Alzheimer's Disease: Outreach and Education for Native Communities

Partnerships for Native Health Washington State University University of Washington ADRC

Dedra Buchwald, MD, Professor Meghan A Jernigan (Choctaw), MPH, Faculty Elson S. Floyd College of Medicine



- Background on Partnerships for Native Health and American Indian/Alaska Native population (AIAN)
- Healthcare
- ADRC community and education activities and projects
- What we know (or don't know)
- Study of cerebrovascular disease in Als
- Links to training program

Partnerships for Native Health: Engagement and Research

- Urban and reservation-based AIAN populations across the lifespan
- Physical and mental health, disease prevention, health services
- ~160 partners: tribal colleges, AIAN organizations, and tribes (30 active sites)
- Community-based action research
- 55 projects funded since 2007
- Training and education

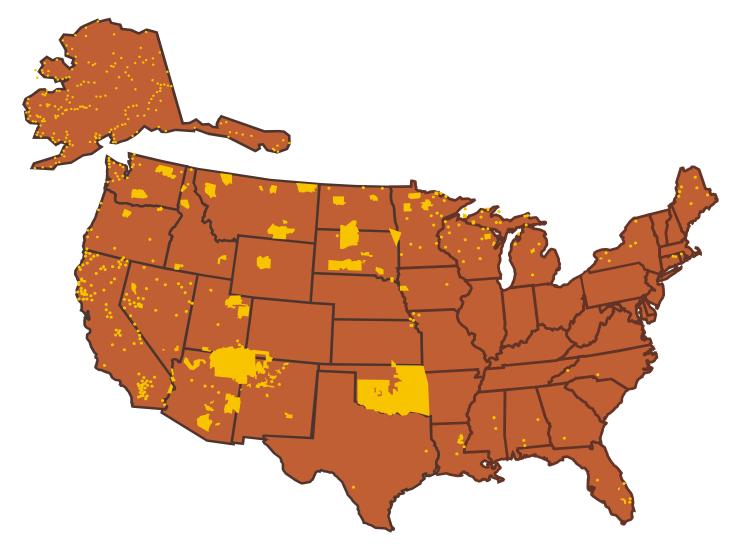


Tribal Sovereignty

- Federal government ratified ~370 treaties with Indian nations that define who is Indian and their relationship to federal government
- U.S. recognizes tribal governments as sovereign nations and increased tribal control of own programs
- Indians are not just a minority, they have different political status than other minorities
- Major implications for research (tribal review processes), clinical services (Indian Health Service and urban Indian facilities), public health practice (smoking bans), and policy (nursing homes)

Indian Lands Today

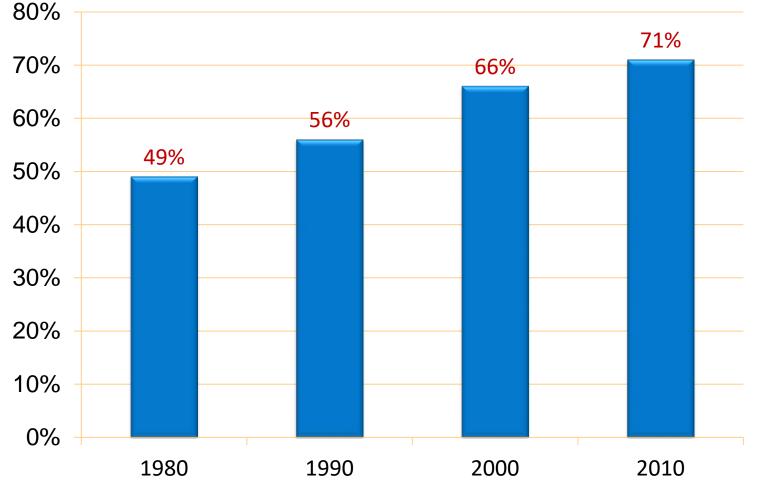




Urbanization of American Indians and Alaska Natives

Urban Percentage of AIAN Population: US Census Data

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Healthcare System

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 - Federal system
 - 33 hospitals
 - 59 health centers and 50 health stations
 - 34 Urban Indian Health Organizations provide health and referral services
 - Tribally operated facilities
 - 15 hospitals
 - 179 health centers and 117 health stations
 - 9 residential treatment centers
 - 180 Alaska village clinics

