



Challenges and Solutions to Accessing Data that Benefits Tribal Communities

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Overview

In this session we will discuss the following topics:

- Background and history of the National Resource Center on Native American Aging (NRCNAA).
- The NRCNAA research model utilized when working with Title VI programs.
- Discuss how tribes can assess their needs using the “Identifying our Needs: A Survey of Elders.”
- Informing tribes on how to effectively utilize their data.
- Provide data visual representation of Cycle VI tribal aggregated data from the “Identifying our Needs: A Survey of Elders VI.”
- Benefits of data and how it can be utilized at the local, state, tribal, and federal level.

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National Resource Center on Native American Aging (NRCNAA)

The NRCNAA is one of three centers that are funded through the Administration for Community Living (ACL). The other two centers are:

- The National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders (Alaska)
- National Resource Center for Native Hawaiian Elders (Hawaii)

The NRCNAA was established in 1994

- Center for Rural Health, University of North Dakota, School of Medicine & Health Sciences.

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Mission and Vision

Mission

Identify and increase awareness of evolving Native elder health and social issues.

Vision

To empower Native people to develop community based solution.

Honoring and helping to maintain cultural values.

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NRCNAA Programs and Resources

- *Identifying Our Needs: A Survey of Elders*
- WELL (Wise Elders Living Longer) Balanced Program
- Native Elder Caregiver Curriculum (NECC)
- Service Locator Map
- Heroes Project

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Data Challenges

- Data not being readily available to tribes.
- Significant gaps in data.
- National data sets are skewed due to misclassification of race/ethnicity.
- Small sample size in some cases.
- Unreliable

(Urban Indian Health Commission, 2007)

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Why is data important?

- Today, many decisions are based on data; therefore, populations with little or no data are easily overlooked (Urban Indian Health Commission, 2007).
- Provides an accurate picture of the Native elder population
 - Collecting custom fit data
- Helps set goals and priorities
- Identifies specific areas of health and social needs
 - Resource allocation
- Relevant actionable data
 - Assists policymakers, tribal leadership, directorship, and management make decisions based on facts and numbers.

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Why is data important?

- Fulfill Title VI grant requirements
- Other funding opportunities
 - Secure funding and additional resources for Native elders

MOST IMPORTANT
USE THE DATA

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Identifying Our Needs: A Survey of Elders

- Assesses the health and social needs of Native Elders in Tribal Communities
- 3 year cycles
- Opportunity to collect information for their communities
- Technical assistance and training



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Tribal Diversity

- NRCNAA research model addresses diversity between and within tribes.
 - Measurement of local needs
 - Unique fit to tribal community
 - Custom-fitting measure
 - ONE SIZE DOES NOT FIT ALL

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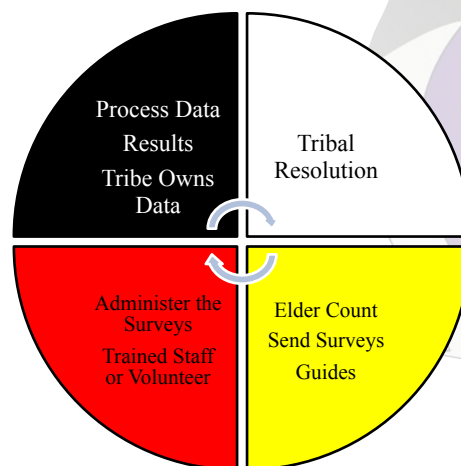
Population

- Native elders that primarily reside on or within reservation areas, Alaskan villages, and Hawaiian homesteads.
- Age 55 years and older
- Important to note:
 - Age 55 years and over for Native elders is considered comparable to non-Native elders 65 years and older in the general population.

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NRCNAA Research Model

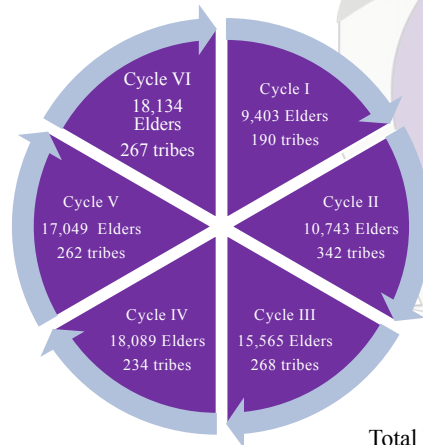


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Needs Assessment Participation



Total N = 89,436 surveys

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Cycle VI Summary

- Data collected in the time span of April 1, 2014 to March 31, 2017
- 18,134 AI/AN elders
- 164 sites
- 267 tribes
- Representation from:
 - 11 out of 12 Indian Health Service (IHS) Regions
 - 9 out of 10 Department of Health and Human Services (DHHS) regions
 - 28 out of 50 states

*Cycle VII began April 1, 2017 and will end March 31, 2020

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Survey Needs Data

- General health status of elders
- Indicators of chronic health
- Activities of Daily Living (ADL's)
- Screenings
- Indicators of visual, hearing, and dental
- Memory and Disability
- Health Care Access
- Tobacco and alcohol use patterns
- Diet, nutrition, and exercise
- Social support pattern and housing
- Social Functioning
- Use and acceptance of services
- Demographics

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Identifying our Needs: A Survey of Elders VII

Identifying Our Needs: A Survey of Elders VII

Coating for this project is provided by Cooperative Agreement #900086 from the Administration for Community Living, ADA - Older Americans National Resource Centers (an agency within the US Department of Health and Human Services).

* Use black or blue pen or a number 2 pencil. * Make dark marks that fill the oval completely. * Do not use pens with ink that seeps through the paper. * Make no stray marks and do not bend survey.

GENERAL HEALTH STATUS

1. Would you say your health in general is excellent, very good, good, fair, or poor?

☐ Excellent
☐ Very Good
☐ Good
☐ Fair
☐ Poor

2. During the past 12 months, how many different times did you stay in the hospital overnight or longer?

3. Has a doctor ever told you that you had any of the following diseases...? (Please mark all that apply)

<input type="checkbox"/> Arthritis?	<input type="checkbox"/> Prostate Cancer?
<input type="checkbox"/> Congestive Heart Failure?	<input type="checkbox"/> For men only.
<input type="checkbox"/> Stroke?	<input type="checkbox"/> Colon/Rectal Cancer?
<input type="checkbox"/> Asthma?	<input type="checkbox"/> Lung Cancer?
<input type="checkbox"/> Diabetes?	<input type="checkbox"/> Breast Cancer?
<input type="checkbox"/> High Blood Pressure?	<input type="checkbox"/> Cervical Cancer?
<input type="checkbox"/> Osteoporosis?	<input type="checkbox"/> For women only.

4. How many falls, if any, have you had in the past year?

ACTIVITIES OF DAILY LIVING (ADL'S)

5. Because of a health or physical problem that lasted more than 3 months, did you have any difficulty... (Please mark all that apply)

☐ Dressing?
☐ Bathing or showering?
☐ Eating?
☐ Getting in or out of bed?
☐ Walking?
☐ Using the toilet, including getting to the toilet?

6. Because of a health or physical problem that lasted longer than 3 months, did you have any difficulty... (Please mark all that apply)

☐ Preparing your own meals?
☐ Shopping for personal items (such as toilet items or medicines)?
☐ Using the telephone?
☐ Using hand instruments (such as scrubbing floor, or washing windows)?
☐ Doing housework (such as doing dishes, sweeping, or light clean up)?
☐ Getting outside?

SCREENING

7. About how long ago has it been since you last visited a doctor/health care provider for a routine check-up? (Please mark all that apply)

☐ Never had a checkup
☐ Within the past year
☐ Within the past 2 years
☐ 3 or more years ago

8. How long has it been since you had your blood tested for blood using a home kit?

☐ Never had a checkup
☐ Within the past year
☐ Within the past 2 years
☐ 3 or more years ago

9. (FOR WOMEN ONLY) How long has it been since you had your last mammogram?

☐ Never had a checkup
☐ Within the past year
☐ Within the past 2 years
☐ 3 or more years ago

10. (FOR WOMEN ONLY) How long has it been since you had your last pap smear?

☐ Never had a checkup
☐ Within the past year
☐ Within the past 2 years
☐ 3 or more years ago

11. (FOR MEN ONLY) How long has it been since you had your last PSA, prostate-specific antigen test, a blood test used to check for prostate cancer?

