



NATIVE WELLNESS
For the LOVE of THE PEOPLE

REALIZING INDIGNEOUS DATA SOVEREIGNTY: THE ROLE OF TRIBAL SERVING ORGANIZATIONS

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Albuquerque Area Southwest Tribal Epidemiology Center



ADVOCATING FOR TRIBAL SPECIFIC SURVEY QUESTIONS:

For example, to differentiate between commercial and traditional tobacco use on YRRS

AMERICAN INDIAN YOUTH IN NEW MEXICO

- **CIGARETTE USE:** Approximately 1 in 6 American Indian high school students in NM (16.1%) and 1 in 13 American Indian middle school students (8.4%) smoked cigarettes in the past 30 days.
- **GENDER DIFFERENCES:** American Indian male high school students were three times more likely to currently use chewing/spit tobacco than American Indian female students (13.4% vs. 4.5%), and two times more likely to use cigars or cigarillos (14.6% vs. 7.6%).
- **HOOKAH:** 15% of American Indian high school students smoked tobacco with a hookah in the past 30 days.
- **ACCESS:** More than 1 in 5 American Indian high school students who currently smoke cigarettes, bought them in a store (22.8%).
- **SCHOOL PROPERTY:** Among American Indian youth who smoke, 33% of middle school students and 27% of high school students smoked on school property.
- **QUIT ATTEMPTS:** More than half of American Indian high school and middle school students who currently smoke tried to quit in the past 12 months.

NOTE: these data do not distinguish between commercial and ceremonial tobacco use

**ADVOCATING FOR TRIBAL CONSULTATION FOR DATA RELATED DECISIONS
THAT IMPACT AMERICAN INDIAN PEOPLE:
For example, changes to race/ethnicity presentation in health data (2013)**

When there isn't the right check box for race/ethnicity on applications and surveys I always write in _____.

The Searchers.
Arguably John Ford's greatest film. Also widely regarded as the most racist movie in history.

Pocahontas.
She was 12 when she met John Smith. Let that sink in...nice work Disney.

Dances With Wolves.
Avatar was the best remake ever!

Being marginalized.
Being placed in a position of minimal importance, influence, or power.

Civilized.
Civility costs nothing and buys everything.

Idle No More.
Sustained Indigenous resistance to the rape, pillage, and exploitation of this continent and its women that has existed since 1492. Or when your car runs out of gas.

Hunter-gatherers.
There isn't anything else more to life. Hunt. Gather. That's pretty much all we did!

The token minority.
I understand what it is like being a minority. I'm the only billionaire here.

(From Cards Against Colonization)

January IN TUCSON

INTENSIVE EDUCATIONAL SESSIONS ON **INDIGENOUS GOVERNANCE, LAW & POLICY**

Announcing a **NEW COURSE**:

“EXPLORING DATA FOR NATION BUILDING: Indigenous Data Sovereignty and Governance”

1 Credit Hour | James E. Rogers College of Law | The University of Arizona | January 12- January 14, 2017

FACULTY (co-founders of the US Indigenous Data Sovereignty Network)



Stephanie Carroll Rainie, DrPH

Assistant Professor, Public Health, **Udall Center for Studies in Public Policy**; Associate Director and Manager, Tribal Health Program for the **Native Nations Institute** in the **Udall Center for Studies in Public Policy**; Assistant Professor in the Public Health Policy and Management Program at the **Community, Environment and**

Policy Department, Mel and Enid Zuckerman College of Public Health; and Assistant Director for the **Center for Indigenous Environmental Health Research**



Desi Rodriguez-Lonebear, MA

Graduate Research Associate, **Native Nations Institute** at the **Udall Center for Studies in Public Policy** and dual

doctoral student in sociology at the **University of Arizona** and demography at the **University of Waikato** in New Zealand

