

# Oregon Indian Country: Tribal Sovereignty's Impact on Health Care



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# Disclosure Statement



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- Department of Defense Pancreatic Cancer Research Program - Idea Development Award (Brody/Kills First) 09/2024 – 08/2027 - Addressing disparities in the Native American population: a pilot collaboration with the Warm Springs tribe
- Knight Cancer Institute – Mini-Quest Award (Kills First/Mayo) 04/2024-07/2026 - A First Step: Critical Missing Piece to Interventions in Tribal Communities in Oregon
- Kuni Foundation Cancer Research Fellowship (Kills First) 02/2026 – 01/2027

# Learning Objectives



- 1) Recognize historical and cultural factors that influence healthcare utilization among Tribal members.
- 2) Describe how Tribal sovereignty influences healthcare delivery in Oregon Indian Country.
- 3) Identify strategies to support culturally responsive care and collaboration with Tribal members.
- 4) Summarize collaborative research techniques to engage with Tribal partners

# Pre-Test Questions



- 1) Which of the following has historically influenced how many Tribal members interact with healthcare systems?
  - A. Increased availability of specialty care in Tribal clinics
  - B. Recent changes in federal insurance programs
  - C. Sterilization procedures in Indian Health Service
  - D. Differences in personal preference for certain providers

# Pre-Test Questions



- 2) What does Tribal sovereignty generally mean in the context of healthcare?
- A. Tribal health services must be managed by federal agencies only
  - B. Tribes have authority over decisions affecting their own healthcare systems
  - C. Healthcare decisions for Tribal members are made by state health departments
  - D. Tribes operate as regular private clinics within state regulations

# Pre-Test Questions



- 3) Which approach is most likely to support culturally responsive care for Tribal patients?
- A. Using standardized medication education techniques for all Tribal patients
  - B. Asking patients to adapt to clinic processes without modification
  - C. Limiting interactions to brief clinical visits
  - D. Showing openness to learning about the patient's cultural perspectives

# Pre-Test Questions

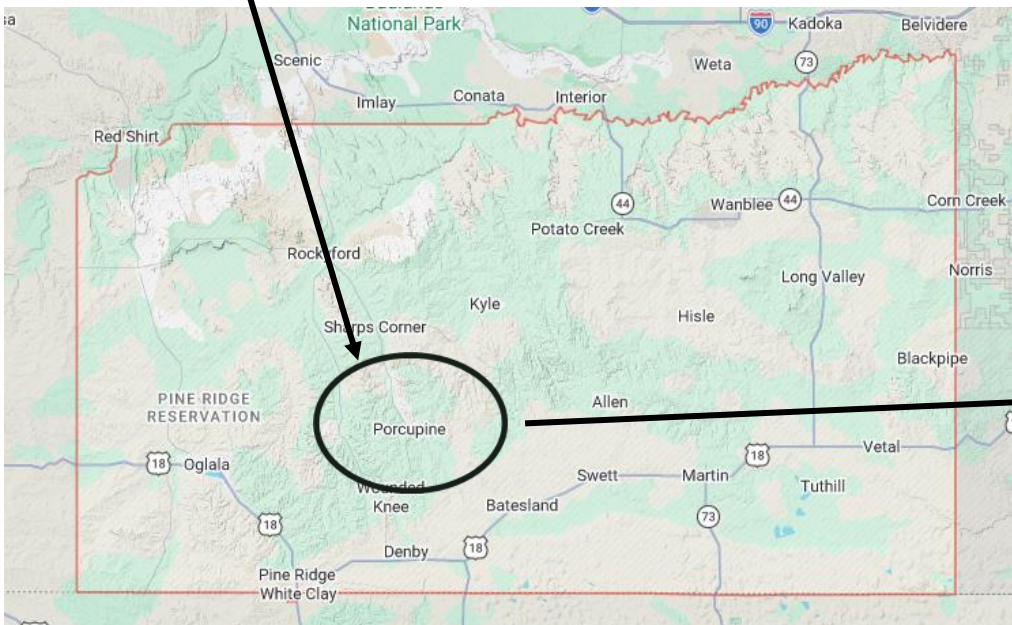
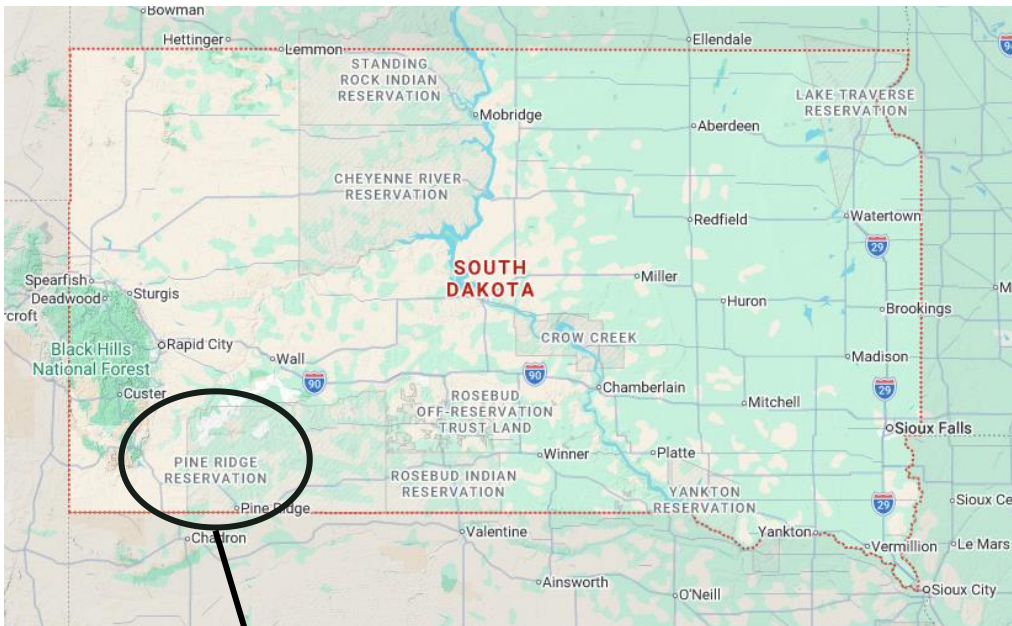