☐ Never had a checkup
☐ Within the past year
☐ Within the past 2 years
☐ 3 or more years ago

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VISION, HEARING & DENTAL

13. Do you have total blindness in one or both eyes?
☐ Yes ☐ No

14. Do you use glasses or contact lenses?
☐ Yes ☐ No

15. Do you have trouble seeing (even when wearing corrective lenses)?
☐ Yes ☐ No

16. Have you seen an optometrist (eye doctor) in the past year?
☐ Yes ☐ No

17. Do you now have total deafness?
☐ Yes ☐ No

18. Do you use a hearing aid?
☐ Yes ☐ No

19. Do you have trouble hearing (even when wearing your hearing aid)?
☐ Yes ☐ No

20. Have you had a hearing test in the past year?
☐ Yes ☐ No

21. Have you seen a dentist or dental hygienist in the past year?
☐ Yes ☐ No

22. What type of dental care do you need now? (Please mark all that apply)
☐ Teeth filled (for example, fillings, crowns, and/or bridges)
☐ Teeth pulled
☐ Denture work (new dentures)
☐ Root of post
☐ Work to improve appearance (for example, braces or bonding)
☐ Other
☐ None

MEMORY & COGNITION

23. Have you been diagnosed with Alzheimer's disease, dementia or other problems with memory or thinking?
☐ Yes ☐ No

24. Has someone you are helping care for been diagnosed with Alzheimer's disease, dementia or other problems with memory or thinking?
☐ Yes ☐ No (If you answer NO to questions 23 & 24, skip to question 29)

25. I or the person I am helping care for was diagnosed in a timely way once we started noticing problems.
☐ Yes ☐ No

26. I know what to do to help myself or the person I'm caring for and I know where to get help if I need it.
☐ Yes ☐ No

27. The people helping me care for myself or me if I'm a caregiver feel well supported.
☐ Yes ☐ No

27. My wishes for the kind of care I want to get are listened to and respected.
☐ Yes ☐ No

28. Are you disabled?
☐ Yes ☐ No (If you answer NO, skip to question 30)

29. How were you disabled?
☐ Congenital (from birth)
☐ In military service
☐ Due to chronic disease
☐ Due to accident/injury

HEALTH CARE ACCESS

30. What type of health care coverage do you have? (Please mark all that apply)
☐ Medicare ☐ Veteran's Administration
☐ Medicaid ☐ Indian Health Services
☐ Health/Medicaid ☐ Organization Health
☐ Private insurance ☐ Indian Health/Tribal Insurance
☐ Long-term care ☐ None

31. Do you have one person you think of as your personal doctor or health care provider?
☐ Yes ☐ No ☐ Don't know/not sure

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)
☐ A doctor's office ☐ Urgent care center
☐ A hospital outpatient department ☐ Ambulance/EMS
☐ A hospital emergency room ☐ Traditional healer

33. Have any of the following kept you from medical care in the past 12 months? (Please mark all that apply)
☐ Cost ☐ No child care
☐ Doctor wasn't open ☐ No transportation
☐ When I could get there ☐ No place for people
☐ Too long a wait for an appointment ☐ Too long a wait in waiting room
☐ I don't speak my language ☐ Other

TOBACCO & ALCOHOL USE

34. Do you smoke tobacco now?
☐ Yes ☐ No (If no, please mark all that apply)
☐ Cigarettes ☐ Pipe tobacco
☐ Yes, some days (If so, please mark all that apply)
☐ No (If no, skip to question 36)

35. How many cigarettes do you smoke per day?

ADDITIONAL INFORMATION

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36. Do you use chewing tobacco or snuff?
☐ Yes ☐ No

37. How many containers of snuff or chewing tobacco per week do you use?

38. The next few questions are about drinks of alcoholic beverages. By a "drink," we mean a can or bottle of beer, a glass of wine or a wine cooler, a shot of liquor, or a mixed drink with liquor in it. How long has it been since you last drank an alcoholic beverage?
☐ Within the last 30 days
☐ More than 30 days but within the past 12 months
☐ More than 12 months ago but within the past 5 years
☐ I have never had an alcoholic drink in my life
☐ If you have never had an alcoholic drink, skip to question 40

39. During the past 30 days, on how many days did you have five or more drinks on the same occasion? (By occasion, we mean at the same time or within a single hour of each other)
☐ None ☐ 1 or 2 days ☐ 3 to 5 days ☐ 6 or more days

WEIGHT & NUTRITION

40. How tall are you without shoes?

41. How much do you weigh today?

42. Are you presently trying to lose or gain weight?
☐ Yes, trying to lose weight
☐ Yes, trying to gain weight
☐ No

43. Over the past 30 days, what vigorous exercises did you do? (Please mark all that apply)
☐ Walking ☐ Swimming
☐ Bicycling or bicycling on a stationary bike ☐ Aerobic dance
☐ Gardening ☐ Weight lifting
☐ Jogging ☐ Tai chi
☐ Fishing ☐ Traditional dancing (Pocahontas, Hula)

44. Please mark all that apply to your nutritional health.
☐ I have lost or gained weight that made me change the kind and/or amount of food I eat.
☐ I eat fewer than 2 meals per day.
☐ I have 3 or more drinks of beer, liquor or wine almost every day.
☐ I have tooth or mouth problems that make it hard for me to eat.
☐ I eat alone most of the time.
☐ I have 3 or more different prescriptions or over-the-counter drugs a day.
☐ I feel a constant need to eat.
☐ I am not always physically able to shop, cook and/or feed myself.

SOCIAL SUPPORT/HOUSING

45. Do you participate in cultural practices that include traditional food, music, and customs?
☐ All of the time ☐ Some of the time
☐ Most of the time ☐ 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)?

47. How long have you lived at your present address?
☐ Less than 5 years
☐ 5-10 years
☐ Over 10 years

48. What type of housing do you presently have?
☐ Single family residence
☐ An apartment
☐ Mobile home/trailer
☐ Retirement home
☐ A health facility (available medical personnel)
☐ Homeless
☐ Other (If retirement home/health facility is marked, skip to question 49)

49. Are you living with family members, non-family members, or alone?
☐ With family members
☐ With non-family members
☐ With both family and non-family members
☐ Alone

50. How many (INCLUDING YOURSELF) live in your household?

51. Do you have a family member who provides care for you?
☐ Yes ☐ No

52. Do you take care of grandchildren?
☐ Yes ☐ No

53. Are you the primary caregiver of grandchildren?
☐ Yes ☐ No

SOCIAL FUNCTIONING

54. During the past month, how much of the time were you a happy person?
☐ All of the time ☐ Some of the time
☐ Most of the time ☐ None of the time

55. How much of the time, during the past month, have you felt calm and peaceful?
☐ All of the time ☐ Some of the time
☐ Most of the time ☐ None of the time