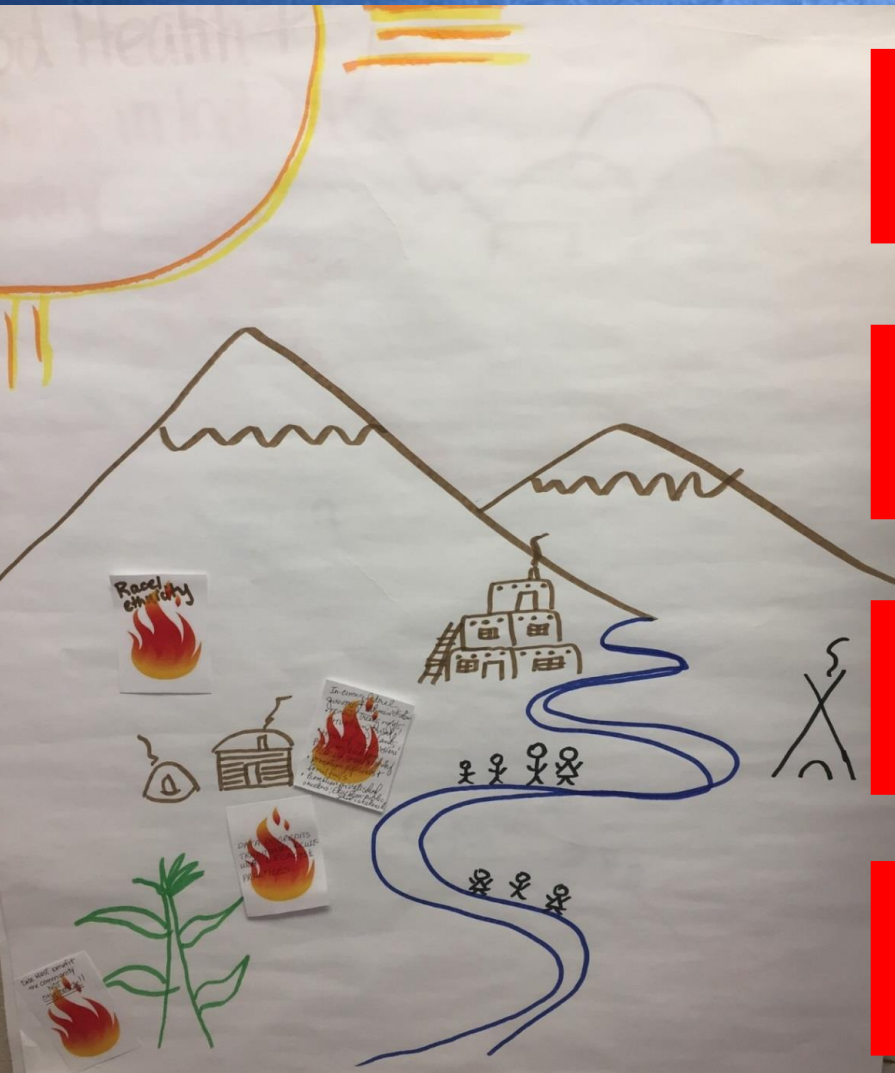
COURSE DESCRIPTION

The demand for data is increasing in Indian Country as tribes engage in economic, social, and cultural development on a rapid scale. This course will examine the role of data as an exercise of sovereignty in Native nation governance and self-determination. It will dually explore data collected internally by tribes and Native communities, and information collected by external sources.

This course examined the role of data as an exercise of sovereignty in Native nation governance and self determination.

- How can data facilitate nation building?
- How can Tribes influence the better collection of data on their people and resources by third parties?

Concerns About Data:

