Data Sovereignty

Arizona Advisory Council on Indian Health Care:
Summer Training Series

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HEALTH CARE

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Prairie Band Potawatomi & Navajo

Overview

- Part 1: Understanding Data Sovereignty
- Part 2: The Significance of Chronic Disease Data
- Part 3: Design Thinking Workshop
- Part 4: Guided Scenario-Based Activity
- Conclusion

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Objectives

- Define and explain the concept of Indigenous Data Sovereignty, including its significance and relevance in the context of communities in this state.

- Introduce different approaches to Indigenous Data Sovereignty concepts, discussing how various communities approach the management and control of their data.

- Investigate the application of Indigenous data sovereignty principles in organisational settings.

- Discuss varying perspectives on Indigenous Data Sovereignty within the State of Arizona.

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Ice Breaker

What book or album would you bring to a desert island?

[Mentimeter](#)

Understanding Data Sovereignty

Sovereignty
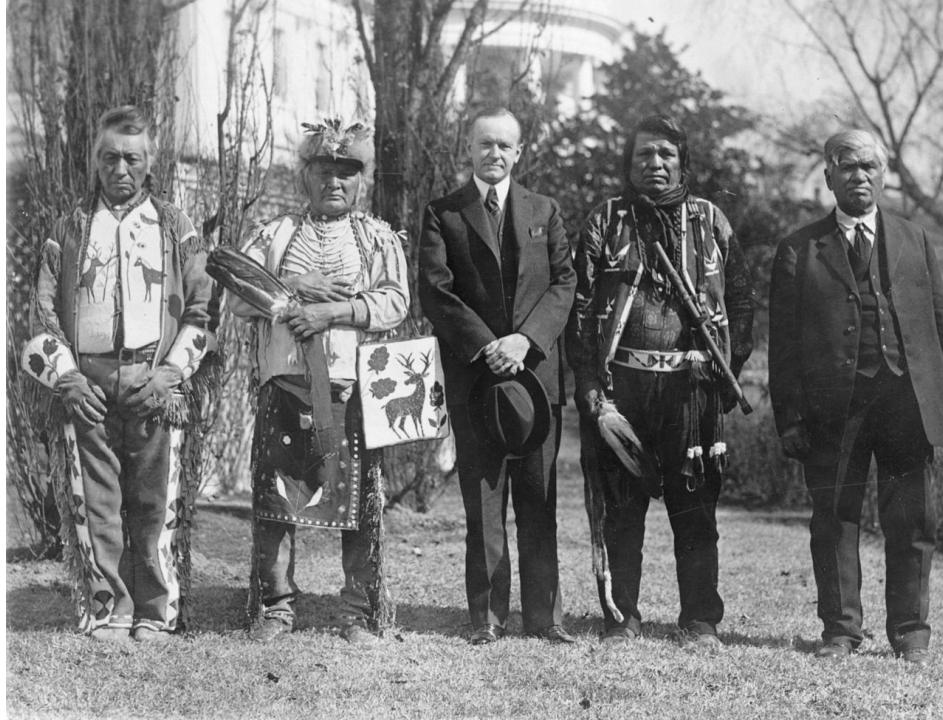
In the United States, Indigenous Tribes hold inherent authority to govern themselves

Allows Tribes to honor and preserve their cultural practices and traditional ways of life

Allows for advocacy and action towards self-determination

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What is Data Sovereignty?

Data sovereignty is the concept that information is subject to the laws and governance structure of the nation where it is collected

Indigenous Data Sovereignty (IDSov) is the right that Indigenous peoples globally have access and control over data about their Peoples, territories, lifeways and resources.

It comes from Tribal Sovereignty and the rights Tribes have to govern lands, resources, and themselves.

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History of Data and Tribal Communities

Since time immemorial, Indigenous people have collected and used data from themselves and their environment to inform their day to day lives and cultural practices.

It is recorded and shared among the community. Data is viewed as a living, breathing, changing thing.

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History of Data and Tribal Communities

Ethnology: study of characteristics of different populations of people

Method of colonization that used social categorization to exploit the land and the original inhabitants

Justification for government-funded programs that aimed to "civilize" Native populations

History of Data and Tribal Communities in Arizona

- John Wesley Powell
- Geologist, Anthropologist
- First Director of the Bureau of Ethnology at the Smithsonian Institution, 1879

Categorized human societies based on their social and familial relationships, adoption of technology, and intellect.