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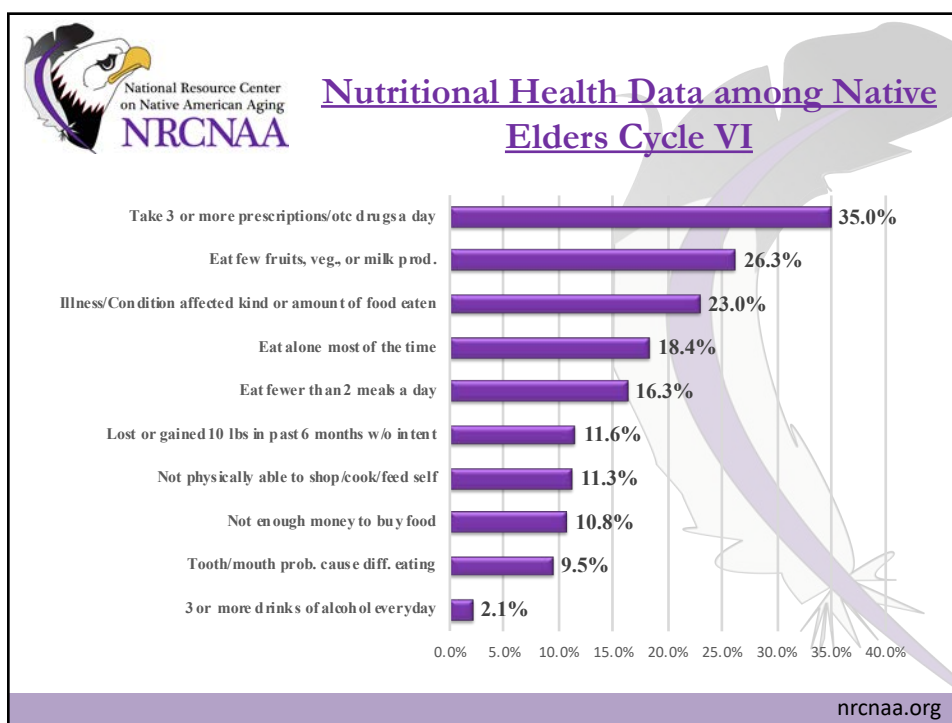
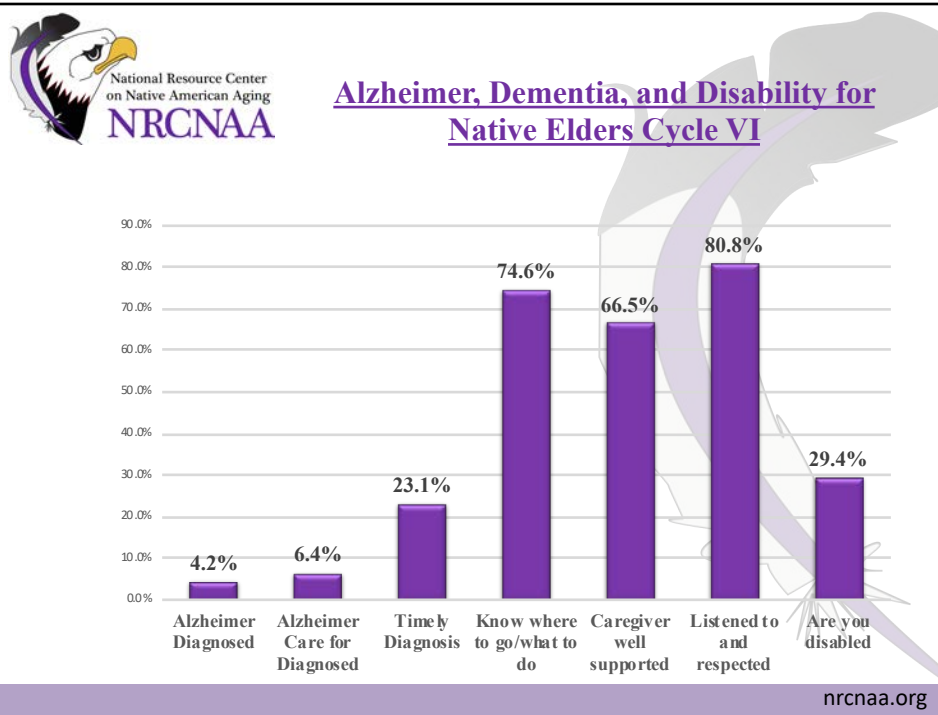
DEMOGRAPHICS	
1. Gender	<input type="radio"/> Male <input type="radio"/> Female
2. Current marital status	<input type="radio"/> Single/never married <input type="radio"/> Married/registered partner <input type="radio"/> Widowed
3. What is your individual annual income?	<input type="radio"/> \$0 - \$24,999 <input type="radio"/> \$25,000 - \$34,999 <input type="radio"/> \$35,000 - \$44,999 <input type="radio"/> \$45,000 - \$54,999 <input type="radio"/> \$55,000 or more
4. Have you been employed full or part-time during the past 12 months?	<input type="radio"/> Full-time <input type="radio"/> Part-time <input type="radio"/> Retired <input type="radio"/> No
5. What is the highest grade or year of school you completed?	<input type="radio"/> Never attended or kindergarten only <input type="radio"/> Elementary <input type="radio"/> High School <input type="radio"/> College/Technical School <input type="radio"/> Graduate/Professional School
6. What zip code do you currently reside in?	<input type="text"/> ZIP CODE
7. What county/torough do you currently reside in?	<input type="text"/> COUNTY/TOROUGH
8. Are you American Indian, Alaska Native, Native Hawaiian, Descendant or other?	<input type="radio"/> American Indian <input type="radio"/> Alaska Native <input type="radio"/> Native Hawaiian or descendant or parent is an enrolled tribal member. <input type="radio"/> Other
9. Do you reside on/in a reservation, trust land, Alaska village, or Hawaiian homestead?	<input type="radio"/> Yes <input type="radio"/> No
10. Are you an enrolled member of a federally recognized tribe?	<input type="radio"/> Yes <input type="radio"/> No
11. Have you ever served on active duty in the U.S. Armed Forces, Military Reserves, or National Guard?	<input type="radio"/> Yes <input type="radio"/> No

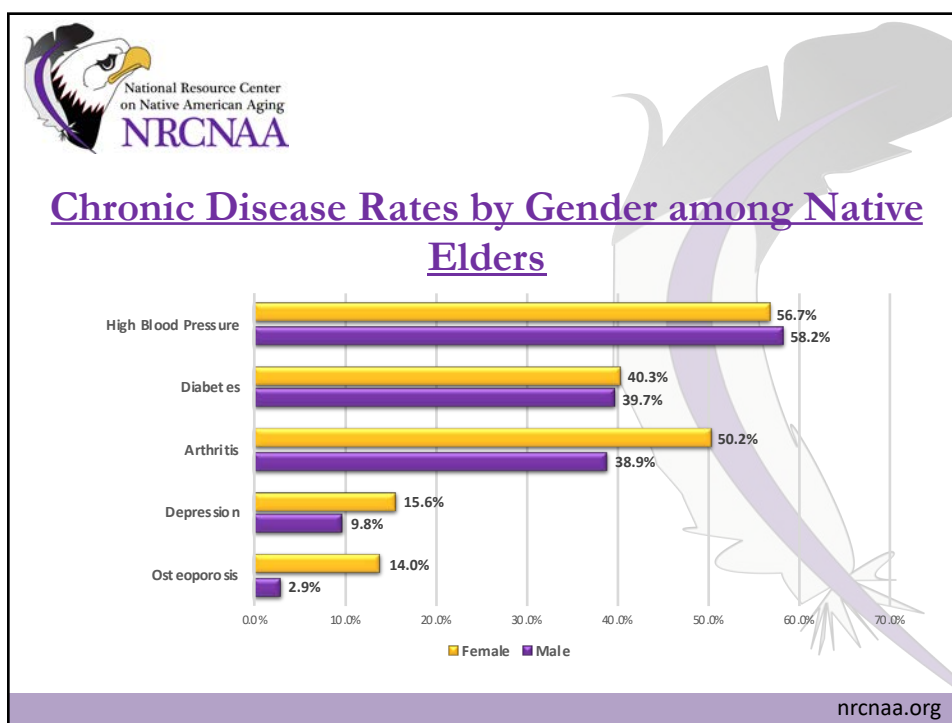
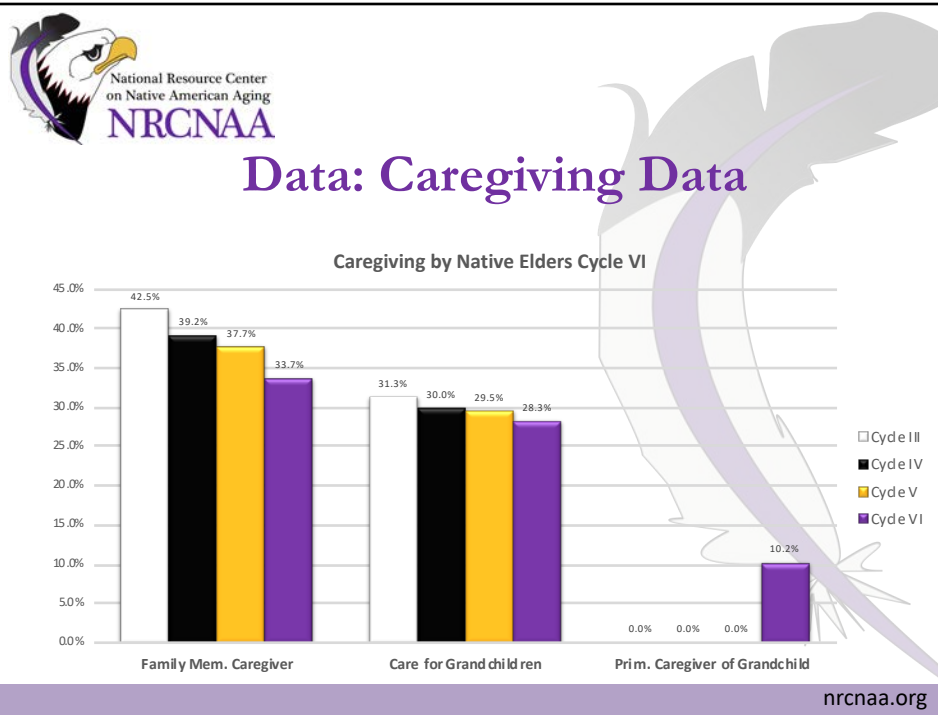
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Comparison Sheet

