


Health Disparities: Research Strategies for Narrowing the Gap



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Partnerships for Native Health: Areas of Engagement and Research

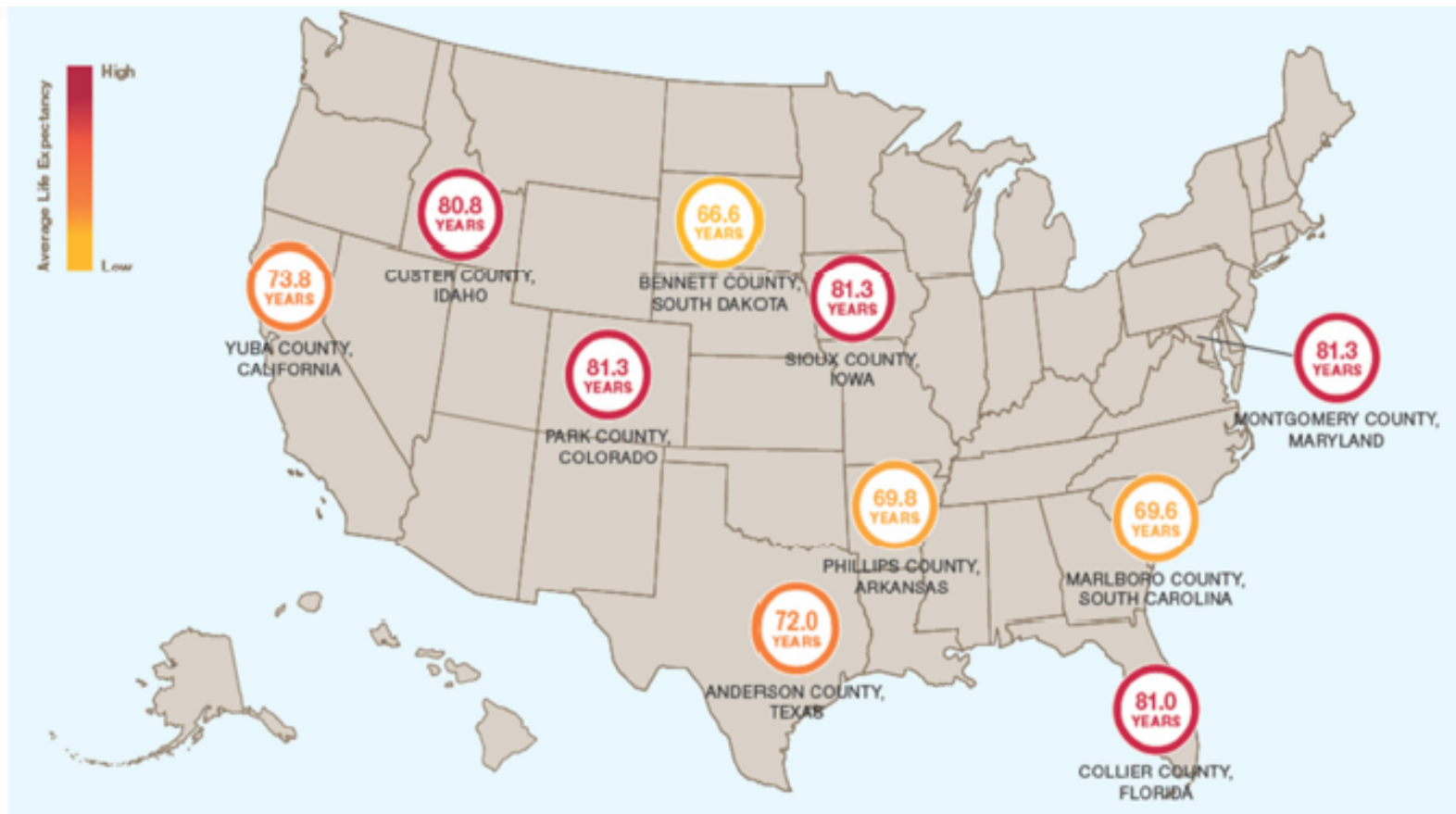
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- ◆ Reservation-based and urban Native populations across the lifespan
 - ◆ Physical and mental health, disease prevention, health services
 - ◆ Engage ~160 partners: tribal colleges, Native organizations, and tribes (30 active sites)
 - ◆ Conduct community-based action research – 45 projects funded since 2007
 - ◆ Training and education

Vision

Diverse American Indian and Alaska Native constituents and academic partners working together in real-world settings to improve health through research, education, and technical assistance and by focusing on community strengths.




