Tribal Data Repository and U24 Resource Center for Tribal Epidemiology Centers

**December 7, 2022** 

**NIH Annual Tribal Advisory Committee** 

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### COVID-19 Estimated Vaccine Coverage in the U.S. April 2021 and November 2021

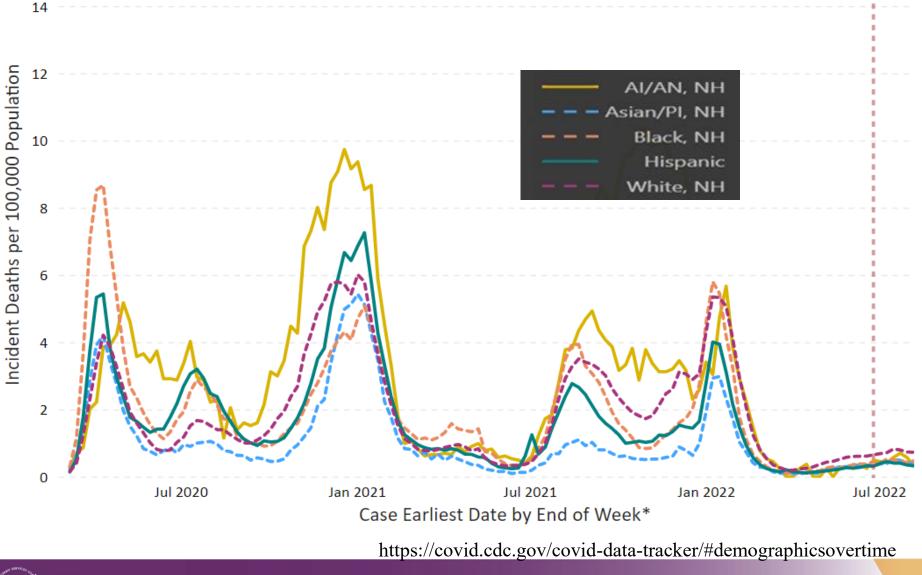
Race or Ethnicity	April 2021	November 2021
White	59.0%	78.7%
Black	46.3%*	78.2%
Latino/Hispanic	47.3%*	81.3%*
Asian	69.6%*	95.2%*
AI/AN	38.7%*	61.8%*
NH/PI	45.9%*	75.7%
Other or multiple race	42.6%*	68.0%*

Note. Vaccine coverage defined as at least one dose.

National Immunization Survey Adult COVID Module, MWWR-June 10, 2022; 71(23);757-763



### COVID-19 Weekly Overall Death Rates in the U.S March 7, 2020 – Sept 3, 2022



National Institute on Minority Health and Health Disparition X

### **RADx-UP by the Numbers**

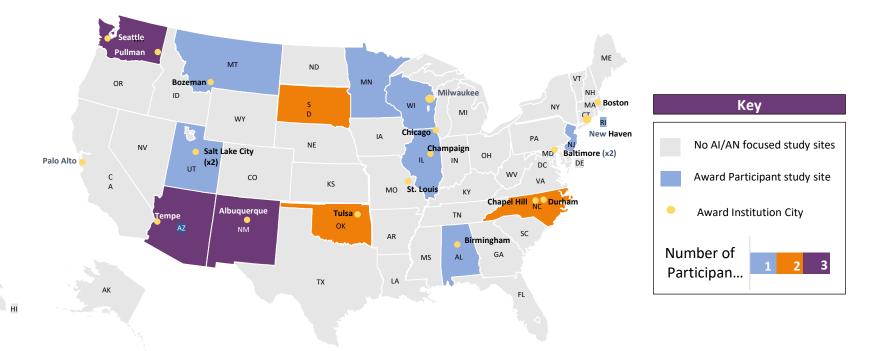
- 137 unique projects funded as competitive revisions, supplements and new U01s
- Coordination and Data Collection Center at Duke/UNC collecting Common Data Elements
- >353,000 unique participants enrolled
- >409,000 tests conducted
- >1.67 million individual tests abstracted from EHR
- 49 Community Collaboration mini-grants awarded
- 16 Rapid research pilot awards
- 100 projects have submitted CDE data to CDCC
- AJPH Special Supplement to be published on 11/29



### **RADx-UP Awarded Projects**

#### American Indian or Alaskan Native Populations and Residents of Tribal Lands or Reservations (10 total)

The awarded projects include the RADx-UP Phase I and Return to School Program awarded projects. This map shows projects that either focus on or include AI/AN populations.