Tribe Name (N=) Comparison Data to Aggregate Tribal Data and National Data				
Question	Response(s)	Tribal Data (55 and over)	Aggregate Tribal Data (55 and over)	National Data ^a (55 and over)
1. Would you say your health in general is excellent, very good, good, fair, or poor?	General Health Status			
	Excellent			13.8% ¹
	Very Good			29.2% ¹
	Good			32% ¹
	Fair			16.8% ¹
	Poor			7.8% ¹

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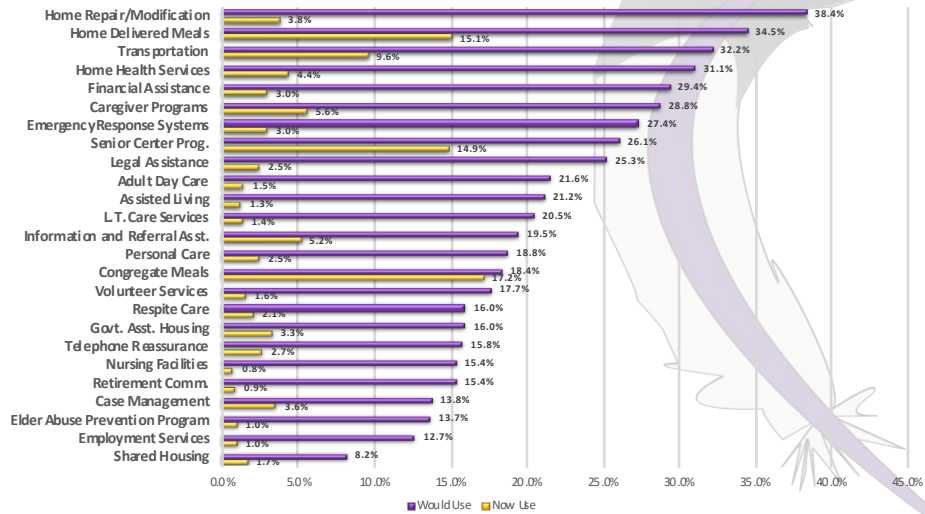






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Cycle VI Tribal Aggregate Unmet Needs

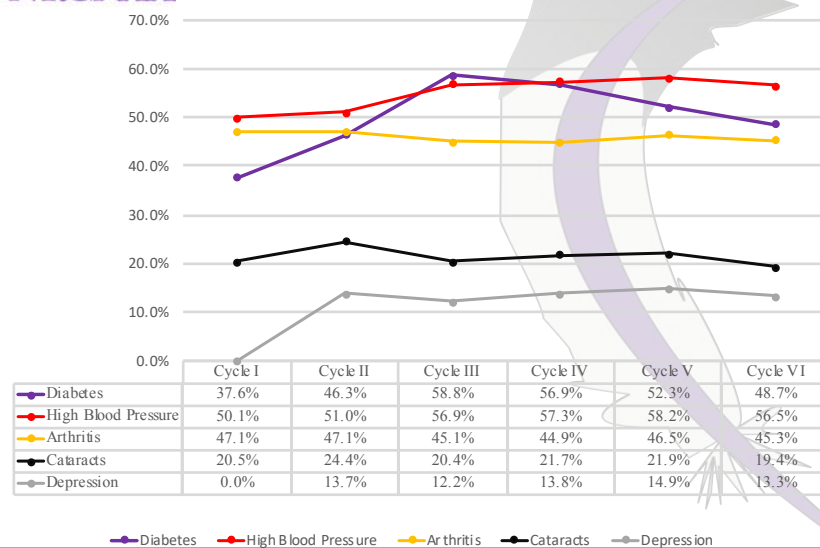


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Trending Data for Top 5 Chronic Diseases among AI/AN elders

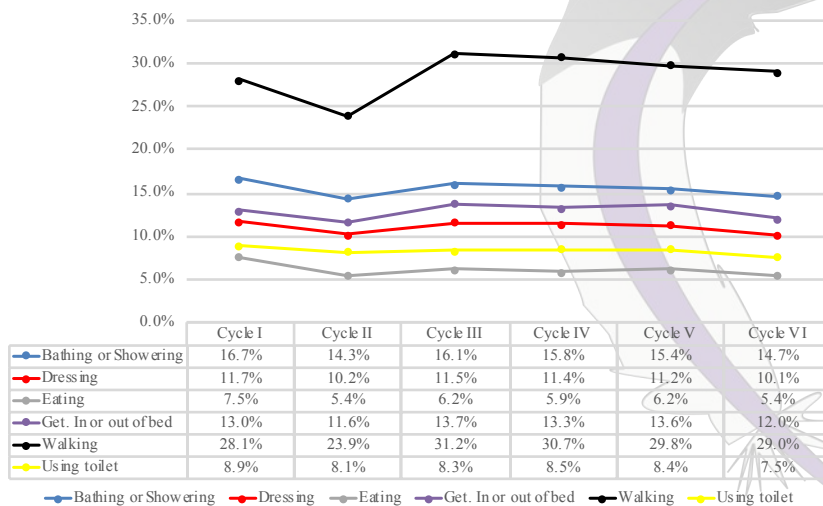


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Trending Data for Activities of Daily Living for AI/AN elders

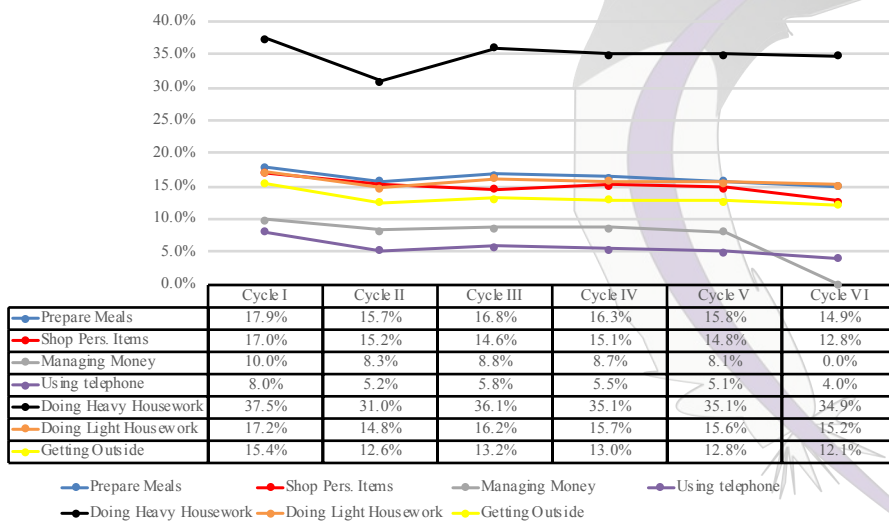


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Trending Data for Instrumental Activities of Daily Living for AI/AN elders



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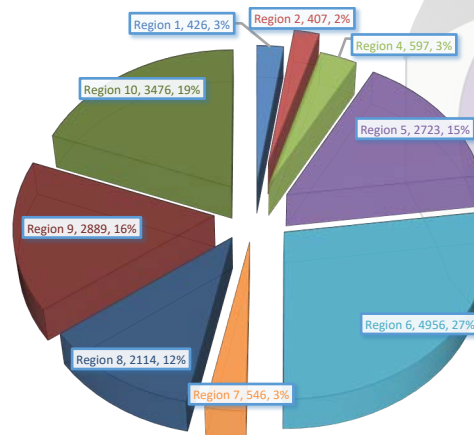
Top Chronic Diseases for Native Elders by Region and Tribal Aggregate