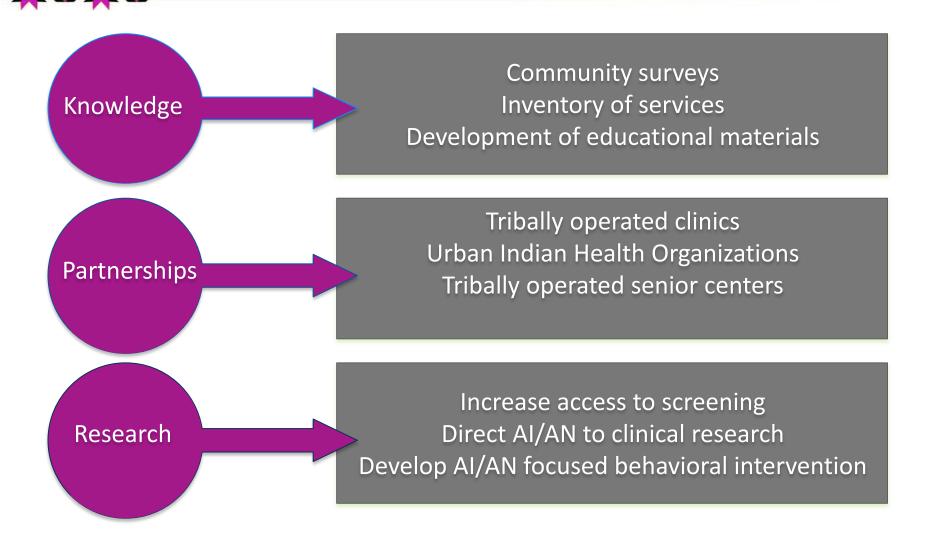
Healthcare System

- Indian Health Service federal funding provides only 55% of level needed to ensure AIAN people receive healthcare services equivalent to other groups
- Annual expenditures per enrollee
 - Medicaid = \$5,490
 - Federal employees = \$2,980
 - Indian Health Service = \$1,776

Aging Native Population

- Life expectancy for AIAN people has improved dramatically in past 40 years but still lower
- 2014 American Community Survey estimates 202,000 AIAN over the age of 65
- Indian Health Service and urban health facilities struggle to provide appropriate screenings, services, and programs for elders without set aside funds
- Few tribes have tribally-run nursing homes (~12) so care is often far from home
- Virtually all care for elders in the home

ADRC Outreach and Education Strategies



Assessing Knowledge: Methods

- Used Alzheimer's Disease Knowledge Scale
- Consists of 30 item true/false items
- Covers risk factors, assessment and diagnosis, symptoms, course, life impact, treatment and management
- Collected surveys from 327 AIAN community members (58% female, 43% rural) at powwows in Spring and Summer 2016



- 77% of respondents have heard of Alzheimer's disease
- 37% have immediate family member with trouble thinking or memory loss
- If personally diagnosed, 61% would agree or strongly agree to donate a blood sample to help researchers find causes and treatments for the condition

Outreach Activities

- Develop culturally tailored outreach and recruitment materials
 - Place in clinic waiting rooms
 - Targeted mailings
 - Distribute through Community Health Representatives
- Conduct provider trainings
 - Integrate practice recommendations described by the Alzheimer's Association
 - Promote principals of person-centered care

Research Activities

- Host community event featuring confidential memory screenings to determine prevalence
- Refer patients with possible Alzheimer's disease, including mild cognitive impairment, to the University of Washington's Alzheimer's Disease Research Center
- Partnerships for Native Health will provide AIAN patient navigators





- Identify needed services for detecting, diagnosing, and treating dementia
- Determine patient, family, and community knowledge about Alzheimer's disease
- Determine Service Utilization
 - Complete a community-wide inventory of services offered
 - Identify service gaps and desired services