- 4) Why is it important for research teams to work directly with Tribal governments when planning health studies?
- A. To make data collection faster and easier
  - B. To replace the need for institutional review boards
  - C. To ensure research aligns with Tribal priorities and respects governance
  - D. To reduce the number of review requirements

# A Brief 20,000 Year History



- 20,000 years of inhabitation
- 7 to 18 million indigenous people in 1492
- 2.7 million as of 2020 census
- 574 federally recognized tribes
- 326 Tribal territories and reservations
- Tribal Sovereignty



Map data: ©2026 Google

# Our Culture Lives on Our Land



# Medical Mistrust and Dissatisfaction



- Native patients showed higher medical mistrust than non-Native patients.
- Mistrust was linked to lower satisfaction with communication.
- Greater mistrust = feeling care is less culturally aligned.

*“I worry that doctors and nurses will do experimental studies on me without telling or asking me.”*

*“I have put off getting medical care when I have had health problems because I do not trust doctors and nurses.”*

*“I have put off getting medical care in the past because I felt that I would be treated disrespectfully.”*

# Potential Contributing Factors



NNACoE, "Our Impact," [nnacoe.org](http://nnacoe.org)

- Access to care
- Historical trauma
- Medical misconduct
- Research misconduct
- Data misuse



# Access to Care

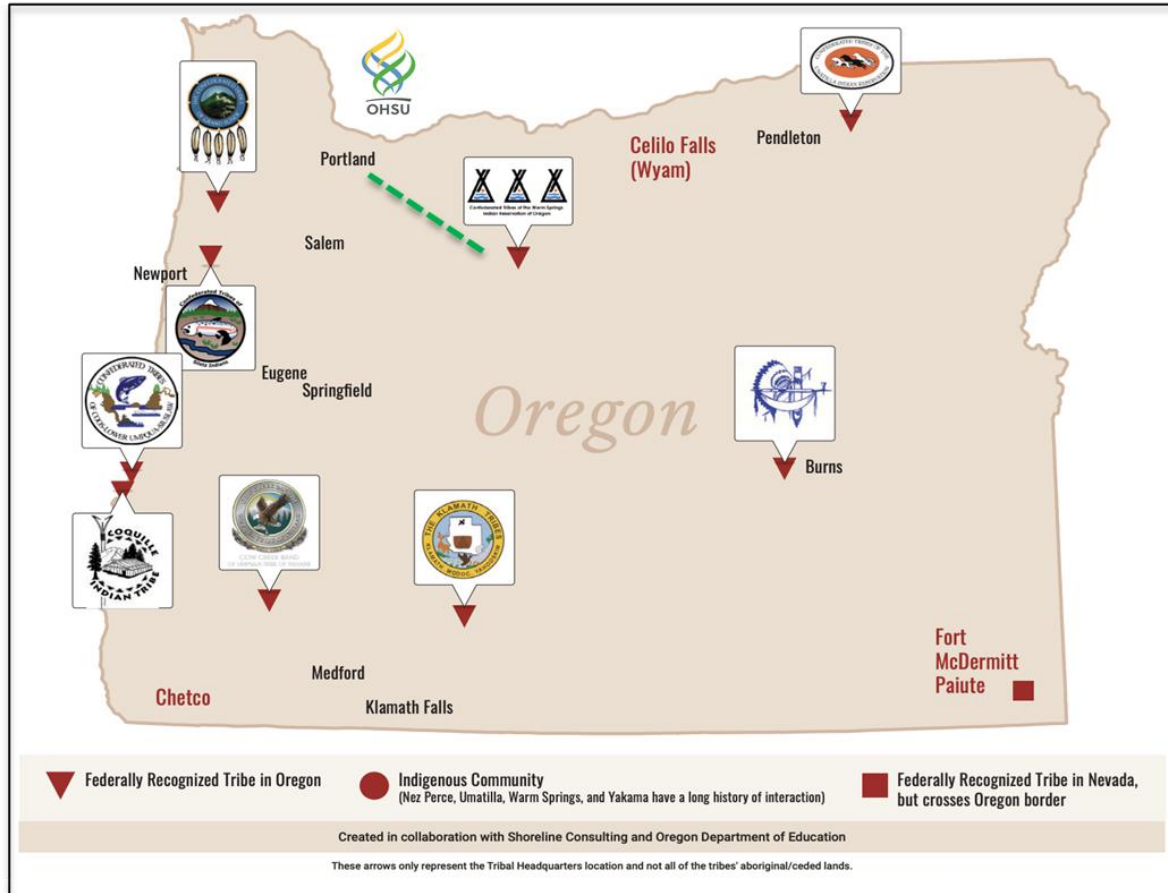
## Indian Health Service (IHS)

- Indian Health Care Improvement Act (1976)

To provide *“the highest possible health status to Indians and to provide existing Indian Health services with all resources necessary to effect that policy.”*

Agency	Per Capita Funding
Indian Health Service	\$4,078
Medicaid	\$8,109
Veteran Affairs	\$10,696
Medicare	\$13,185