	Diabetes	High Blood Pressure	Arthritis	Cataracts	Depression	Asthma
National	18%	55.2%	47.4%	40.2%	17.2%	12%
Tribal Aggregate	**48.7%	*56.5%	***45.3%	19.4%	13.3%	12.6%
Region 1	***47.9%	*55.2%	**49.3%	12.7%	15%	13.8%
Region 2	***45.7%	*56%	**51.4%	18.4%	14.7%	16%
Region 4	**57.8%	*64.3%	***41.7%	23.5%	12.2%	12.1%
Region 5	**52.4%	*57.2%	***48.7%	21.6%	17.6%	14.6%
Region 6	*52.5%	**43.1%	***43%	17.8%	12.5%	10.3%
Region 7	*61.7%	**60.6%	***58.2%	20.9%	12.6%	12.3%
Region 8	*48.3%	*55.1%	*45.4%	15.8%	10%	12.8%
Region 9	***53%	*57.1%	**56.7%	19.6%	10.7%	12.6%
Region 10	***33.8%	*54%	**47.2%	22.2%	15.1%	13.9%

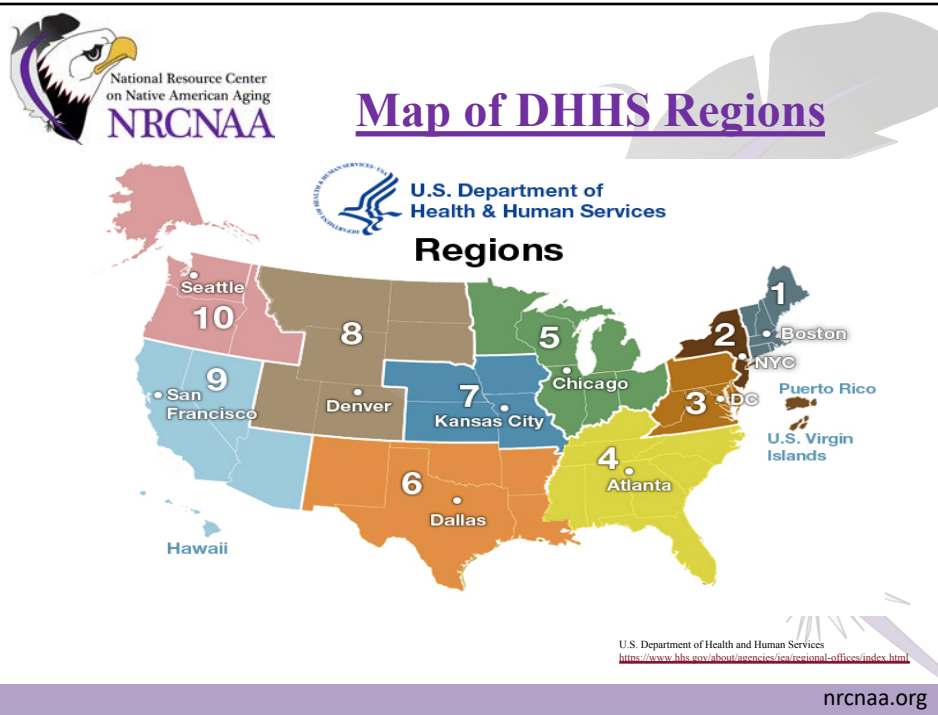
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Participation by DHHS Regions for Cycle VI



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Identifying Our Needs: A Survey of Elders VI Urban vs. Rural Data

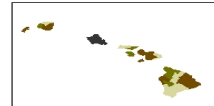
- RUCA codes for *Identifying Our Needs: A Survey of Elders VI* data
- AI/AN/NH elders who utilize Title VI services who reside within, near, or a certain radius of a defined urban area
 - Important to note: May live on the reservation or off the reservation, but reside in a certain proximity of an urban area.



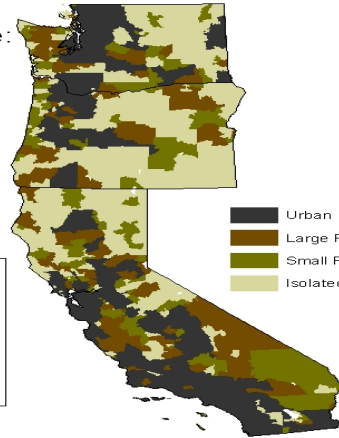
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RUCA Map Census Division Nine: Pacific

Census Division Nine:
Pacific



NOVA811 Pacific Health Research Center
L. Gay Hart, Ph.D., Director
U.S. Department of Health & Human Services



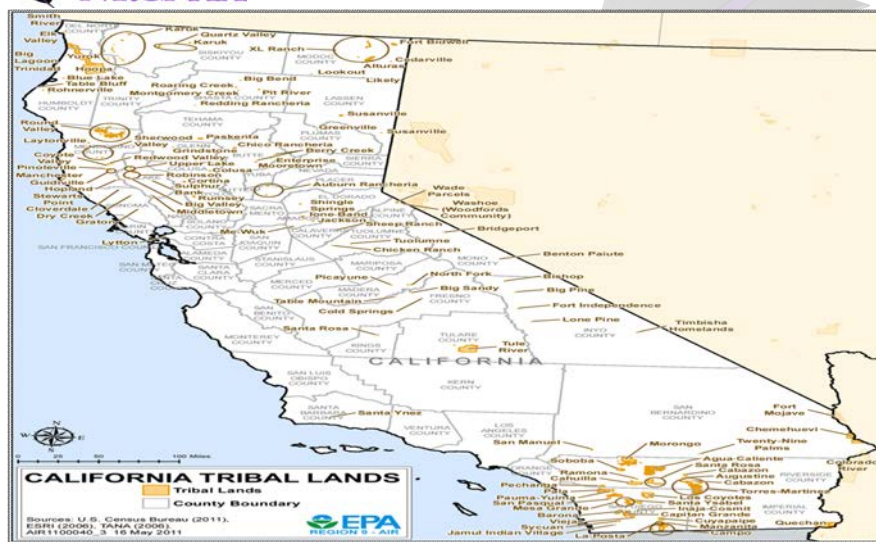
Hart, G.L. (2006). Maps Census Division Nine: Pacific. RUCA Rural Health Research Center. Retrieved from:
http://depts.washington.edu/urwruca/map_4_divisions.php

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California Tribes



United States Environmental Protection Agency (2018). Air Quality Analysis California Tribal Lands and Reservations: Pacific Southwest, Region 9. Retrieved from: <https://www3.epa.gov/region9/air/monitoring/tribe.html>

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Urban vs. Rural Comparisons

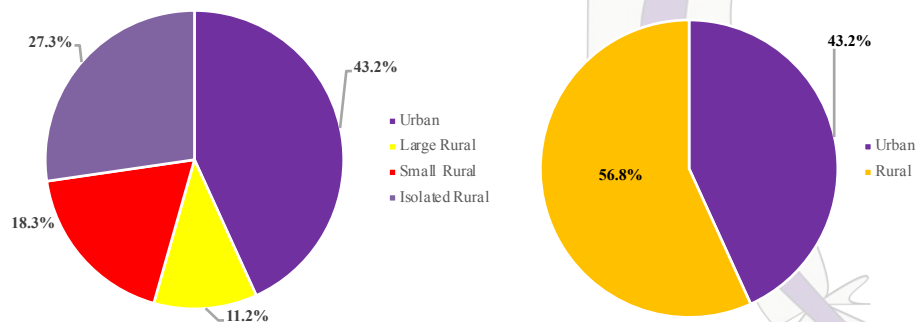
Identifying Our Needs: A Survey of Elders Data