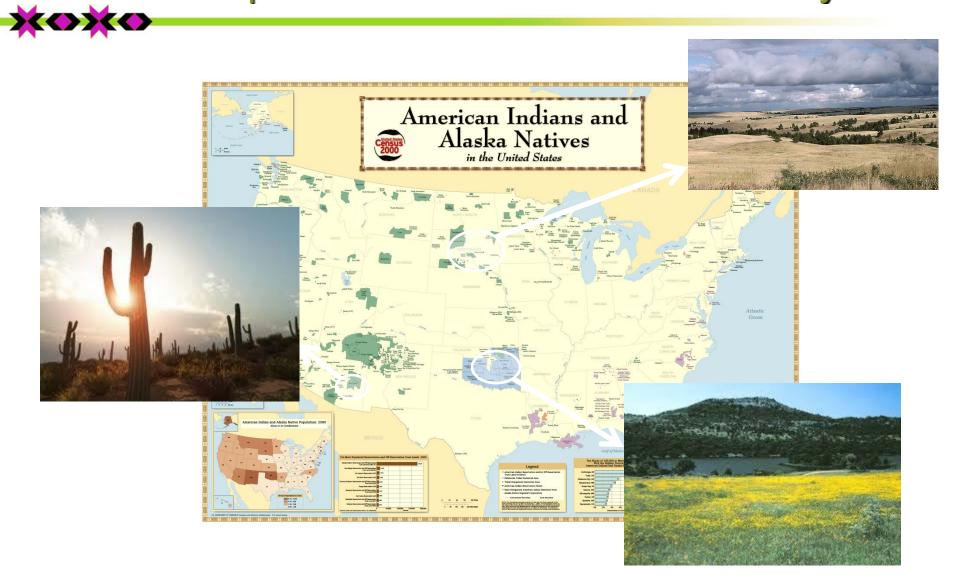
Develop Unique Culturally Tailored Research

- Incorporate legacy activities: share wisdom and stories to preserve personhood. In randomized control trials:
 - Legacy activities reduce caregiver stress, increase social interaction, and improve communication
 - Improve patient cognition, mood and general behavior function
- Adapt Healthy Action to Benefit Independence and Thinking (HABIT) intervention for AIAN communities

Few Dementia Data

- Fractured healthcare and surveillance system across urban and rural areas
- Barriers to screening along with inconsistent diagnostic criteria
- AIANs hugely under-represented in epidemiological and clinical studies of Alzheimer's disease
- National Alzheimer's Coordinating Center has ~160 AIAN cases; our ARDC has enrolled 3 in 30 years
- Kaiser study showed AIANs 2nd highest new onset dementia diagnosis (2000 to 2103)

Cerebrovascular Disease and Its Consequences in American Indians Study



Cerebrovascular Disease and Its Consequences in American Indians Study

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 - **Aims:** Improve understanding of non-symptomatic vascular and structural brain disease in elderly, rural AIs
 - Participants: 1,033 Als in Strong Heart Study recruited from 13 tribes. Drawn from cohort of 4,549, <u>ages 45-74 in 1989-91</u>
 - **Design and Methods:** Follow up conducted from 2010 to 2013
 - Cranial MRI: Sagittal T1; axial T2; axial T2; axial T2; FLAIR; T1 echo.
 Variables: white matter hyperintensities; sulci; ventricles; hemorrhages; sulci; hippocampal, white matter, whole brain, intracranial volumes
 - Cognitive Tests: Modified Mini-Mental State, Wechsler Adult Intelligence Scale-IV coding test, California Verbal Learning Test, Controlled Oral Word Association Test, Halstead finger tap
 - Exam: Self-reported health, behaviors, medical history; medication; chair stand, timed stand, timed walk, grip strength, ECG, lipids, glucose, Creactive protein, cystatin C, creatinine, HbA1c; urine creatinine, albumin

Findings

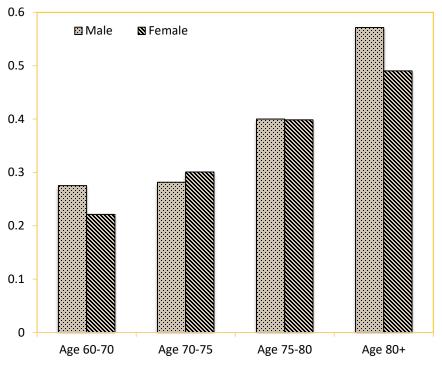


- Vascular brain disease in 30-40%; structural disease in 50-70%; related to age, high blood pressure, smoking, diabetes.~30% with some level of cognitive impairment
- Caveats: 1) cognitive test standards not appropriate for elderly American Indians; 2) survivor effect present

Test Scores by Sex

	Male	Female	
	N=322	N=711	P-value
Cognitive Score (3MSE)	87.7 (9.6)	87.9 (9.4)	0.702
Processing Speed	41.3 (15.2)	43.2 (16.2)	0.068
Verbal (COWA-FAS)	22.6 (11.5)	24.1 (11.3)	0.064
Immediate Recall (CVLT)	21.9 (5.6)	22.9 (5.3)	0.007
Short Free Recall (CVLT)	5.6 (2.1)	6.1 (2.1)	0.003
Long Free Recall (CVLT)	5.3 (2.5)	5.6 (2.2)	0.016