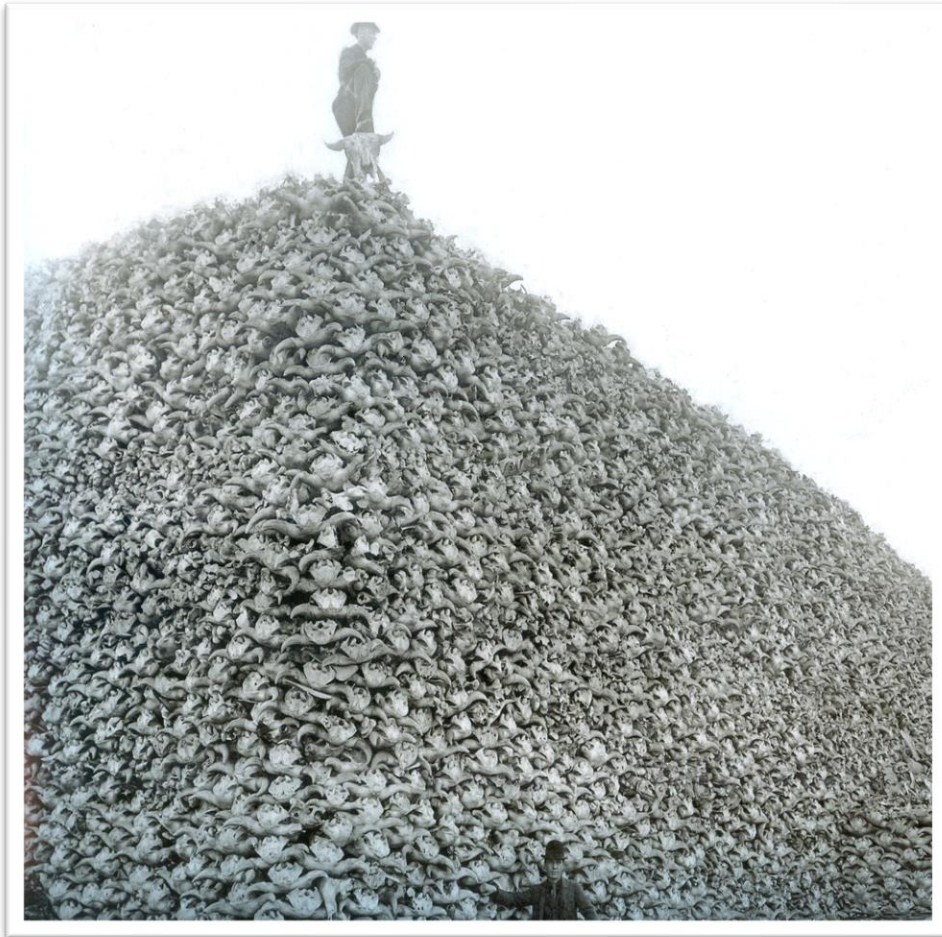
# Access to Care



## Rural Communities

- 68% of Indigenous people live on/near Indian reservations
- 1/3 of Indigenous people live under the poverty line

# Historical Trauma



- Starvation Campaign, 1800s
- Act for the Government and Protection of Indians, 1830-1862
- Indian Removal Act, 1830
- Morrill Land-Grant College Act, 1862
- Indian Relocation Act, 1956
- Indian Residential Schools
- Forced Sterilization, 1976
- American Indian Religious Freedom Act, 1978
- Missing and Murdered Indigenous Women

# Indian Boarding Schools



*“Kill the Indian, save the man.”*  
– Cpt. Richard Henry Pratt

- 408 Indian boarding schools
- Forcibly removed children as young as 4 years old
- 53 marked and unmarked burial sites
- Federal assimilation policies



# Medical Misconduct



- Forced sterilization of Native women (1960s-1970s)
  - 3,406 sterilizations
  - 25-50% of Native women of childbearing age
- Failures of clinic leadership to protect Tribal members
  - Case of Dr. Stanley Patrick Weber
- Government Accountability Office – Widespread oversight failures
  - Ethical professional conduct standards
  - Credentialing and privileging
  - Procedures of managing misconduct
- Medical racism
  - Separation of Native mothers and newborns

# Research Misconduct & Data Misuse



- Radioactive Iodine Experiments on Alaska Natives (1950s)
- Barrow Alcohol Study (1979) – Utqiagvik, Alaska
  - Findings were released to the national press before being shared with the community
- Havasupai Tribe DNA Misuse by Arizona State University (1990s–2000s)
  - Consented for diabetes study
  - Later used for mental illness, inbreeding, human migration theories

# Pre-Test Questions



- 1) Which of the following has historically influenced how many Tribal members interact with healthcare systems?
  - A. Increased availability of specialty care in Tribal clinics
  - B. Recent changes in federal insurance programs
  - C. Sterilization procedures in Indian Health Service
  - D. Differences in personal preference for certain providers

# What is Tribal Sovereignty?



- Definition of Tribal Sovereignty
  - The inherent authority of Tribes to self-govern and manage internal affairs
  - Government-to-government relationship
  - The Indian Self-Determination and Education Assistance Act (ISDEAA) - 1975
- Tribal Sovereignty in Healthcare
  - Tribes to control federal health programs through Self-Governance
  - Authority over Tribal health programs and traditional healing practices
  - Tribal authority over health needs, cultural frameworks, and data governance

