



National Resource Center
on Native American Aging
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Tribal Communities

- Tribal Sovereignty
 - “the inherent authority of indigenous tribes to govern themselves within the borders of the United States” (Goins et al., 2015, p. 8).
 - In research, tribes have research sovereignty through Tribal IRBs.
 - Sovereign nations who have special rights; they have the ability to set the course of tribal research in terms of data use and ownership, findings and research products.

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Research Trauma

- Unethical research practices in tribal communities.
 - Trachoma
 - Tarsectomy used on American Indians from 1900-1930s to treat trachoma. Radical practice involving removal of eye lids (Schanche Hodge, 2012).
 - Indian Health Service Sterilization Practices 1970s
 - American Indian women and girls were sterilized without their knowledge or consent (Schanche Hodge, 2012).

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Research Trauma

- Indian Health Service Sterilization Practices 1970s.
 - American Indian women and girls were sterilized without their knowledge or consent (Schanche Hodge, 2012).
 - General Accounting Office Report-3,406 American Indian females between the ages of 15 to 44 years old were sterilized by Indian Health Services doctors in four of the 12 IHS regions between 1973-76 (Schanche Hodge, 2012, p. 433).
 - Permission forms
 - Medical consent forms were inadequate, illegally obtained, and not in compliance with IHS regulations (Schanche Hodge, 2012, p. 433).

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Research Trauma

- Havasupai and Arizona State University Study
 - 200 blood samples obtained with agreement to study type 2 diabetes for Havasupai Indian tribe (Schanche Hodge, 2012).
 - Without tribe's knowledge samples removed from study site and used for non-diabetes studies including genetic basis of schizophrenia and inbreeding (Schanche Hodge, 2012).
 - Publications produced and doctoral dissertation (Schanche Hodge, 2012).
 - Cultural belief is that all biological human material must be intact for the individual to travel to the afterlife; however, the location of some of the blood samples were unknown (Schanche Hodge, 2012).

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Research Trauma

- Benefit Researcher (One-Sided Helicopter Research)
 - Academic publications, reports, etc.
- No Benefit to Tribal Community
 - Do not see the results
 - Do not own the data
 - Feel used
 - Data collected does not change policy or assist in bringing in resources to the community to address health and social issues.

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Modifying the Research Process for Tribal Communities: *Identifying Our Needs: A Survey of Elders*

- Tribal Resolution
- Survey Administered by Staff or Volunteer from Tribal Title VI office.
- Tribal Title VI Director (Liasion)
- Building Tribal Research Capacity
- Data owned by tribe
 - NRCNAA serves as “guardian” or “gatekeeper” of the data; we are unable to transfer data files.
- Tribal Participatory Research Model

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Modifying the Research Process for Tribal Communities: *Identifying Our Needs: A Survey of Elders*

- Culturally Competent Survey Questions/Options
- Examples:
 - Type of health insurance coverage
 - Options include Indian Health Services, Alaska Native Health Organization, and Indian Health/Tribal Insurance.

30. What type of health care coverage do you have?
(Please mark all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Medicare | <input type="checkbox"/> Veteran's Administration |
| <input type="checkbox"/> Medicaid | <input type="checkbox"/> Indian Health Services |
| <input type="checkbox"/> Private Insurance:
Health/Medical | <input type="checkbox"/> Alaska Native Health
Organization |
| <input type="checkbox"/> Private Insurance:
Long-term care | <input type="checkbox"/> Indian Health/Tribal Insurance |
| <input type="checkbox"/> None | |

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Modifying the Research Process for Tribal Communities: *Identifying Our Needs: A Survey of Elders*

- When you are sick or need professional advice about your health, to which of the following places do you usually go?
- Traditional Healer
- Have any of the following kept you from medical care the past 12 months?
- No one spoke my language

32. When you are sick or need professional advice about your health, to which of the following places do you usually go? (Please mark all that apply)

- | | |
|---|--|
| <input type="checkbox"/> A doctor's office | <input type="checkbox"/> Urgent care center |
| <input type="checkbox"/> A clinic | <input type="checkbox"/> Community health Aide/(CHA/CHR) |
| <input type="checkbox"/> A hospital outpatient department | <input type="checkbox"/> Traditional healer |
| <input type="checkbox"/> A hospital emergency room | |