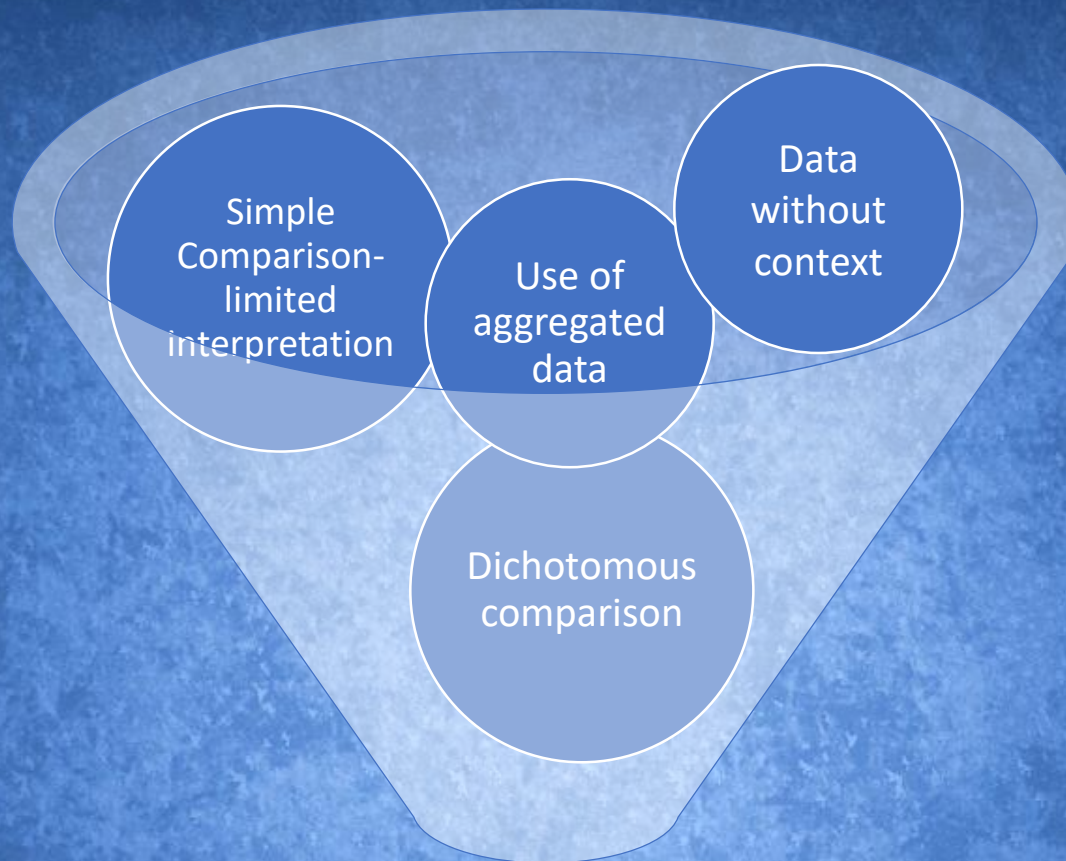


Data discredits traditional & cultural legacy and practices

Data MUST benefit communities and not stigmatize

New federal administration – concerns about data and treaty rights, social welfare programs, environment, education, etc.

Race and ethnicity issue is complex



Deficit Indigene

Narrow, yet encompassing representation

Adapted from Walter, M. & Andersen, C. (2013). *Indigenous Statistics: A Quantitative Research Methodology*. Walnut Creek, CA: Left Coast Press.

Health Characteristics of the American Indian or Alaska Native Adult Population: United States, 2004–2008

by Patricia M. Barnes, M.A.; Patricia F. Adams; and Eve Powell-Griner, Ph.D.
Division of Health Interview Statistics

Abstract

Objective—This report compares national estimates for selected health status indicators, health behaviors, health care utilization, and immunizations, and human immunodeficiency virus (HIV) risk factors among the American Indian or Alaska Native (AIAN) and Hispanic adults aged 18 years and over.

Methods—The estimates in this report are based on the Sample Adult core components of the National Health Interview Surveys, conducted by the Centers for Disease Control and Prevention's Center for Health Statistics. Estimates were adjusted for differences in the SUDAAN statistical package to account for differences in the survey design.

Results—In general, compared with other groups, non-Hispanic AIAN adults are more likely to have poorer health, unmet medical needs due to cost, diabetes, trouble hearing, activity limitations, and to have experienced feelings of psychological distress in the past 30 days. Non-Hispanic AIAN adults are more likely to be current smokers and current drinkers compared with other adults.

Conclusion—The non-Hispanic AIAN community faces many health challenges as reflected in their higher rates of risky health behaviors, poorer health status and health conditions, and lower utilization of health services.

Keywords: • National Health Interview Survey • health behaviors • health care utilization • conditions.

Introduction

The American Indian or Alaska Native (AIAN) population are persons having origins in any of the original populations of North, Central, or South America who maintain tribal affiliation or community attachment. The 2000 U.S. Census showed that 4.3 million (1.5%) adults in the United States were

AIAN. Approximately 56% (2.4 million) of AIAN adults are of one race or ethnicity, whereas the remaining 44% are AIAN in combination with one or more other races. The AIAN population is heterogeneous, with 569 federally recognized tribes, as well as numerous other tribes not federally recognized (1). Although AIAN persons live throughout

the United States, they are more likely to live in some areas of the country than others. According to the 2000 census,

17% of the AIAN population lived in the South, 17% in the West, and 9% lived in the Midwest.

AIAN populations face many health challenges, including higher rates of tuberculosis, pneumonia, cirrhosis, and suicide, and higher rates of homicide compared with other racial and ethnic groups (3). In the AIAN population, chronic liver disease and cirrhosis was the sixth leading cause of death, but was not ranked in the top 10 for the white, black, or Asian or Pacific Islander populations in 2005 (4). During that same year, accidents accounted for more than twice the percentage of deaths (11.7%) of the AIAN population compared with other population groups combined (4), and their age-adjusted suicide rates were 1.73 times as high as the corresponding rates for all persons combined (4). The AIAN population has a life expectancy at birth that is 2.4 years less than that of all U.S. populations combined (5), and they have 1.2 times as many years of potential life lost at age 75 as that of all other populations combined (4). The mortality differentials noted are

Non-Hispanic AIAN adults are more likely to be current smokers and current drinkers compared with other adults.