Resources (\$) and Health Inequities: Differences in Life Expectancy




2008 Robert Wood Johnson Foundation
Commission to Build a Healthier America

Access and Healthcare Inequities: Inadequate Funds

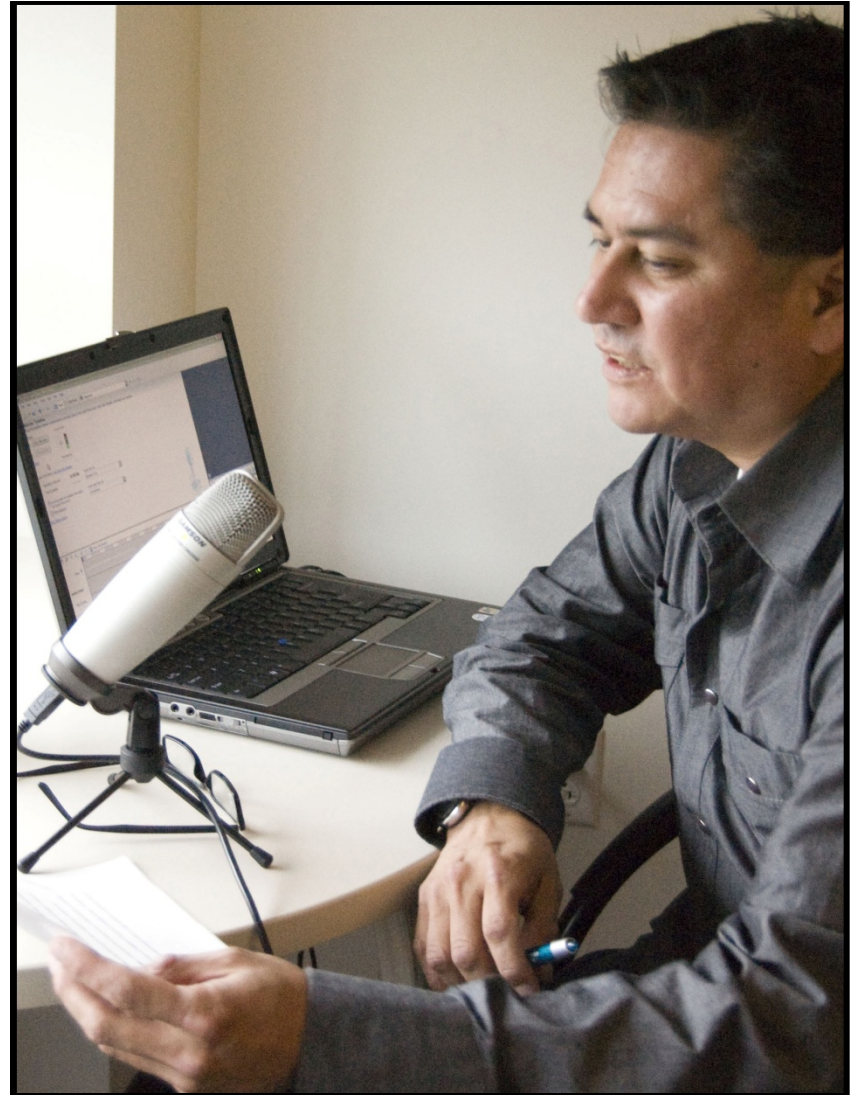
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- ◆ Indian Health Service funding provides **55%** of level needed to ensure Native people receive healthcare services equivalent to mainstream America
 - ◆ Annual expenditures per enrollee
 - ◆ Medicaid = \$5,490
 - ◆ Federal employees = \$2,980
 - ◆ Federal prisoners = \$2,625
 - ◆ Indian Health Service = **\$1,776**

Research Strategies

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- ◆ Find a champion and engage community
 - ◆ Respect tribal sovereignty and urban tribal entities
 - ◆ Don't say it can't be done
 - ◆ Don't just gather data
 - ◆ Find new experts for newly discovered concerns
 - ◆ Make cultural adaptations
 - ◆ Don't make assumptions
 - ◆ Consider the setting
 - ◆ Be flexible, change what doesn't work
 - ◆ Train and involve Native researchers and build capacity

Engage Communities: Digital Storytelling

- Create 2 – 4 minute personal narrative
- Draft a script
- Record your voice...the way we tell stories, not the way we write them
- Add pictures, music, edit using free video software programs



Cost-Effective and Sustainable

- Create learning communities, peer mentoring
- Disseminate via podcasts, Internet, cell phones, etc.
- Can be used as culturally-tailored evaluation tool to show change