**Note:** Four projects have studies across multiple states; the total number of participant study sites does not add up to the total number of projects represented.



### **Project Information- Primarily focused on AI/AN Populations and Residents of Tribal Lands or Reservations**

The chart below highlights the RADx-UP projects focusing on American Indian and Alaska Native populations

Contact PI	Project Summary	Institution	Study Locations
MARSIGLIA, FLAVIO FRANCISCO	This study will perform targeted SARS-CoV-2 testing within defined testing deserts in Arizona and will compare a subset of affected individuals who undergo the proposed testing and educational protocol with those who receive the same testing through standard systems available in the state.	ARIZONA STATE UNIVERSITY-TEMPE CAMPUS	Arizona
KHAN, SOHAIL	This study will enhance understanding of COVID-19 within the significantly and disproportionally impacted residents of Cherokee Nation. The researchers will perform rapid point-of-care testing, antibody testing, and contact tracing, and will develop educational materials for the community. Rapid data analysis will be used to nimbly move testing sites to areas of need.	CHEROKEE NATION	Cherokee Nation (NE Oklahoma)
CWIK, MARY	This study will address high rates of morbidity and mortality due to COVID19 among American Indian (AI) and Navajo Nation (NN) communities in the US. The goal of this study is to increase and speed up the testing among those with symptoms and improve adherence to recommended strategies.	JOHNS HOPKINS UNIVERSITY	East Central Arizona and Western New Mexico
ARMSTRONG, KATRINA	This research will perform a phased study of three Lakota tribes in South Dakota to address attitudes and access to testing.	MASSACHUSETTS GENERAL HOSPITAL	Lakota Tribes of the Western Plains, Western South Dakota
ADAMS, ALEXANDRA K	This study will use pragmatic randomized testing to evaluate home based testing through comparing community health workers with mail in at-home testing and their related feasibilities.	MONTANA STATE UNIVERSITY - BOZEMAN	Flathead Reservation in MT and Yakima Valley in WA



### Project Information- Primarily focused on AI/AN Populations and Residents of Tribal Lands or Reservations

The chart below highlights the RADx-UP projects focusing on American Indian and Alaska Native populations

Contact PI	Project Summary	Institution	Study Locations
KUMAR, DEEPAK	This study will evaluate the impact of work to increase testing uptake for American Indians in North Carolina.	NORTH CAROLINA CENTRAL UNIVERSITY	Lumbee Tribe of North Carolina, In Robenson, Scotland, Hoke and Cumberland
MALDONADO, YVONNE A	This study will upgrade and sustain local capacity at the Native BioData Consortium (NBDC) with training and development of Personal Protective Equipment (PPE) and Lab Protocols to improve COVID-19 testing and outcomes for Tribal populations by creating an improved diagnostics lab/local data resource and by testing the use of wearables on early diseases detection.	STANFORD UNIVERSITY	Great Plains Tribes, South Dakota
BUCHWALD, DEDRA	This study focuses on satellite centers that partner with six geographically contiguous Urban Indian Health Programs (UIHPs) across the United States to launch studies under Community Organizations for Natives: COVID-19 Epidemiology, Research, Testing, and Services (CONCERTS). Satellite Centers and partners include: Alaska Satellite Center & Southcentral Foundation, Pacific Northwest Satellite Center and Denver Indian Health and Family Services, Rocky Mountain Satellite Center and Indian Health board of Minneapolis, Southwest Satellite Center and First Nations Community Health source, and Southern Plains Satellite Center and Hunter Health Clinic.	WASHINGTON STATE UNIVERSITY	National sample of urban Indians
JAMES, JUDITH A	The Oklahoma Shared Clinical and Translational Resources (OSCTR) proposes to implement a multi-faceted, culturally-responsive, and versatile testing program that will compare the effectiveness and acceptability of two different testing schemes designed to increase diagnostic testing in minority and rural underserved communities and to better understand specific testing challenges in vulnerable populations.	UNIVERSITY OF OKLAHOMA HEALTH SCIENCES CENTER	Southern Plains Tribal Health Board, Chickasaw Nation
BARLOW, ALISON	The proposed study will utilize a community-based participatory research process to understand implementation barriers to in-person school instruction and various testing strategies (e.g., students vs. teachers; screening vs. surveillance; at-home vs at-school) in schools that serve Native American students ages 3-16 years.	JOHNS HOPKINS UNIVERSITY	Arizona, New Mexico