- White men (31.0%) were more likely than AIAN (23.8%), Hispanic men (22.0%), black men (20.6%), or Asian men (13.4%) to be current moderate or heavier drinkers.
- White women (14.7%) and AIAN women (11.6%) were more likely than black women (5.8%), Asian women (4.5%), or Hispanic women (4.5%) to be current moderate or heavier drinkers.

Data inconsistencies

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Objective—This report compares national estimates for selected health status indicators, health behaviors, health care utilization, health conditions, immunizations, and human immunodeficiency virus (HIV) testing status for American Indian or Alaska Native (AIAN) adults with those for white, black, Asian, and Hispanic adults aged 18 years and over.

Methods—The estimates in this report were derived from the Family Core and the Sample Adult core components of the 2004–2008 National Health Interview Surveys, conducted by the Centers for Disease Control and Prevention’s National Center for Health Statistics. Estimates were generated and compared using the SUDAAN statistical package to account for the complex sample design.

Results—In general, compared with other groups, non-Hispanic AIAN adults are more likely to have poorer health, unmet medical needs due to cost, diabetes, trouble hearing, activity limitations, and to have experienced feelings of psychological distress in the past 30 days. Non-Hispanic AIAN adults are more likely to be current smokers and current drinkers compared with other adults.

Conclusion—The non-Hispanic AIAN community faces many health challenges as reflected in their higher rates of risky health behaviors, poorer health status and health conditions, and lower utilization of health services.

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the United States, they are more likely to live in some areas of the country than others. According to the 2000 census, 43% of AIAN population lived in the West, 31% lived in the South, 17% lived in the Midwest, and 9% lived in the Northeast (2).

AIAN communities face many health challenges including higher mortality rates from tuberculosis, chronic liver disease and cirrhosis, accidents, diabetes, pneumonia, suicide, and homicide compared with other racial and ethnic groups (3). In the AIAN population, chronic liver disease and cirrhosis was the sixth leading cause of death, but was not ranked in the top 10 for the white, black, or Asian or Pacific Islander populations in 2005 (4). During that same year, accidents accounted for more than twice the percentage of deaths (11.7%) of the AIAN population compared with other population groups combined (4), and their age-adjusted suicide rates were 1.73 times as high as the corresponding rates for all persons combined (4). The AIAN population has a life expectancy at birth that is 2.4 years less than that of all U.S. populations combined (5), and they have 1.2 times as many years of potential life lost at age 75 as that of all other populations combined (4). The mortality differentials noted are

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Simple comparison/limited interpretation

Use of aggregated data

Dichotomous comparison

Data without any context



A satellite view of Earth showing the Americas and surrounding oceans, with the text "We are all related" overlaid.

We are all related

We must be mindful about our
recommendations locally.



Indigenous Data Sovereignty

Recognizes that data related to
Indigenous peoples should be
subject to the laws/governance
of those peoples.

(Adapted from Te Mana Raraunga – Maori Data Sovereignty
Network Chapter)

Indigenous Data Sovereignty Purpose

- Assert Indigenous rights and interests in relation to data
- Ensure Indigenous data are safeguarded and protected
- Advocate for Indigenous involvement in governance of data repositories
- Assert Indigenous rights in relation to decisions about collection of, access to, Indigenous data

RIGHTS VS. INTERESTS

*If we ground data using sovereignty framework, then
rights always outweigh interests.*