33. Have any of the following kept you from medical care in the past 12 months? (Please mark all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Cost | <input type="checkbox"/> No child care |
| <input type="checkbox"/> Distance | <input type="checkbox"/> No transportation |
| <input type="checkbox"/> Office wasn't open when I could get there | <input type="checkbox"/> No access for people with disabilities |
| <input type="checkbox"/> Too long a wait for an appointment | <input type="checkbox"/> Too long a wait in waiting room |
| <input type="checkbox"/> No one spoke my language | <input type="checkbox"/> None |
| | <input type="checkbox"/> Other: _____ |

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Modifying the Research Process for Tribal Communities: *Identifying Our Needs: A Survey of Elders*

- Over the past 30 days, what vigorous exercises did you do?
- Traditional Dancing (Pow-wow, Hula)
- Do you participate in cultural practices that include traditional food, music, and customs?
- How often do you get out and socialize?
- Cultural activities/traditional ceremonies

43. Over the past 30 days, what vigorous exercises did you do? (Please mark all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Aerobics | <input type="checkbox"/> Walking |
| <input type="checkbox"/> Bicycling or bicycling on a stationary bike | <input type="checkbox"/> Swimming |
| <input type="checkbox"/> Gardening | <input type="checkbox"/> Weight Lifting |
| <input type="checkbox"/> Jogging | <input type="checkbox"/> Yard Work |
| <input type="checkbox"/> Running | <input type="checkbox"/> Traditional Dancing (Pow-wow, Hula) |

45. Do you participate in cultural practices that include traditional food, music, and customs?

- | | |
|---|---|
| <input type="checkbox"/> All of the time | <input type="checkbox"/> Some of the time |
| <input type="checkbox"/> Most of the time | <input type="checkbox"/> None of the time |

46. How often do you get out and socialize (attend church/religious meetings, clubs/organizations you belong to or cultural activities/traditional ceremonies)?

TIMES PER MONTH

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Modifying the Research Process for Tribal Communities: Identifying Our Needs: A Survey of Elders

- Are you American Indian/Alaska Native, Native Hawaiian, mixed race or other?
 - American Indian, Alaska Native, Native Hawaiian, Descendent (Grandparent or parent is an enrolled member)
- Do you reside on/in a reservation trust land, Alaska village, or Hawaiian homestead?
- Are you an enrolled member of a federally recognized tribe?
 - Tribal Affiliation

69. Are you American Indian, Alaska Native, Native Hawaiian, Descendent or other?

- ☐ American Indian ☐ Native Hawaiian
☐ Alaska Native ☐ Other
☐ Descendent (Grandparent or parent is an enrolled tribal member.)

70. Do you reside on/in a reservation, trust land, Alaska village, or Hawaiian homestead?

- ☐ Yes ☐ No

71. Are you an enrolled member of a federally recognized tribe?

- ☐ Yes ☐ No
Tribal Affiliation: _____

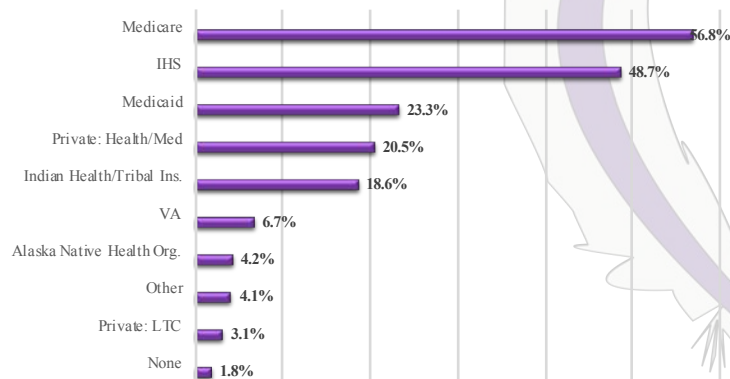
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Culturally Specific Data

Insurance Coverage



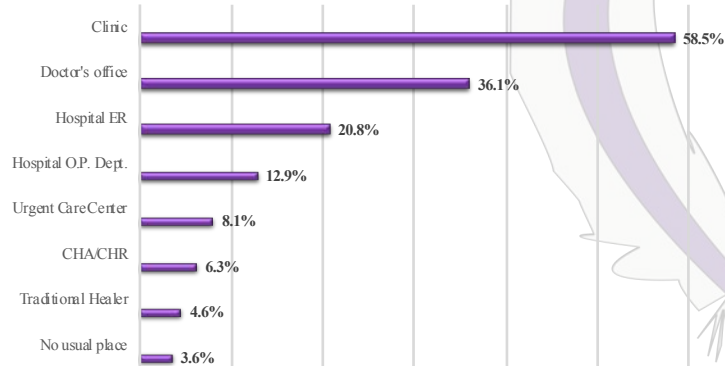
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Culturally Specific Data