Respect Tribal Sovereignty

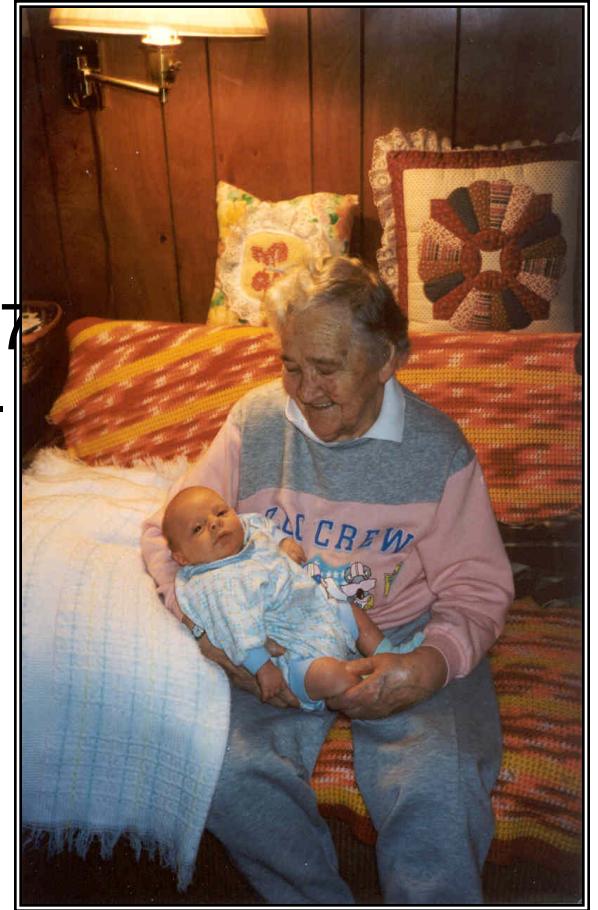
U.S. recognizes tribal governments as sovereign nations. Tribes have the right to regulate research and control their data, which may. . . .




- Create layers of research review by tribal entities, Indian Health Service, and universities
- Conflict with federal data sharing policies to “ensure that all data produced under an award will be made available to the public”

Don't Say It Can't be Done: Strong Heart Stroke Study

- ◆ Large cohort study of cardiovascular disease risk in 12 tribes spanning 25 years
- ◆ From 1988 through 2004, 306 of 4,507 (7%) participants diagnosed with first-time stroke
- ◆ Rate of ~ 700/100,000 people is almost **3 times rate** in Whites
- ◆ Average age at stroke = 66.5 years
- ◆ ~20% die within first year of stroke



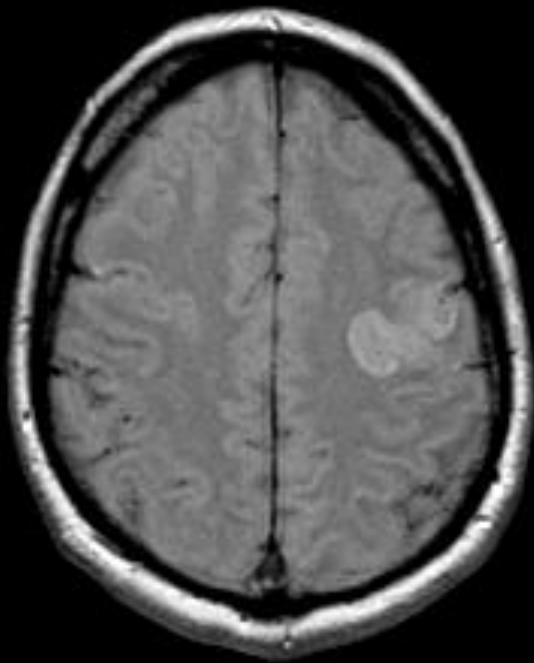
Strong Heart Stroke Study Aims

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- ◆ Estimate prevalence and quantify extent of MRI-defined cerebrovascular disease (CBVD, e.g., white matter grade, infarcts)
 - ◆ Document strength of associations of CBVD with cognitive impairment, motor deficits, depression
 - ◆ Assess relation of demographic, clinical, lifestyle, and cultural risk factors with MRI-defined CBVD