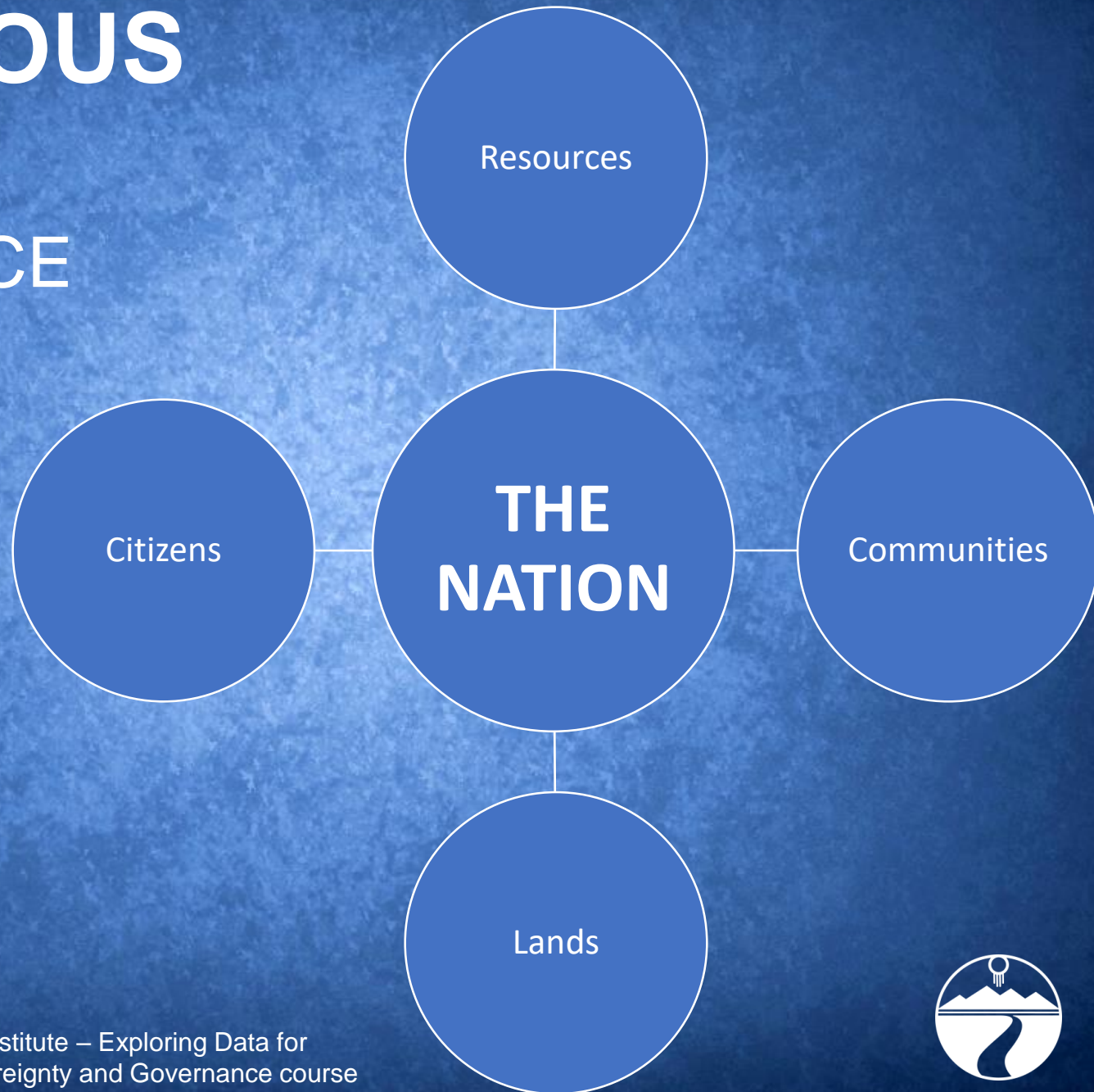
From University of Arizona, Native Nations Institute – Exploring Data for
Nation Building: Indigenous Data Sovereignty and Governance course

INDIGNEOUS DATA SOVEREIGNTY IS THE RIGHT OF A NATION TO GOVERN THE COLLECTION, OWNERSHIP, AND APPLICATION OF ITS OWN DATA.



From University of Arizona, Native Nations Institute – Exploring Data for Nation Building: Indigenous Data Sovereignty and Governance course

INDIGNEOUS NATION GOVERNANCE OF DATA IS ABOUT:



April 5-6, 2017

**What ACTION is needed
to move toward Tribal
Data Sovereignty?**

What is AASTEC's role?

What is your role?

**ENGAGE IN
CONVERSATIONS WITH
THE COMMUNITY
REGARDING THEIR ROLE
IN INDIGENOUS DATA
SOVEREIGNTY**



What is AASTEC's role?

Provide technical support for tribes to build on tribal organization infrastructure regarding IDS.

Advocate for Indigenous research methodologies, indigeneity, and IDS in the scientific community and with funders.

Build comfort and understanding regarding research methods, data, and scientific process among community members.



What is your role?

Work with tribal leaders, directors, program managers on local efforts to challenge funders regarding type of data used to make funding decisions.

Serve as translators and intermediaries between community and non-Native partners.

Develop Indigenous data collection instruments and analytic approach.

Contact Information

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