Savagery → Barbarism → Civilization
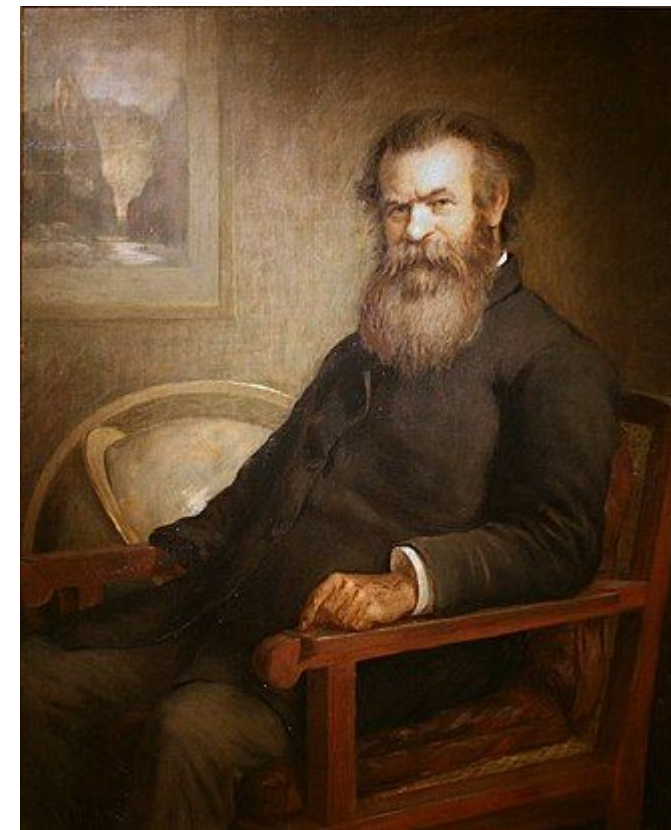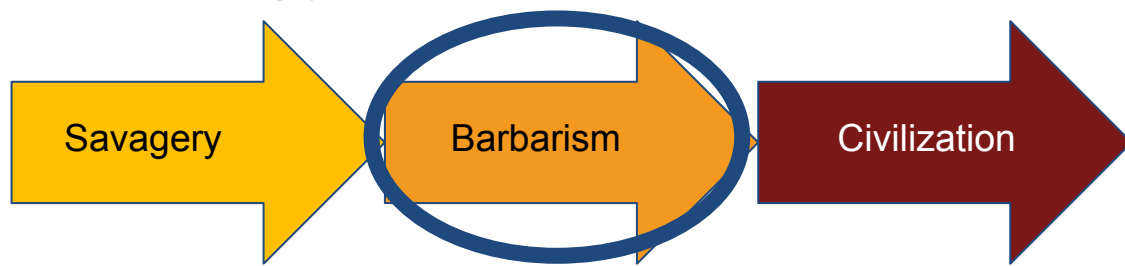
History of Data and Tribal Communities

- For many years, data has been collected *on* Tribal communities in large part due to the myth of the "Vanishing Indian"

-

- The romanticization of Native people led to other stereotypes
  - Noble Savage
  - Indian Princess

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Impact of Western Data Collection

Over time, Tribes formed a solid mistrust of researchers and those that took data from Tribes for their own gain, financially or academically.

Researchers often collected data on Tribes without any consultation or intention of returning any findings

Havasupai: A Case Study

In 1990, bio samples were taken from members of the Havasupai by Arizona State University under the premise that the samples would be used for diabetes research.

In 2004, it was discovered that the samples were being used by ASU for purposes that the community had not consented to.

The studies that were conducted were in direct offence to the Havasupai and their Tribal history.

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Havasupai: A Case Study

The immediate fallout of this incident was a lawsuit that Havasupai won against the Arizona Board of Regents.

The long term effects of the events created an even deeper mistrust towards not only researchers, but to healthcare providers as well

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Current Landscape

Arizona has circumstances that are unique. This area is the ancestral home of 22 federally recognized tribes.