Go to for Medical Care Advice



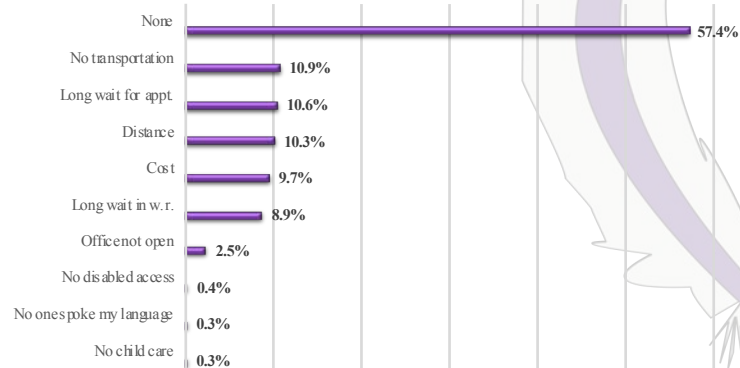
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Culturally Specific Data

Barriers and Challenges for Medical Care Services



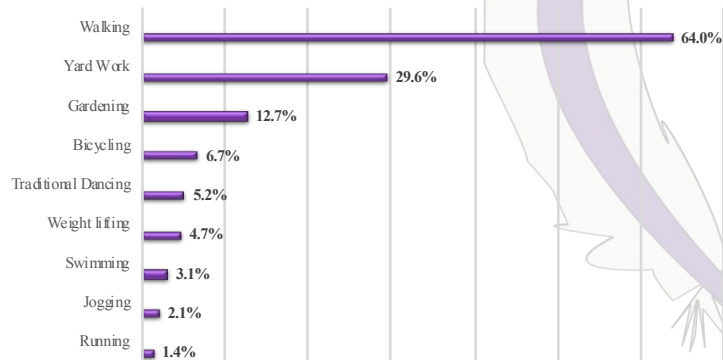
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Culturally Specific Data

Vigorous exercises performed in the past 30 days



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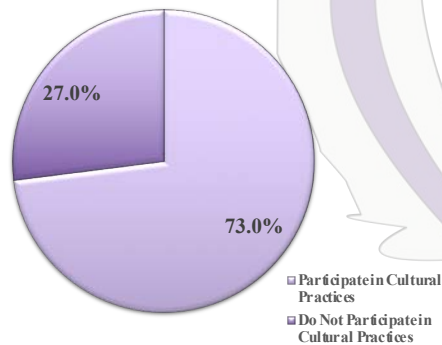


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Culturally Specific Data

Participate in cultural practices

- 73% of AI/AN elders participate in cultural practices.
- 27% do not participate in cultural practices.



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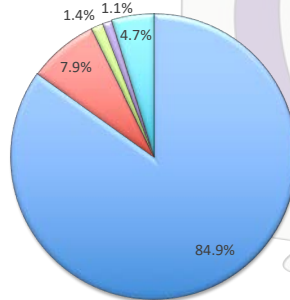


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Culturally Specific Data

Ethnicity

- 84.9% of participants identified as American Indian
- 7.9% of participants identified as Alaska Native
- 1.4% of participants identified as Native Hawaiian
- 1.1% of the participants identified as Descendent
- 4.7% of the participants identified as Other



■ American Indian ■ Alaska Native ■ Native Hawaiian ■ Descendent ■ Other

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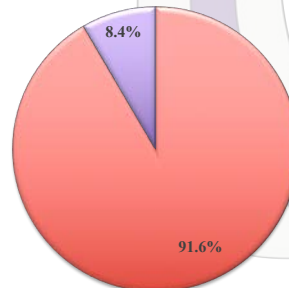


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Culturally Specific Data

Enrolled member of federally recognized tribe

- 91% of the participants are enrolled in a federally recognized tribe.
- 8.4% of the participants are not enrolled in a federally recognized tribe (state recognized).



■ Yes ■ No

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Research and Tribal Communities

- *Partnership with the Tribe*
 - Open communication and transparency about the research and data
- *Building Tribal Capacity*
 - People within the community administering surveys and assisting in conducting the research.
- *Obtaining proper permission to conduct research within tribal community*
 - Tribal Resolutions
 - Tribal IRB or RRB Boards
- *Benefits to the partners (tribe and researcher)*
 - Data assists in bring additional resources or funding to address health and social issues or disparities. Helps to change policy relating to the AI/AN elder population.
- *Tribe owns data*

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NRCNAA Contact Information

For more information contact:

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