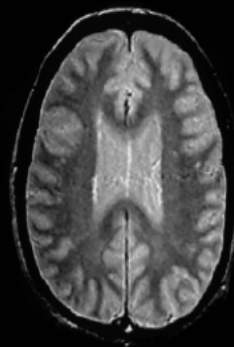
MRI Findings

Infarcts
Number, size, location

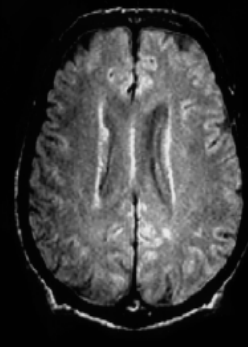
White matter grade
0 to 10



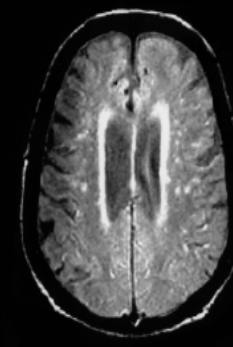
Grade 1



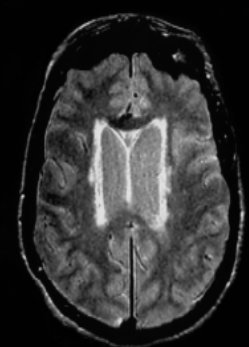
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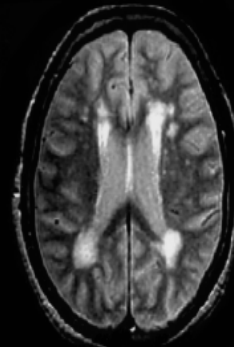
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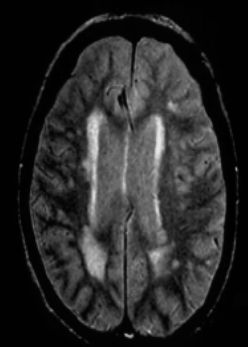
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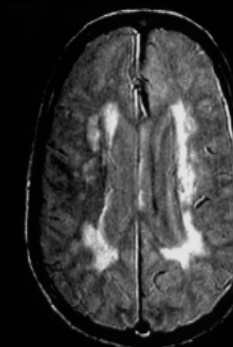
Grade 5



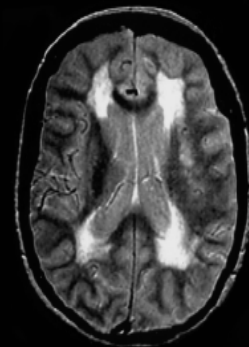
Grade 6



Grade 7



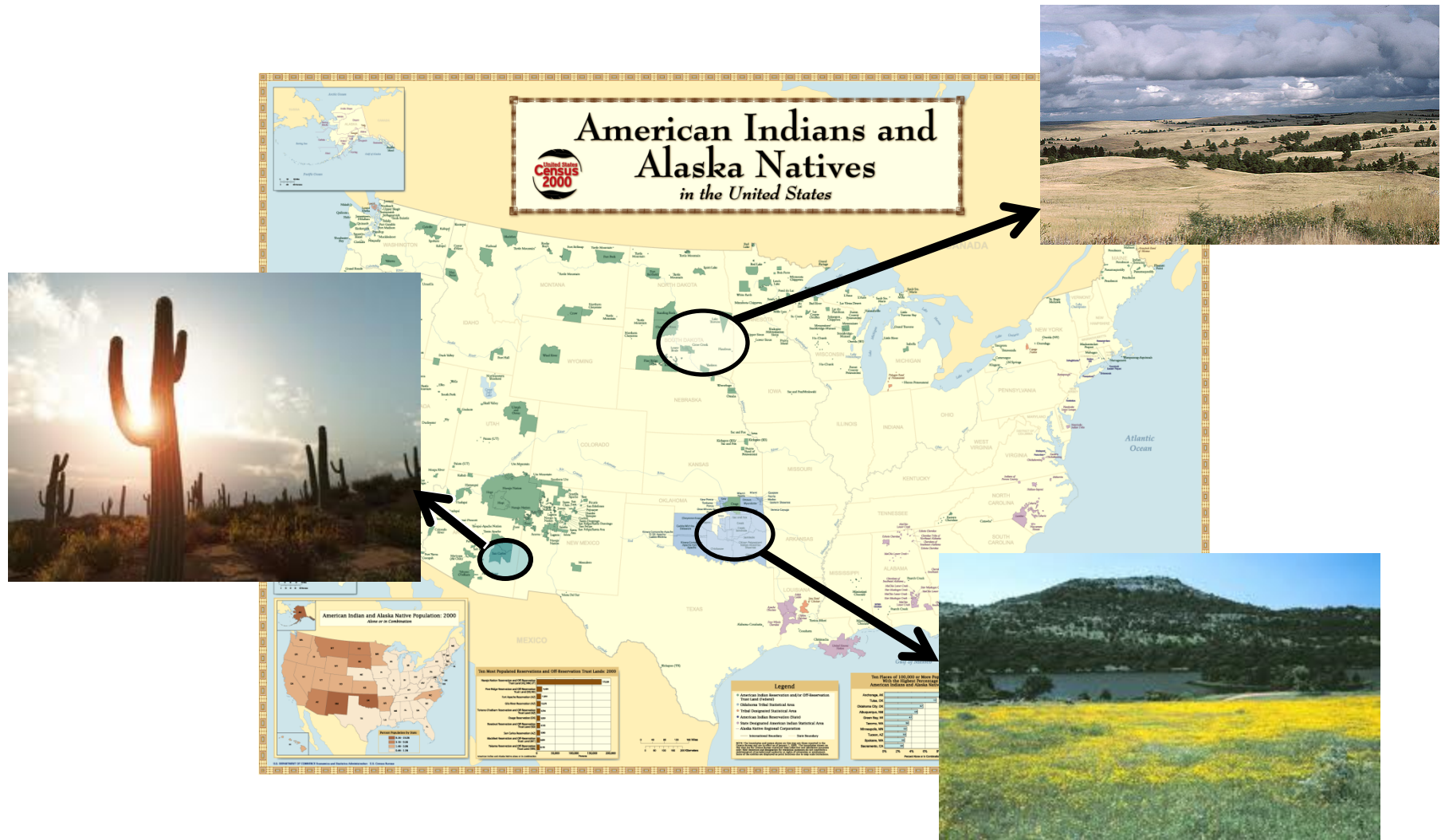
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Methods: Logistics