There is a great opportunity to practice and to advocate for Indigenous Data Sovereignty in our work.
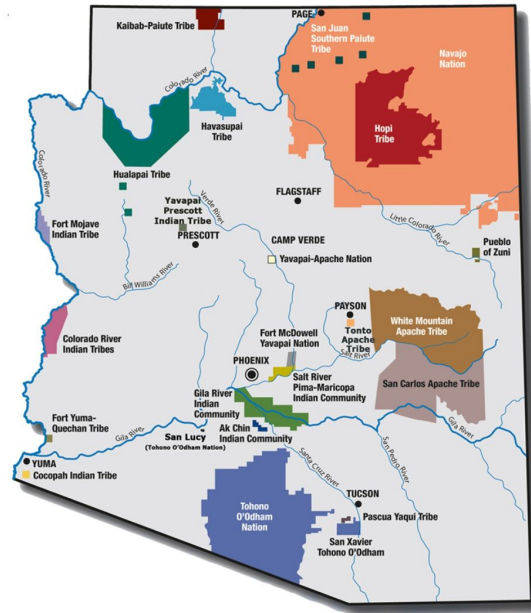
CARE Principles of Indigenous Data Sovereignty

The current world of data is being pushed in an "open" direction. the FAIR principles were developed as guidelines for the researchers to be able to access data.

The Significance of Chronic Disease Data

Data Source

Information referenced within this presentation is based on two AHCCCS Data Releases, provided to the Arizona Advisory Council on Indian Health Care (AACIHC) by AHCCCS in 2022 and 2023.

The AACIHC would like to thank our partners at AHCCCS, in particular:
- Current AHCCCS Director, Carmen Heredia;
- Former AHCCCS Director, Jamie Snyder;
- Data team members Judy Wilder, Yu-gin Chiang, Patrick Fyie, Tara Finck;
- DFSM team members Leslie Short and Ewaryst Jedrasik; and
- The entire Data Warehouse team.

Data sets were drawn from Medicaid claims, for Medicaid members who had an American Indian/Alaska Native (AI/AN) indicator on their member enrollment. Please note, that all personal AHCCCS IDs have been removed and replaced with randomized numerical values.

Each data release was requested with different variables.

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2022 Data Release: COVID-19

- **2022 Data Release:** COVID-19 Data Release

  - <u>**Timeframe:**</u>
    - January 1, 2021 to November 9, 2022

  - <u>**Size of Data Set:**</u>
    - 2 millions lines of claims reviewed
    - 66,902 AI/AN individuals

  - <u>**Included Claims:**</u>
    - Included *both* Fee-for-Service (FFS) Claims and Encounters Data
    - **COVID-19 Specific Claims:** Only claims and encounters submitted to the Medicaid program, *that included a COVID-19 diagnosis code* were included in this data set.

  - <u>**Purpose:**</u>
    - Used to discover links between health conditions and social determinants of health (SDOH) on COVID-19 infection, severity and outcomes.

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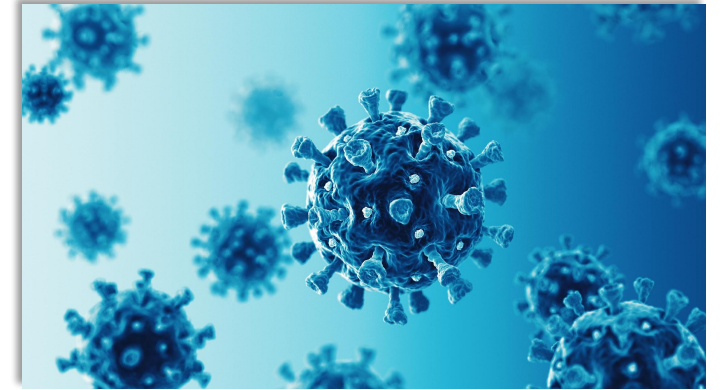
2023 Data Release: All Health Conditions

- **2023 Data Release**: All Health Conditions Data Release
  - **Timeline:**
    - March 1, 2020 to March 31, 2023

  - **Size of Data Set:**
    - 19 million lines of claims (19,625,781)
    - 211,208 AI/AN individuals

  - **Include Claims:**

    Included Fee-for-Service (FFS) Claims Data
    - Plans to potentially review MCO Encounters data of a similar nature are on pause until the full analysis of the FFS Claims data is completed. This is due to computer processing limitations, as these two quantities of data have to be processed separately due to their size and space requirements