# Tribal Sovereignty and Health Policy



- **Government-to-Government Structures**
  - Oregon recognizes Nine Federally Recognized Tribes
  - Mandatory consultation
  - Mutual information exchange, shared decision-making, and policy alignment
- **Influence on Oregon State Health Systems**
  - Tribes influence state priorities for reducing health disparities
  - Oregon Health Authority (OHA) provides Tribal-specific funding

# Tribal Sovereignty and Healthcare Delivery



- Design and Operation of Tribal Health Systems
  - Tribes can build and manage their own healthcare infrastructure
  - Tailor federal health programs
- Culturally Grounded & Traditional Health Practices
  - Oregon Medicaid coverage of Tribal traditional health practices
- Community-Defined Health Strategies
  - Integrate cultural teachings, ceremonies, and language into health promotion and prevention programs
  - Ensures healthcare is governed by Tribal values, histories, and priorities

# Pre-Test Questions



- 2) What does Tribal sovereignty generally mean in the context of healthcare?
- A. Tribal health services must be managed by federal agencies only
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# Principles of Culturally Responsive Care



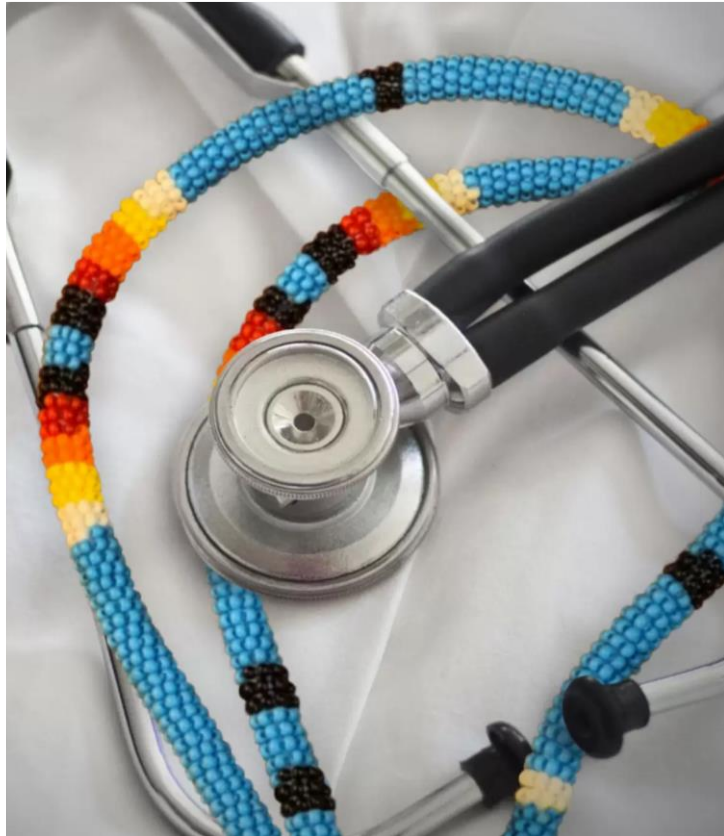
- 574 Federally recognized tribes
- Honor Tribal Sovereignty
- Center cultural humility
- Build trust through relationships
- Allow space for traditional healing practices
- Create culturally safe clinical environments

# Pre-Test Questions



- 3) Which approach is most likely to support culturally responsive care for Tribal patients?
- A. Using standardized medication education techniques for all Tribal patients
  - B. Asking patients to adapt to clinic processes without modification
  - C. Limiting interactions to brief clinical visits
  - D. Showing openness to learning about the patient's cultural perspectives

# Effective Collaboration Strategies



<https://www.nnacoe.org/>

- Engage Tribal partners in planning
- Respect Tribal data sovereignty
- Communicate clearly and transparently
- Strengthen tribal pharmacy capacity
- Practice reciprocity and shared benefit
- Co-design programs and interventions

# Collaborative Care & Research Implementation Examples



- Tribal Liaison
- Community Building and Provider Education
- Tribal Research Advisory Committees (TRACs)
- Data Analysis