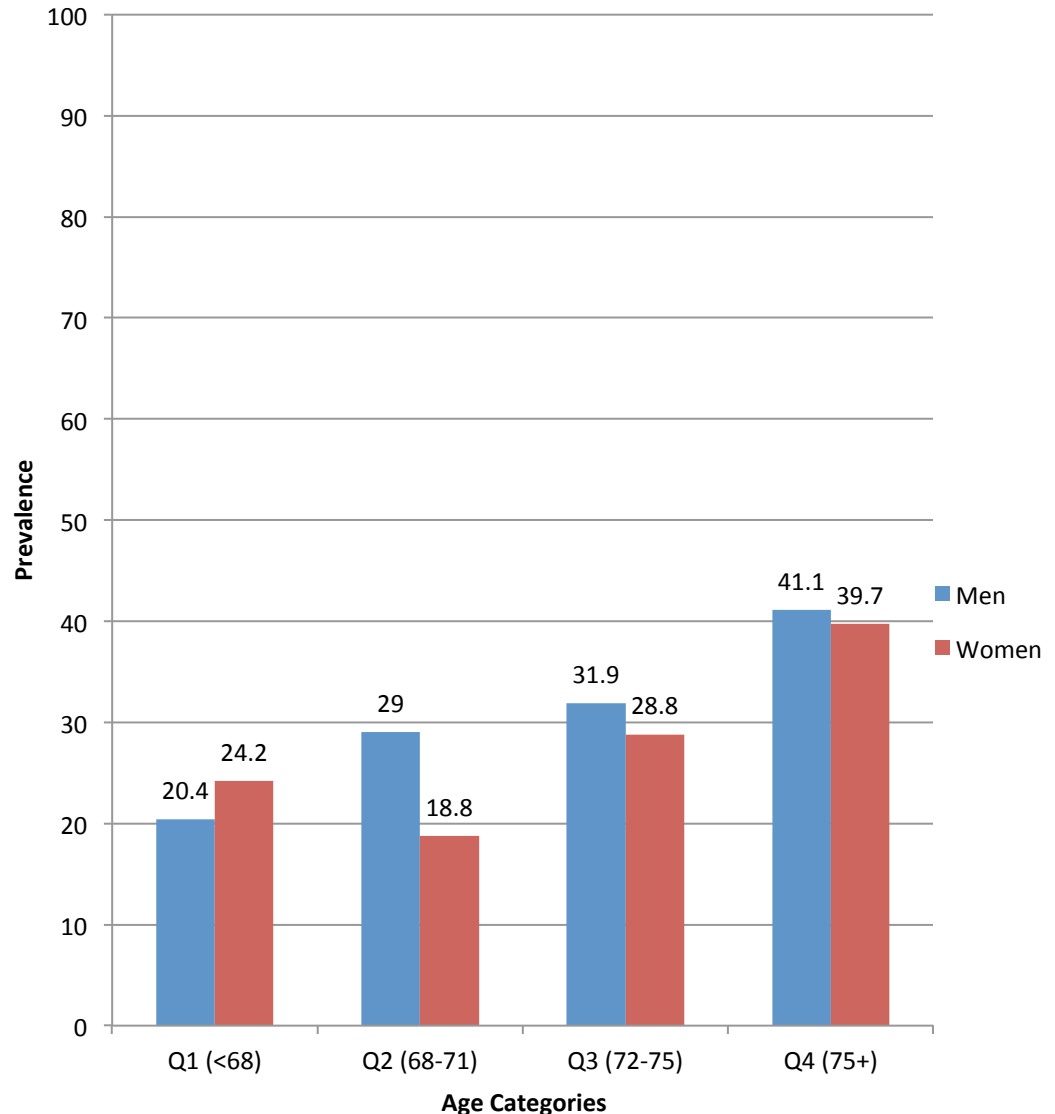
- ◆ Obtain approvals: 12 IRBs Universities, Tribes, Area Indian Health Service
- ◆ Recruit 333 participants from Oklahoma, Southwest, and Dakotas (12 tribes)
- ◆ Contact all living Strong Heart Study participants by visits, calls, and mail
- ◆ Arrange transport and lodging for 3½ hour visit (MRI, EKG, surveys, exam, blood draw)
- ◆ Pay participants \$200