## **RADx Tribal Data Repository**

- To support development of an NIH-supported and Tribally-governed Tribal Data Repository (TDR) to facilitate AI/AN analyses from the RADx initiative
- To facilitate the process through which data produced from this initiative will be provided back to the Tribes to contribute to their knowledge of COVID-19 and making health decisions for their communities
- Supported by NIH Office of Data Science Strategies with RADx appropriations and managed by NIMHD



### **Research Priorities**

- Develop an independent research data repository governed under principles and practices of tribal sovereignty for data sharing
- Provide responsible data sharing and access to researchers and their collaborators who are generating or interested in working with RADx AI/AN research data
- Collaborate with the RADx-UP Coordination and Data Collection Center (RADx-UP CDCC) [https://radx-up.org] and other data collection centers (DCC) funded through the RADx initiative
- Support and promote AI/AN scientists working with these communities



### The RADx Tribal Data Repository will be *an* NIHsupported Tribally governed data repository

- Incorporates and sustains tribal sovereignty
- Provides AI/AN research data collected across the RADx Initiative with a focus on 10 projects
- Provides better understanding of the impact of COVID-19 and data to the tribal health boards
- Informs and supports policies to address current and future pandemics
- Promotes AI/AN biomedical researchers and programs
- \$2 million total costs per year for 4 years



## **Tribal Epidemiology Centers**

- Census reported 9.7 million individuals who self-identify as AI/AN — 2.9% of the population
- Tribal Epidemiology Centers (TECs) were established in 1996 under the re-authorization of the Indian Health Care Improvement Act (IHCIA) and funded by the Indian Health Service (IHS),
- TECs serve AI/AN communities and populations through the collection and analysis of health surveillance data, maintenance of patient registries, implementation and evaluation of public health interventions, development of health awareness campaigns, and mobilization of emergency response to public health crises



## Tribal Epidemiology Centers

### 12 TECs within each of the IHS administrative areas



### https://www.ihs.gov/epi/index.cfm?module=epi\_tec\_tecs



## **Goals of U24 TEC Resource Center**

- Provide subawards of \$100,000 directly to each TEC to enhance capacity to engage in data collection, compilation, analysis, and reporting.
- Provide technical assistance to the TECs through as-needed consultations to individual TECs as well as webinars or workshops
- Offer a research skills development and sustained mentoring program for early-stage investigators based in or closely affiliated with a TEC and other tribal organizations within IHS region
- Disseminate information about NIH and other Federal research funding, training, and mentorship opportunities, and provide technical assistance on applications for research grant funding.
- Maintain a compendium of publicly available resources generated by the TECs, including publications, reports, and public health campaign materials



## Award to University of Colorado

- Co-Pls Spero Manson, PhD and Joan O'Connell, PhD
- Colorado Resource Center for Tribal Epidemiology Centers: \$2,286,000total costs per year for 5 years
- Facilitate transfer of NIMHD support for each TEC
- Creation of a hub for technical assistance to the TECs
- Develop instructional materials, offer online courses and webinars, and promote collaborative research
- Emphasis on data science capacity building with ODSS support



## **NIMHD Vision for TECs**

- Create a network of Tribal-based organizations to conduct research by Native investigators
- Facilitate opportunities for RPG funding from NIMHD and other NIH institutes
- Provide opportunities for supplemental funding through the U24 on specific emerging issues such as COVID and capacity building in data science
- Expand the scope to tribal organizations and Native investigators on a regional basis



### National Institute on Minority Health and Health Disparities Research Framework

		Levels of Influence*				
		Individual	Interpersonal	Community	Societal	
<b>Domains of Influence</b> (Over the Lifecourse)	Biological	Biological Vulnerability and Mechanisms	Caregiver–Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure	
	Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws	
	Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure	
	Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination	
	Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient–Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies	
Health Outcomes		Individual Health	Family/ Organizational Health	合 Community 合合 Health	Health	

National Institute on Minority Health and Health Disparities, 2018

\*Health Disparity Populations: Race/Ethnicity, Low SES, Rural, Sexual/Gender Minority

Other Fundamental Characteristics: Sex/Gender, Disability, Geographic Region

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