  - **Purpose:**
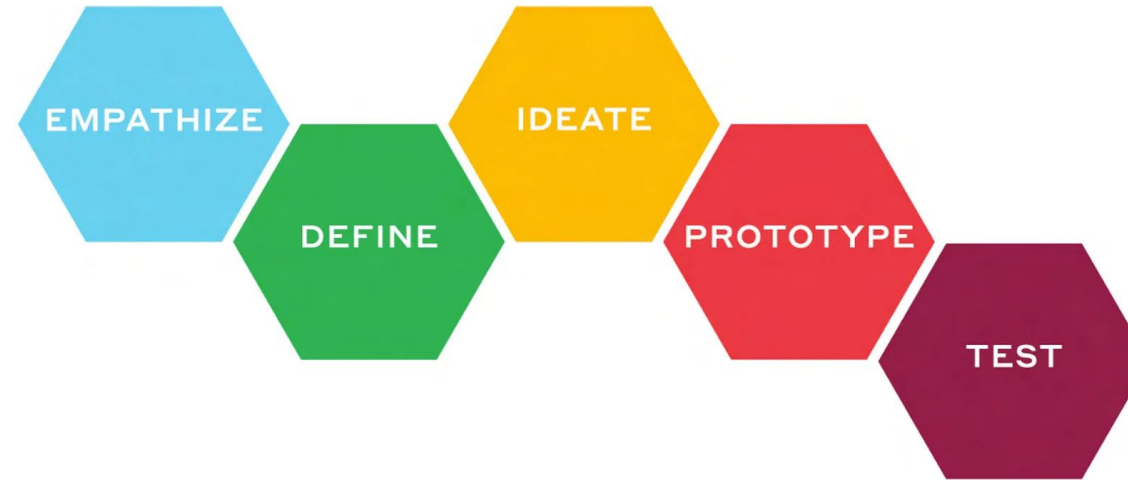   - Used to discover links between health conditions within AI/AN populations.

Why request this data?

Measure and assess health disparities that may be impacting American Indian/Alaska Native populations in Arizona.

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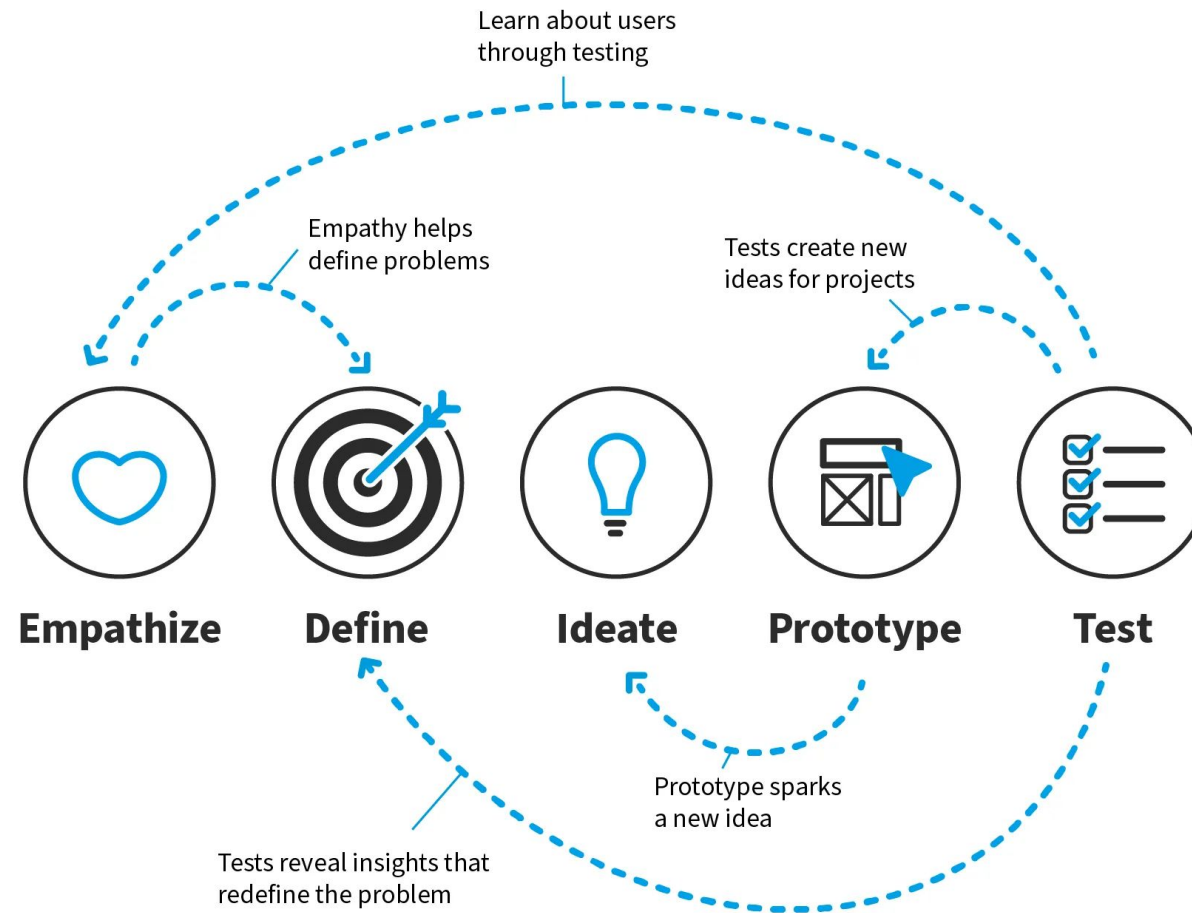HEALTH CARE