Results: Infarcts

- ◆ Prevalence
 - Men: 31%
 - Women: 28%
 - Total: 29%
- ◆ Association between older age and between obesity and increasing prevalence of infarcts



Don't Just Collect Data: Family Intervention in the Spirit of Motivational Interviewing

Study Population


- ◆ Strong Heart Family Study (12 tribes)
- ◆ 11 to 44 years of age in 360 households

Specific Aims

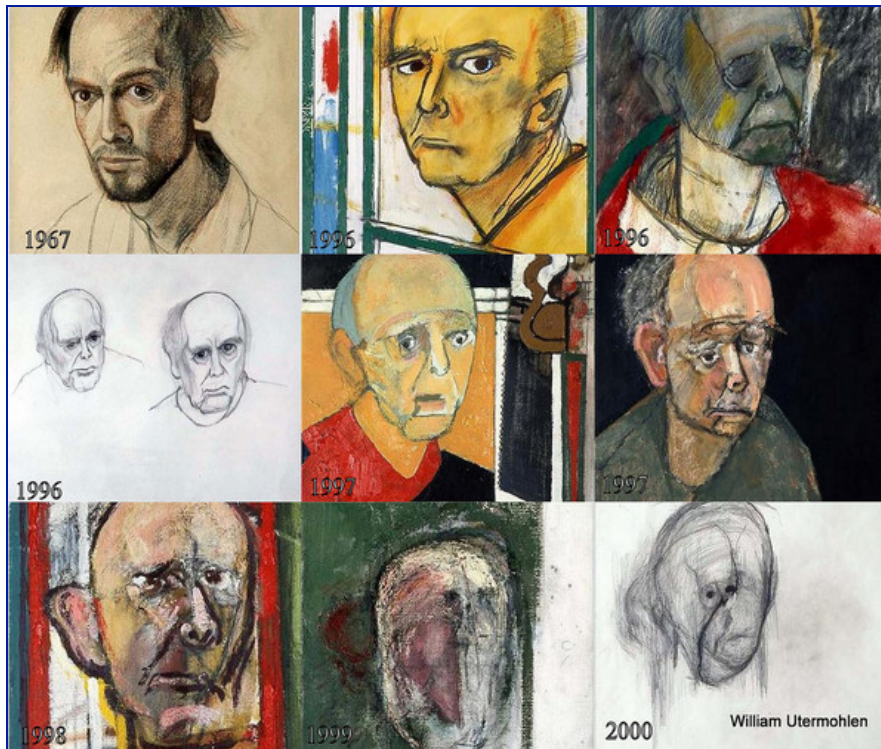
- ◆ Estimate intervention effectiveness to change stroke and cardiovascular disease risk scores from baseline to 1-year follow-up
- ◆ Compare changes in blood pressure and smoking from baseline to 1-year follow-up



Family Intervention in the Spirit of Motivational Interviewing

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- ◆ Randomized controlled trial
 - ◆ Control arm receives culturally relevant brochures
 - ◆ Incorporates digital media, text messaging, motivational interviewing, talking circles
 - ◆ Delivered at household level
 - ◆ Transform household environment to reduce stroke risk

Find New Experts: Alzheimer's Disease Research Center

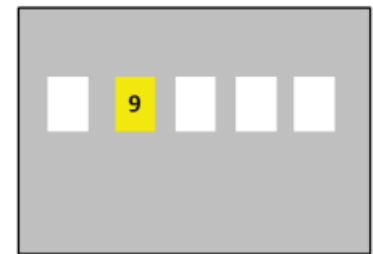


- ◆ New collaboration
- ◆ Follow-up Stroke Study participants and repeat neuropsychological test battery to assess changes in cognition
- ◆ Pilot test feasibility of studying urban American Indian sample