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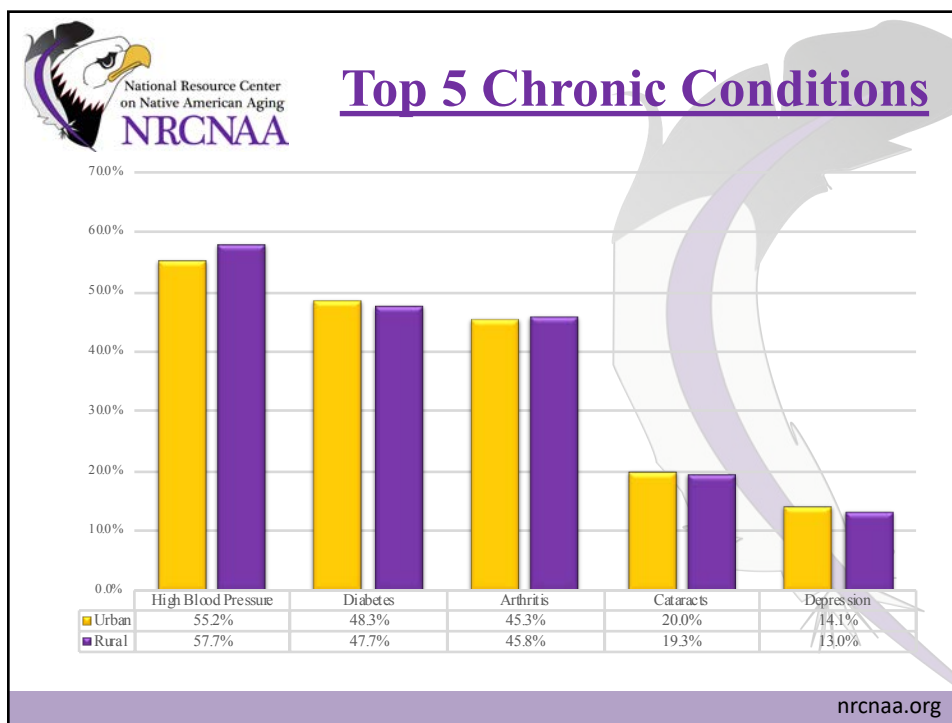
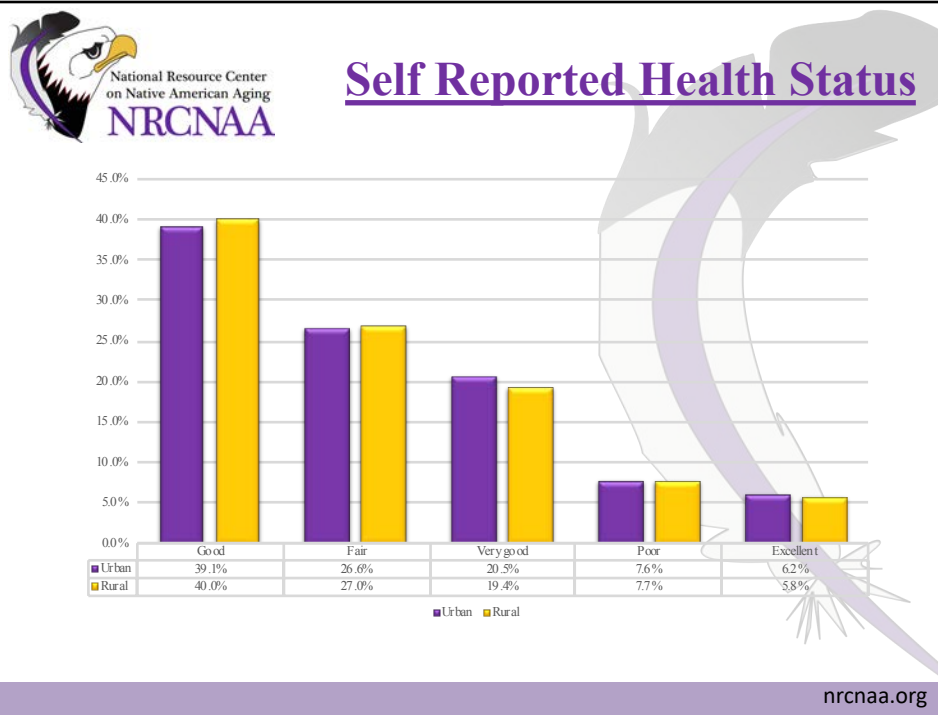
Identifying Our Needs: A Survey of Elders VI

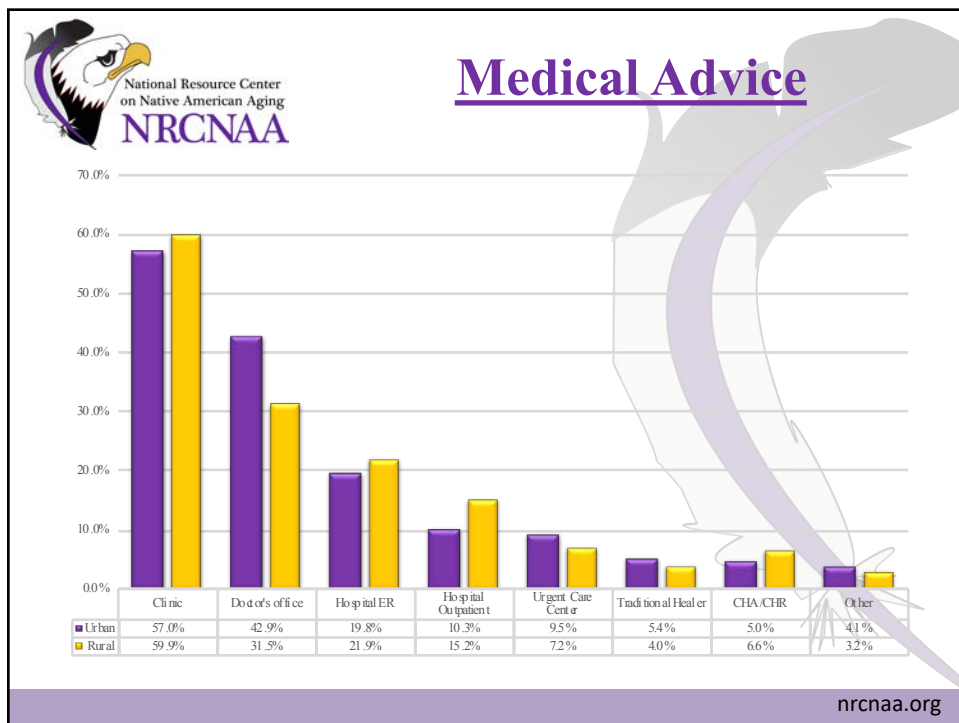
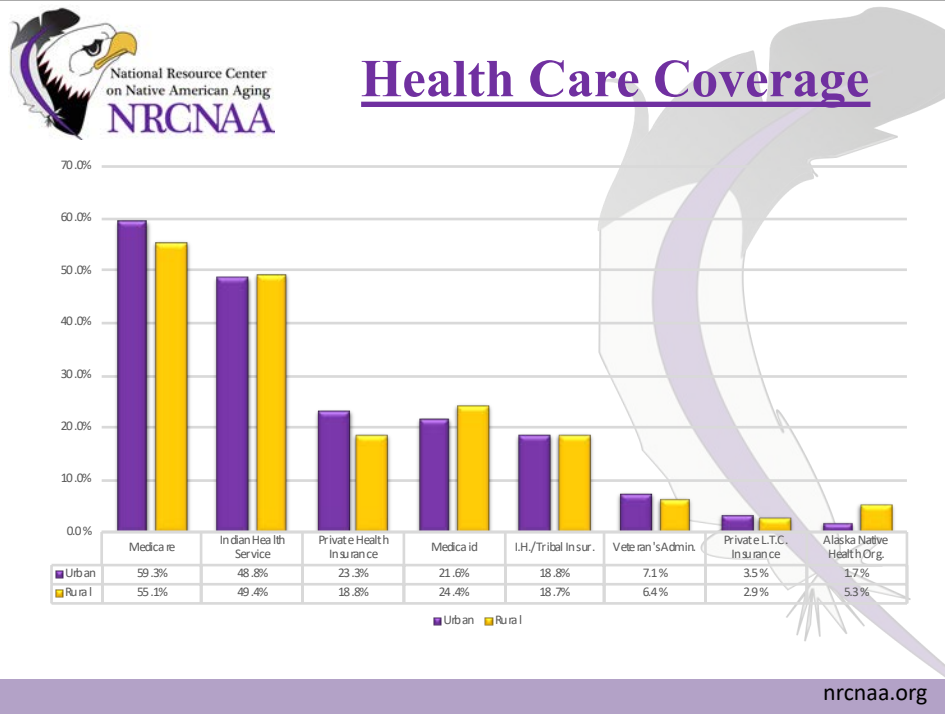
Urban and Rural Populations