Design Thinking

Design Thinking

Non linear framework that allows for collaboration and problem solving

Can be repeated until ideal solution is found

Design Thinking

Learn about users through testing

Empathy helps define problems

Tests create new ideas for projects

Empathize   **Define**   **Ideate**   **Prototype**   **Test**

Prototype sparks a new idea

Tests reveal insights that redefine the problem

Design Thinking and Sa'ah Naaghai Bik'eh Hozhoo

Nitsáhákees (Thinking)

Sihasin (Assuring)

Nahat'á (Planning)
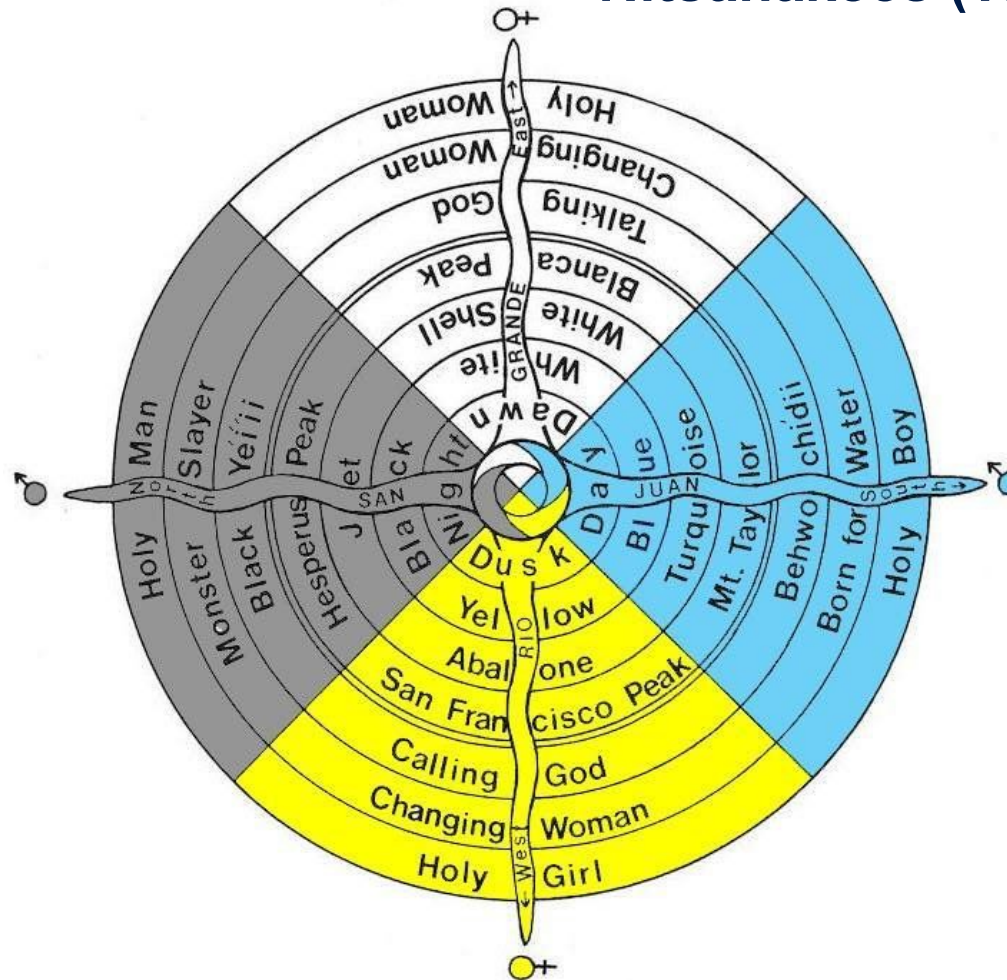
Iiná (Living)