Culturally Adapt Your Research: Rhythm and Timing Intervention

- ◆ Interactive Metronome is a behavioral therapy for cognitive impairment
- ◆ Rhythm and timing exercises (e.g. clapping, tapping toes)
- ◆ Computer based instrument give visual and auditory feedback
- ◆ Enhances quality of life, improves cognition, physical mobility, and gait

Visual Feedback on Monitor



Auditory Feedback in Headphones

Rhythm and Timing Intervention

Specific Aims

- ◆ Improve cognitive impairment
- ◆ Decrease depression
- ◆ Enhance quality of life

Design

Randomize 150 Stroke Study participants with cognitive impairment to 5-week home-based trial of Native drum music or light exercise

Outcome

Pre- and post cognitive and physical function and quality of life



Consider the Setting: Challenges of Research with Small Native Populations

Problem: > 90% of tribes are small

Question: Can we combine tribal data in ethical, culturally appropriate, and scientifically rigorous ways?

Design: Conducted 10 focus groups with members of tribes of various sizes, drafted results, reconvened groups, got tribal approvals



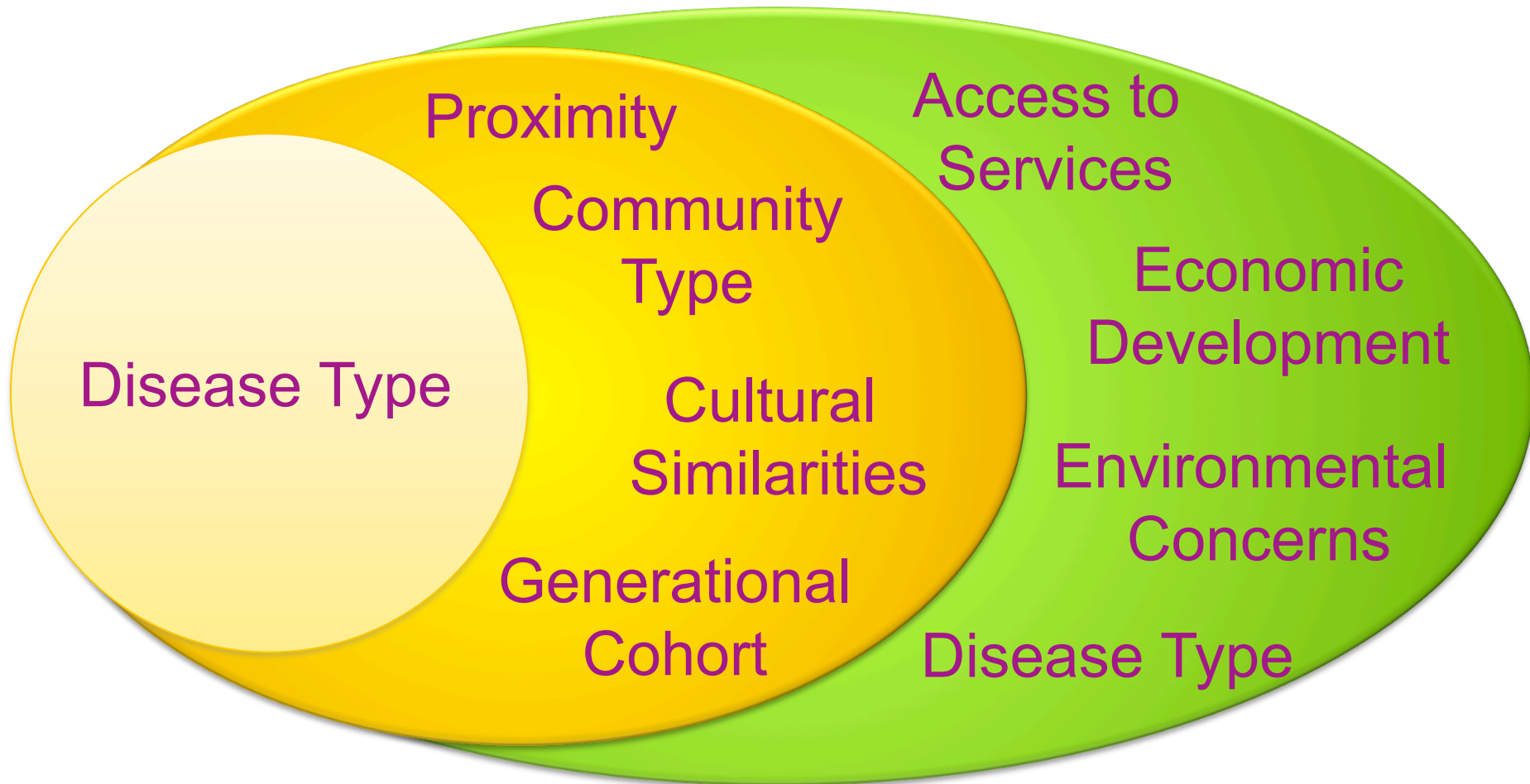
Categories for Grouping Tribal Data



Local

Regional

Nationwide



Don't Make Assumptions: Biobanking

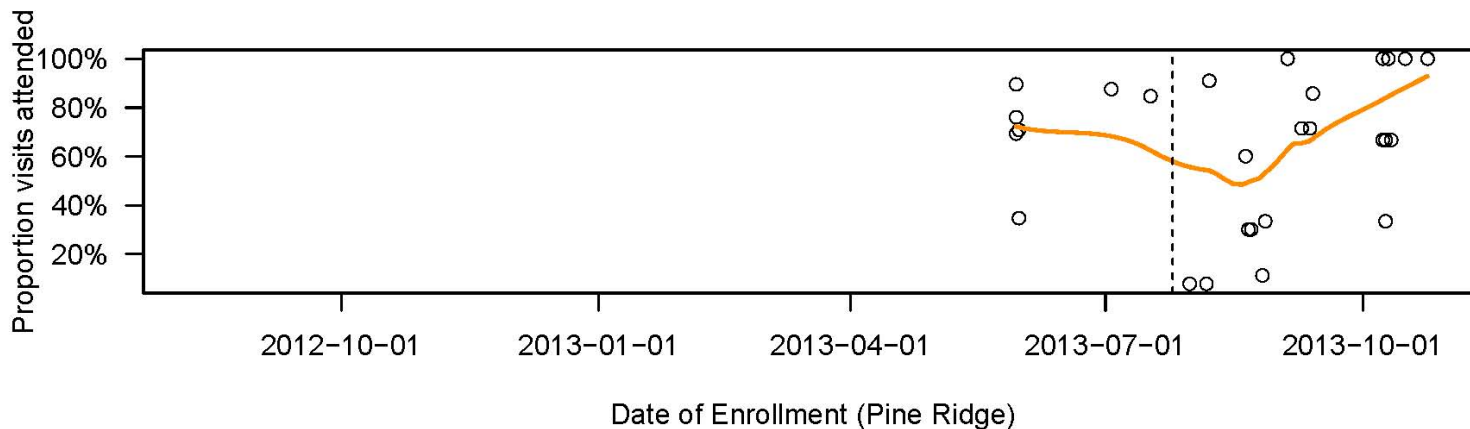
- ◆ Biobanking thought to be taboo among Native peoples
- ◆ Surveyed 300 American Indians at community events
- ◆ 43% were somewhat/very willing to donate a specimen
- ◆ 47% would donate blood
- ◆ Donation increased if family had cancer or biobank run by Native organization
- ◆ Received AHRQ grant on biobanking with National Congress of American Indians and 7 tribal partners