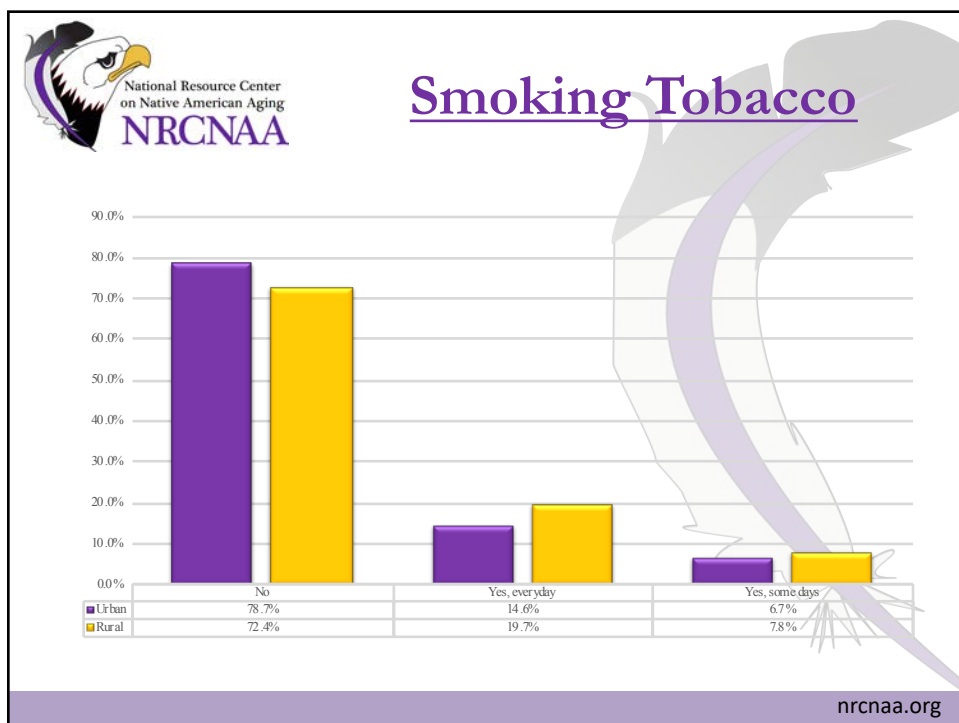
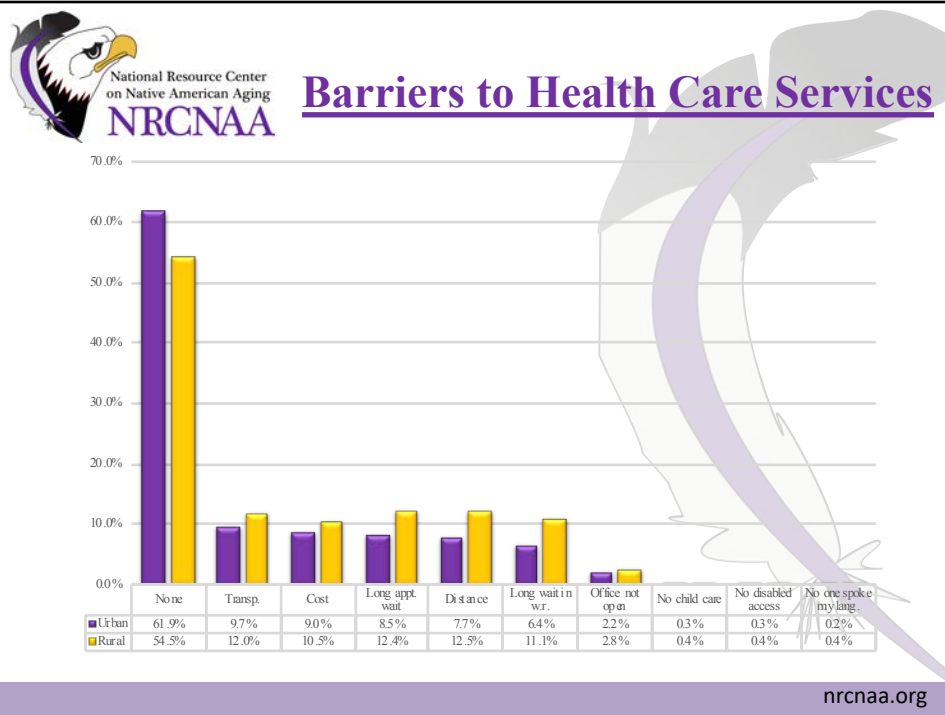


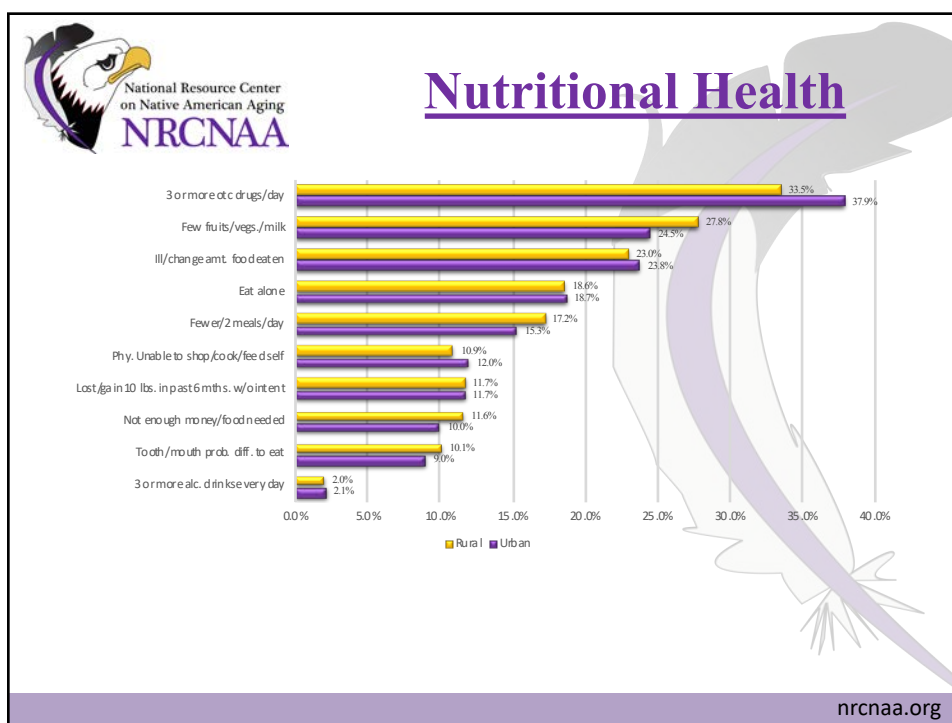
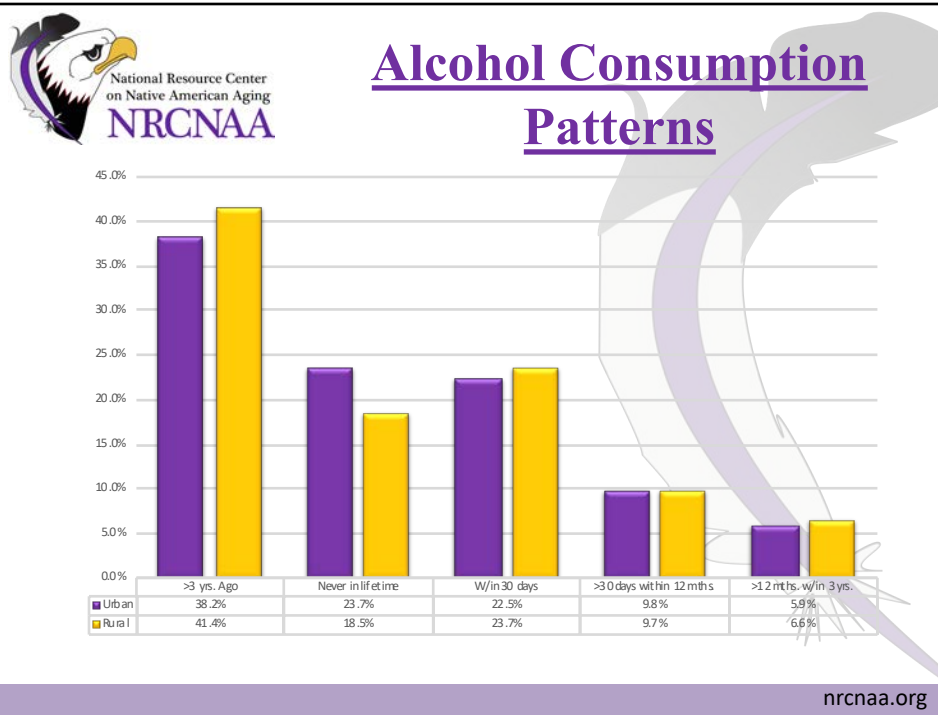
N = 18,134