# Tribal Liaisons

- Tribal members from the community
- Foster trust and credibility
- Ensures culture and improves relevancy of work
- Strengthens sovereignty and self-determination
- Improves communication and sustainability



**Lonnie James**  
Community Cancer  
Control Specialist &  
CTWS Tribal Liaison



**Lynda Crocker-Daniel**  
OHSU Community Research  
Liaison



# Tribal Research Liaison



**Statewide Tribal  
Research Liaison**

Guides project-related  
research with Tribes  
across Oregon



Torrie Eagle-Staff  
[eaglestaff@ohsu.edu](mailto:eaglestaff@ohsu.edu)

# Community Building and Provider Education



- Dinners
- Health Fairs
- Powwows
- Lunch and Learns
- Tribal Council
- Joint Health Commission

# Tribal Research Advisory Committees



- Create Cultural Landscape
  - Direct community input
- Implementation of Research in Oregon Review System (ROCRS)
- Research Review
  - Community focused not researcher focused
- Bi-directional project Implementation

# ROCRS

## 5-STEP JOURNEY FOR RESEARCHER

Regional Liaison + ROCRS Manager summarize RAC's decision and send to (you) Researcher. Yellow & red light decision may restart the ROCRS journey.

(You) Researcher submits request.

1

Regional Advisory Committee (RAC) member pre-reviews request before RAC meeting.

3

2

Regional Liaison + ROCRS Manager screen request.

4

RAC members meet with ROCRS team to give request a green, yellow, or red light.

5



# Pre-Test Questions



- 4) Why is it important for research teams to work directly with Tribal governments when planning health studies?
- A. To make data collection faster and easier
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# Cancer Incidence & Mortality Data Analysis



*“What cancers are we getting in our community?”*

- Data Use Agreement Development
- Incidence and Mortality rates
  - Clinic data
  - State data
- Statistical Analysis
- Allows for tailored project development



Shannon McWeeney, PhD  
Associate Director of Data  
Science

# Informed Collaborative Project Implementation



- Utilizing the ROCRS system
  - Co-designed and co-created
  - Focused on data security, governance, and ownership
- Use of data will be controlled by each tribe
- Project A
  - Indigenous Community Oncology Navigator
- Project B
  - Pancreatic Cancer High Risk Clinic
- Project C
  - Water Contamination Analysis

# Post-Test Questions



- 1) Which of the following factors has contributed to mistrust of healthcare systems among many Tribal members?
  - A. Tribal communities largely being located in rural areas
  - B. Historical trauma and unethical research practices involving Indigenous populations
  - C. Universal health coverage through Tribal health programs
  - D. A lack of interest in preventive health services among Tribal populations

# Post-Test Questions



- 2) Which statement best reflects the concept of Tribal sovereignty in healthcare?
- A. Tribal health programs must follow all state healthcare regulations without exception
  - B. Tribal nations have the inherent authority to govern their own healthcare systems and programs
  - C. Tribal healthcare systems are operated solely by the federal government
  - D. Tribal health programs operate as private healthcare systems independent of government oversight

# Post-Test Questions



- 3) Which of the following strategies best supports culturally responsive care and collaboration with Tribal members?
- A. Applying the same care approach used for all patient populations
  - B. Limiting communication to written materials and clinical instructions
  - C. Engaging Tribal leaders and community members in program planning and healthcare initiatives
  - D. Relying only on federal healthcare guidelines when working with Tribal populations

# Post-Test Questions



- 4) Why is collaboration with tribal governments important in developing projects and research that includes Tribal members?
- A. It allows researchers to collect data more quickly
  - B. It ensures projects and research respect Tribal sovereignty, including Tribal data sovereignty and community priorities
  - C. It eliminates the need for community engagement
  - D. It replaces the need for institutional review boards

# Post-Test Questions



- 5) A research team collects health data from Tribal members through a study approved by a Tribal government. In which situation could the researcher appropriately use or share the data without seeking additional Tribal approval?
- A. Publishing a secondary analysis addressing a new research question not included in the original agreement
  - B. Sharing the dataset with another Tribal nation conducting a similar health study
  - C. Presenting the dataset at a national conference to encourage collaboration with other researchers
  - D. Using the data only for analyses and purposes explicitly approved in the original Tribal research agreement

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