Be Flexible: Native Women's Wellness

- ◆ **Intervention:** Contingency Management for Smoking Cessation and Weight Loss
 - 120 participants
 - 2 visits/week
 - Escalating reinforcement
- ◆ **Problem:** Low Participation
 - Transportation/logistics
 - Insufficient compensation
- ◆ **Solution:** Participant Feedback
 - Decrease visits
 - Increase reinforcement
 - % kept visits increased after protocol adaptations





Train and Build Capacity: Native Investigator Development Program

- ◆ 2 year training program
- ◆ 4-5 Native Investigators each cycle
- ◆ Targeted didactic instruction
- ◆ Intensive mentoring
- ◆ Interdisciplinary faculty
- ◆ Distributed (decentralized) model
- ◆ Goal is to train independent Native researchers



Outcomes

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- ◆ 47 American Indian and Alaska Native MDs/PhDs/JDs from 30 tribes trained in the 8 cohorts to date
 - ◆ 86% retained over 2-year training cycle
 - ◆ 8 tenured at major research universities
 - ◆ \$60 million in NIH grants
 - ◆ PI or Co-PI on 95 funded grants; 63 from federal agencies
 - ◆ R01, K career awards, Diversity Supplements, foundation research awards, state, regional, Indian Health Service
 - ◆ Over 300 peer-reviewed publications

Keys to Success



- ◆ Committed Native and non-Native scientists as role models
- ◆ Ensure adequate scientific preparation in concrete, personally relevant terms
- ◆ Emphasize writing skills
- ◆ Stress deadlines, accountability, efficiencies, time management
- ◆ Prepare for realities of community-based partnerships
- ◆ Recognize that trainees are primary scholarly legacy



 **Past Faculty**



Thank you!

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