Design Thinking

Empathize: Seek to understand the issue

What challenges are being faced by Tribal populations in regards to Data Sovereignty?

EMPATHIZE

Design Thinking

Define: Use previous understandings and outline the problem

What does Data Sovereignty look like to you? Define the core issues that Tribal populations face when accessing and using AHCCCS data.

DEFINE

Design Thinking

Ideate: Brainstorm and create potential solutions

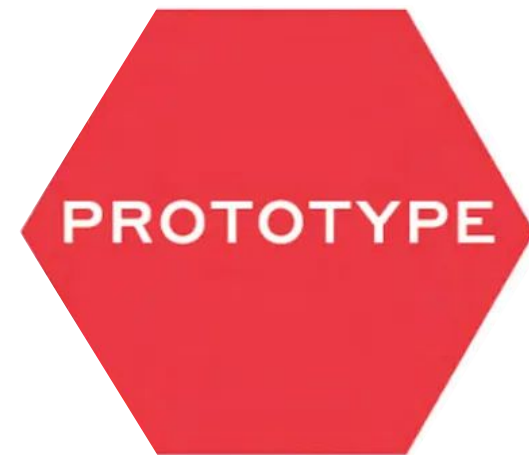In in ideal world, what potential tools or solutions could be implemented to solve data sovereignty challenges?

IDEATE

Design Thinking

Prototype: Experiment and find the best way to solve the problem

What are some tools or resources that could be used to enhance data sovereignty?

PROTOTYPE

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Design Thinking

Test: Try out your prototypes. What works? What doesn't?

How would you implement your solutions? How would you evaluate their effectiveness in enhancing Data Sovereignty?
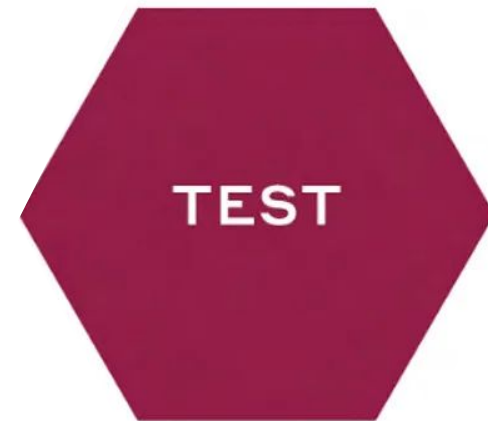
TEST

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Guided Scenario-Based Activity

Hypothetical situation

Hypertension, or high blood pressure, is one of the top 5 chronic conditions among AI/AN in Arizona.

A Tribe in rural Arizona is wanting to reduce hypertension within their community. Their health department wants to create a report that requires several points of data, including some from AHCCCS.

Use the Design Thinking Framework to work through potential challenges and solutions.

Conclusion

In Summary

- Data sovereignty is inherently tied to Tribal sovereignty

- Data sovereignty has no set definition

- Indigenous people should be involved in every step of data collection

- Design thinking can be used as a problem-solving tool for Tribal communities involved with data

- Design thinking has parallels to frameworks already in place

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Additional Resources

Native Nations Institute

https://nni.arizona.edu/

Design Thinking

https://www.interaction-design.org/literature/topics/design-thinking

Dine College

US Indigenous Data Sovereignty Network

https://usindigenousdatanetwork.org/

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+ TTi Miigwett +
+ Ahéhee' nitsaago +
+ Thank you +

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