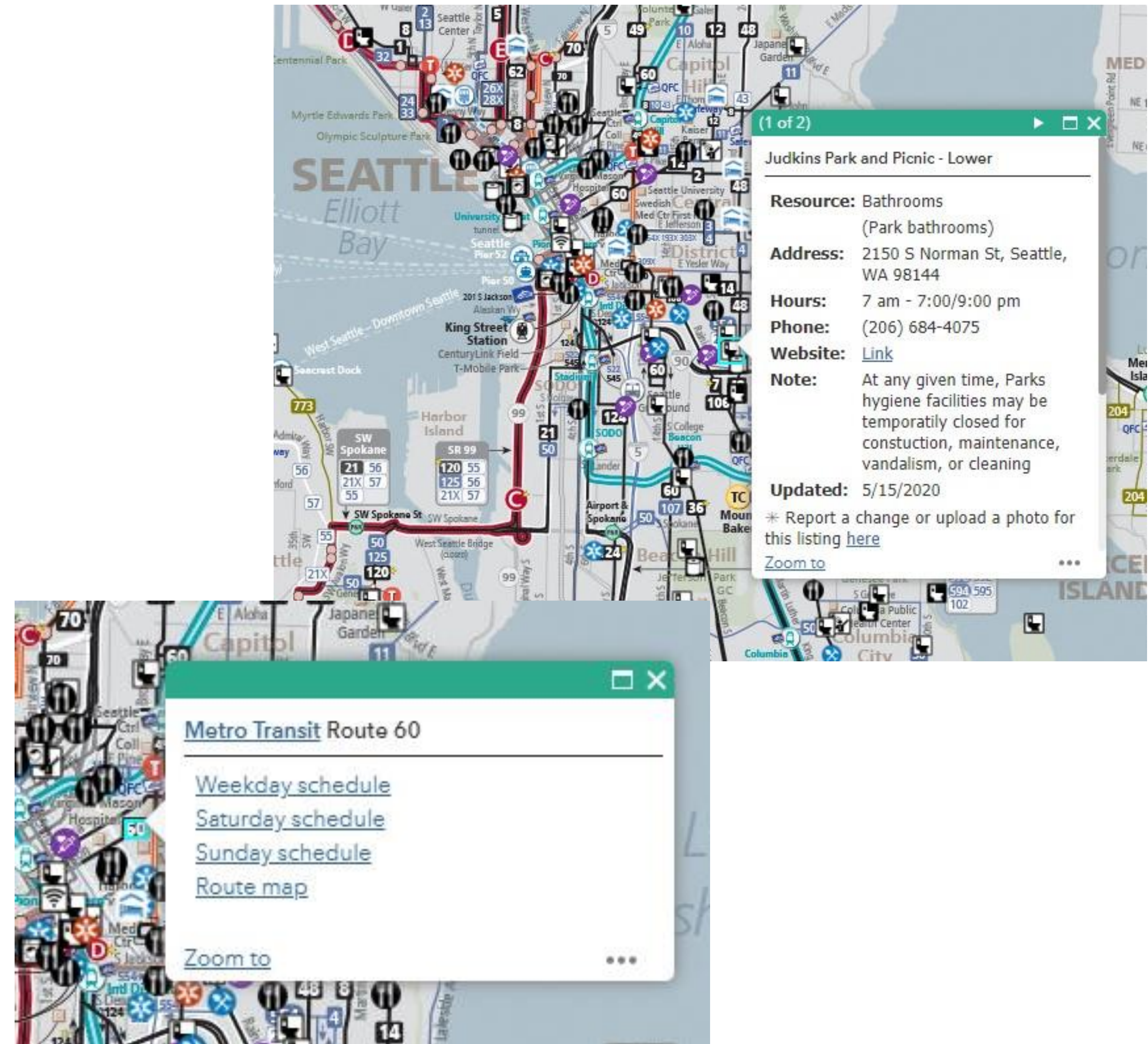
UIHI COVID-19 RESOURCE MAP

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



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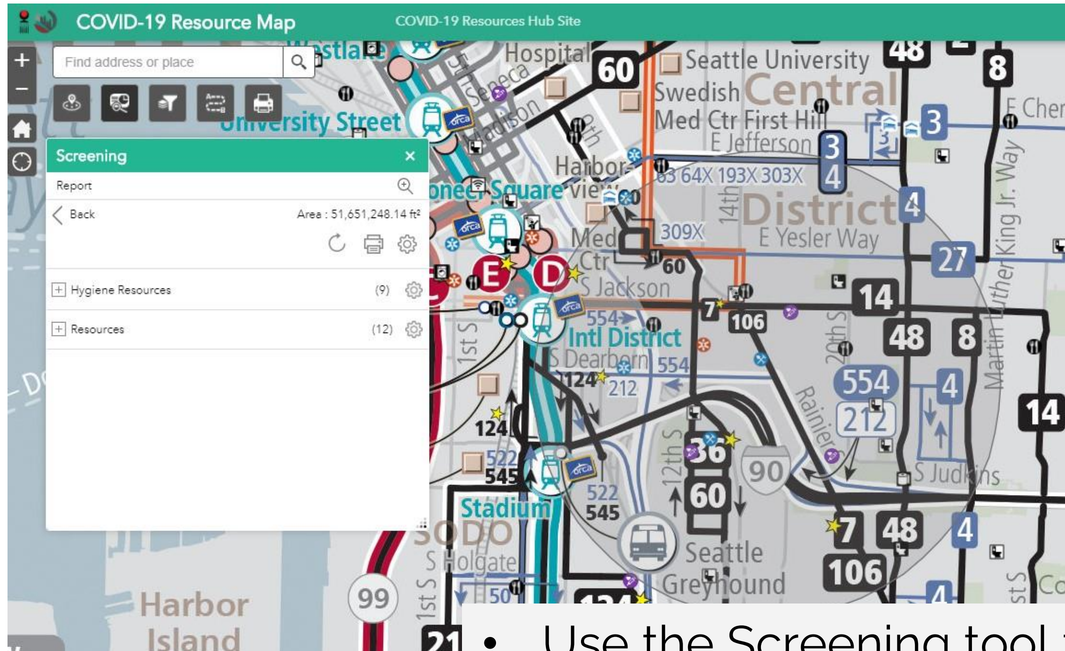

- Use the Screening tool to draw an area of interest
- Create a report displaying the map and a list the resources in that area
- Print report

Resources

Area of Interest (AOI) Information

Area : 51,651,248.14 ft²

Oct 23 2020 10:58:09 Pacific Daylight Time

#	Type	Name	Description	Location	Operating Hours
1	COVID Testing	Neighborcare Health @ Pacific Tower	Screenings for those who are pregnant, showing symptoms, 60 or older or have underlying conditions	1200 12th Ave S (Suite 401), Seattle, WA 98144	M-Thu 7:30-6pm; F 8-5pm
2	COVID Testing	ICHS - International District Clinic	COVID Testing Site	720 8th Ave S, Seattle, WA 98104	Contact site for hours or to make an appointment
3	Mobile Medical Vans	Calvary Lutheran Church	Mobile, walk-up care for homeless or recently homeless only (medical van only)	2415 S 320th St, Federal Way, WA 98003	Tuesday, September 22nd from 3:30pm-7:30pm
4	Needle Exchange & Disposal	Hepatitis Education Project	Needle Exchange	1621 S Jackson St, Suite 201, Seattle, WA 98144	Tuesday/Wednesday/Thursday: 1pm - 5pm
5	Needle Exchange & Disposal	City of Seattle Sharps/Needle Drop-off (Dr. Jose Rizal Park)	Needle/Sharps Disposal	1101 12th Ave S, Seattle, WA 98144	--
6	Needle Exchange & Disposal	City of Seattle Sharps/Needle Drop-off (Rainier Ave & I-90 Trail)	Needle/Sharps Disposal	1199 Hiawatha Pl S, Seattle, WA 98144	--
7	Work Resources	Division of Vocational Rehabilitation (DVR, DSHS) - Seattle Central Office	Medical evaluations, vocational assessments, counseling and job prep, job match, etc. to those who have physical or mental impairment	1200 12th Ave S, Suite 730, Seattle, WA 98144	--
8	Work Resources	Goodwill	Support services/classes, training	700 Dearborn Pl, Seattle, WA 98144	M-F 8:30am-5pm