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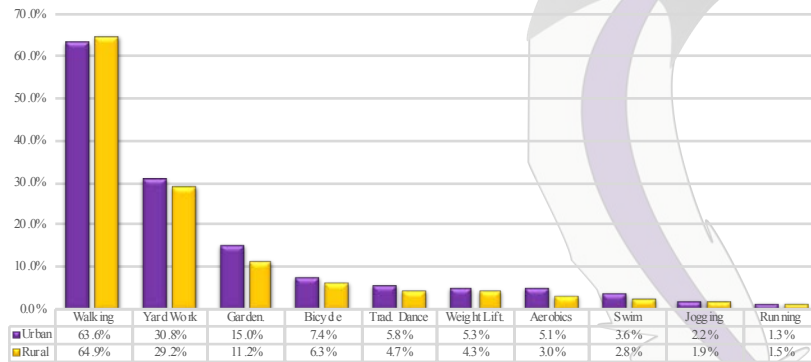








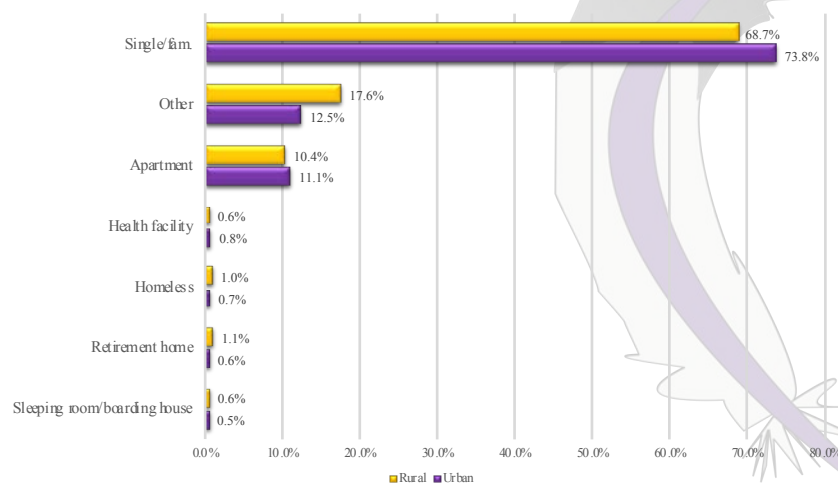
Exercise



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Housing Type

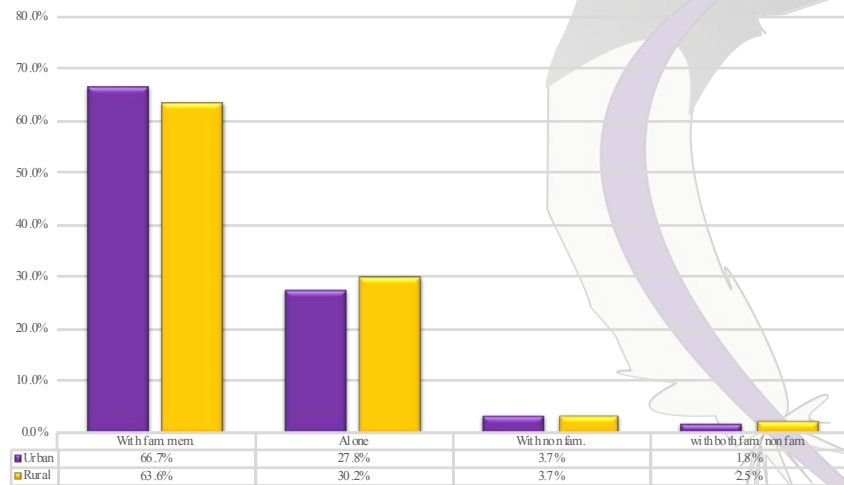


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AI/AN/NH elders residing with family members, non-family members, or alone

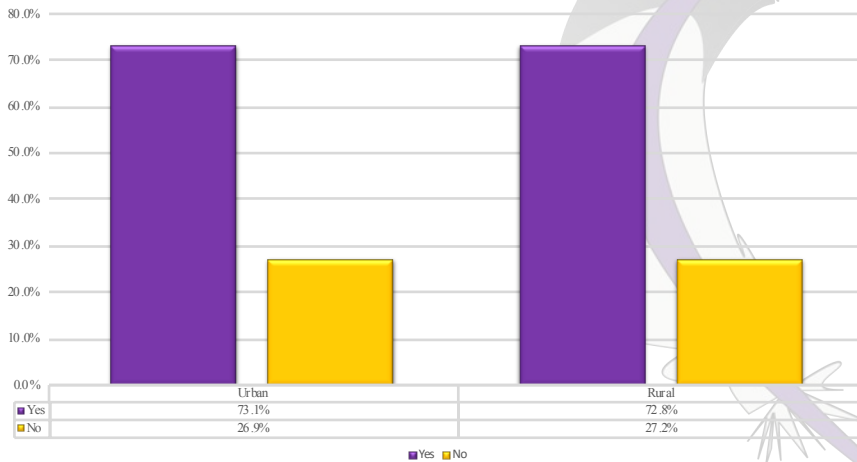


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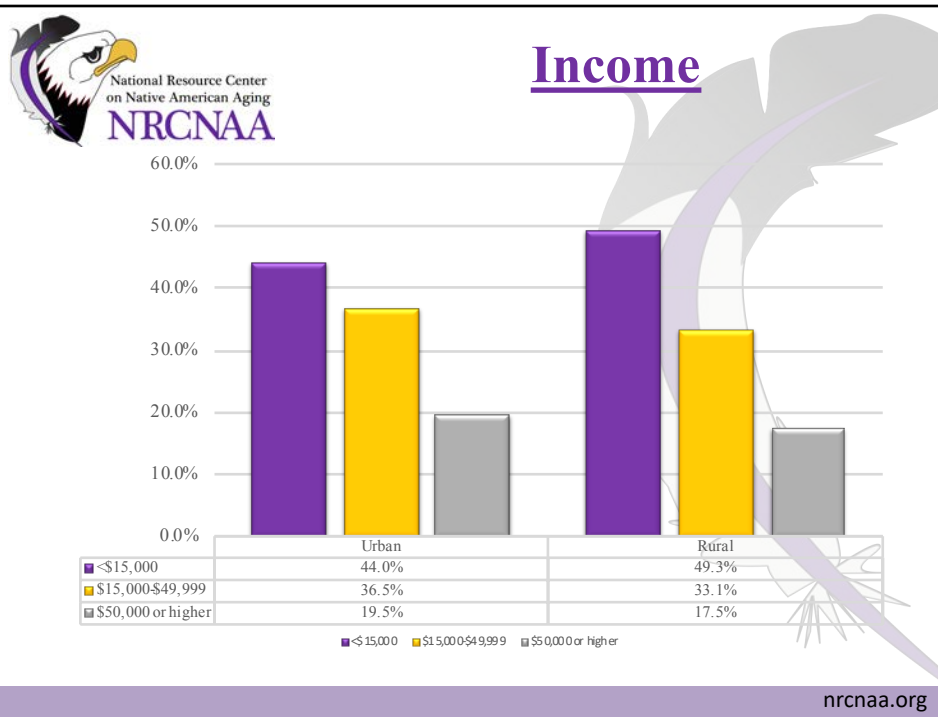



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Participate in Cultural Practices



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 **Utilization of Data for the AI/AN/NH Population**

- Local Level
 - Renewal of Title VI Grants
 - Strengthen Grant Proposals
 - Document health and social disparities
 - Tribal planning and infrastructure
 - Empowers the tribe with information to identify and address health needs
- National Level
 - Training for Native elder service providers
 - Advocating for resources and funding at the state, regional, and national level
 - Filling the research gap for Native elder information
- Training Native researchers in aging field
- Decision-making and policy

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Summary of Data Process

- *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.

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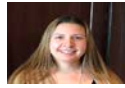
Summary of the Data Process

- *Obtaining proper permission to conduct research within tribal community*
 - Tribal community permissions
 - Tribal Resolutions
 - Tribal IRB or RRBs
 - Verbal consent from participating AI/AN/NH elder
- *Benefits to the partners (tribe and researcher)*
 - Data assists in bringing additional resources or funding to address health and social issues or disparities. Helps to change policy relating to the AI/AN elder population. Provides an invaluable rich data source.
- *Tribe owns*

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Questions?



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