Proportion of Strong Heart Study participants with infarcts, by age and sex



Satellite Core and Core Expansion

- **Aims:** Document changes in disease and cognitive status
- **Design:** Follow-up of 450 surviving participants from 2010-2013 cohort using same protocols and MRI machines

New Measures

- Alzheimer's disease evaluation (Uniform Data Set 3-form C2)
- Montreal cognitive assessment, Craft story recall-immediate and delayed, Benson Complex, Number Span, Category Fluency, Trail Making, Multilingual naming test, Phonemic Fluency
- Functional MRI and 3D brain mapping with comparison to norms for people with and without dementia
- Adjudication for Alzheimer's disease
- Outreach: Education on Alzheimer's disease in 12 tribal communities

Resource Centers for Minority Aging Research: Native Investigator Development Program

• 2 year training period

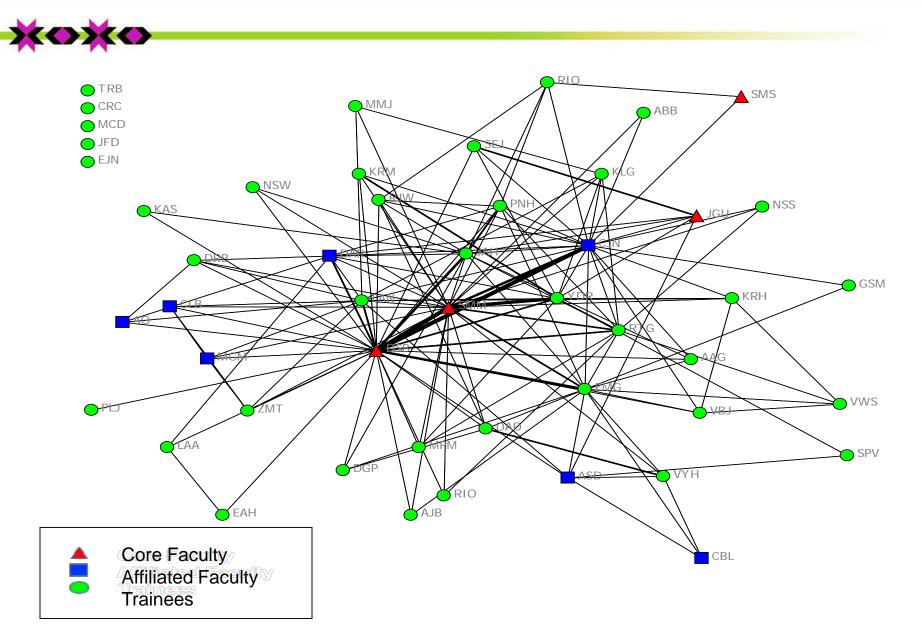
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- 4 6 Native MD, PhD-level social, behavioral and health scientists each cycle
- Targeted didactic instruction
- Intensive mentoring and interdisciplinary faculty
- Distributed, decentralized model (4 face-to-face and 4 video meetings/year, weekly calls)
- University of Colorado Anschutz Medical Campus and Washington State University

Program Outcomes

- 48 AIAN MDs/PhDs/JDs: 34 tribes represented in 10 cohorts
- 86% retained over 2-year training cycle
- 8 tenured at major research universities
- ~\$100 million in NIH grants: Principal or Co-Investigator on 100 funded grants; 68 from federal agencies
- R series, K awards, Diversity Supplements, foundation awards, state, regional, Indian Health Service
- 345 peer-reviewed publications

Social Network Analysis: Manuscripts 1998 to 2015



Native Investigator Development Program Links to ADRC

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 - Trainees
 - Steve Verney, PhD (Tsimshian neuropsychologist) awarded R01 on cognitive rehabilitation of AIAN elders (NIA)
 - Lonnie Nelson, PhD (Eastern Band of Cherokee Indians rehabilitation psychologist) Co-Investigator
 - Jordan Lewis, PhD (Aleut gerontologist) conducting secondary data analyses on cognitive decline and hypertension in Als
 - Faculty
 - Dedra Buchwald, MD and Spero Manson, PhD (Chippewa) awarded supplement for national conference on healthcare costs for Alzheimer's disease among AIANs (NIA)
 - Dedra Buchwald, MD awarded Satellite Core and Core Expansion (NIA)
 - Clemma Muller, MS, PhD, design and methods for grants

Contact Us!

ADRC Community Outreach and Education Lead Meghan Jernigan, MPH Staff Scientist Partnerships for Native Health Meghan.Jernigan@wsu.edu

<u>Research Lead</u> Dedra Buchwald, MD <u>Dedra.Buchwald@wsu.edu</u>

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