9	Food Assistance	Asian Counseling and Referral Service (ACRS)	Food bank	919 S King St, Seattle, WA 98104	Home Delivery only
10	Food Assistance	Food Bank @ St. Mary's	Food Bank	611 20th Ave S, Seattle, WA 98144	M, W, F 10-1
11	Food Assistance	Operation Nightwatch	Sack meals	302 14th Ave S, Seattle, WA 98144	9pm every night
12	Food Assistance	Sound Generations	Meals	917 E Yesler Way, Seattle, WA 98122	Thurs, Sat: 11:45 am - 1:30 pm

"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

Guiding Youth Principles	→	Activities

• Building resiliency
• Promoting cultural connectivity & wellness
• Mentorship – leadership development
• Promoting positive development
• Reduce stigma about:
    • Mental health and substance misuse
	→	• Youth Gathering of Native Americans
		• Kiis Youth Council
		• Question, Persuade, Refer Trainings
		• Urban Indian Underage Usage:
		    • Research & Ed. Campaign

Building Resiliency with Native People

5 Year Initiative

Impacts	Build Capacity

Impacts

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

Build Capacity

- Public Health Infrastructure
- Indigenous-based:
  - Methods
  - Frameworks
  - Evaluation

Building Resiliency and Action to Nurture Community Health

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Serving Relatives Across UIOs

Substance Abuse & Suicide Prevention

24 Funded UIOs

Domestic Violence Prevention

21 Programs → 4 Purpose Areas:

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

14 Programs → 2 Purpose Areas:

1. DVP, Advocacy, Coordinated Community Responses
2. Forensic Healthcare Services

Indigenizing Data:
Knowledge → Sovereignty → Wellness

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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

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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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