NIMHD Vision and Agenda

Research on American Indian and Alaska Native Health

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Annual Summit
Collaborative Research Center for
American Indian Health, Sioux Falls, SD

April 5, 2017



My career was shaped by immigration!

- English is my second language
- I was always "legal" as a "refugee"
- UCSF Primary Care Internal Medicine
- Research Fellowship in GIM
- R01 in Tobacco Control in Latinos at 33
- Cancer Control, Minority Health, Health Disparities, Aging, Diversity, Science
- Professor/Division Chief to IC Director





Lessons after 19 Months at NIH

- Government is more efficient
- Hierarchy is power top down
- All politics are local
- Institutes are autonomous
- Passion for science mission
- Collaborative spirit is strong
- Recognition of Minority Health and Health Disparities





NIMHD History

- Office under the NIH Director through DHHS Secretary Louis W. Sullivan, M.D. in 1990
- Center through legislation championed by Representative Louis Stokes (D-OH) in 2000
- Patient Protection and Affordable Care Act contained language championed by Senator Ben Cardin (D-MD) to transition to an Institute in 2010
- John Ruffin, Ph.D. led all the entities until his retirement in March 2014; Yvonne T. Maddox, Ph.D. became Acting Director
- Eliseo J. Pérez-Stable, M.D., started September 1, 2015; FY 2016 budget was about \$280 million



NIMHD Mission

- Support research that advances understanding and improvement of health and disease in minority racial/ethnic groups in U.S.
- Support research to understand the causes of and define mechanisms leading to interventions that reduce health disparities in specific populations
- Supports the training and development of a diverse scientific workforce as part of broad NIH mandate





Minority Health Definition

- Minority Health Research focuses on health determinants that lead to specific outcomes within a minority group and in comparison to others
- Race and ethnic minorities share a social disadvantage and/or are subject to discrimination as a common theme



OMB Race/Ethnic Classification

- African American or Black
- Asian (>20 countries)
- American Indian or Alaska Native
- Native Hawaiian or other Pacific Islander
- Latino or Hispanic (20 countries)
- •White





Health Disparity Populations

- -Health disparity populations include:
 - racial/ethnic minorities
 - •less privileged socio-economic status
 - •underserved rural residents, and/or
 - sexual gender minorities
- -Populations have poorer health outcomes often attributed in part to social disadvantage, being subject to discrimination, and underserved in the full spectrum of health care.





Health Disparities Definition

- A health disparity is defined as a health difference that adversely affects disadvantaged populations, based on one or more of the health outcomes
- Health disparities research is devoted to:

 advancing scientific knowledge about defining mechanisms of how health determinants affect disparities; and 2) how this knowledge is translated into interventions to reduce disparities

Health Disparity Outcomes

- Higher incidence and/or prevalence
- Burden of disease measured by Disability-Adjusted Life Years (DALYS)
- Premature and/or excessive mortality in areas where populations differ
- Poorer health-related quality of life and/or daily functioning using standardized measures





Mechanisms Leading to Health Disparities

- Individual Behaviors, Lifestyle, Beliefs, and Response to Stress: racism, adverse conditions, food insecurity, witness to violence, immigration, LEP status
- Biological processes and Genetics: Earlier age of onset, gene variants, metabolic differences, susceptibility, faster progression, greater severity
- Physical Environment: place, social system, neighborhood, infrastructure
- Cultural Environment: family, social interactions, network, community cohesion
- Clinical Events and Health Care: Differential treatments, poor communication, adverse events to medications, falls, progression of disease, access, use/abuse of appropriate services end of life care





Minority Health and Health Disparities Research Framework

Fundamental Factors: Race/Ethnicity, Low Socioeconomic Status, Rural Residence

Domains: Health	Levels of Influence			
Determinants	Individual	Interpersonal	Community	Societal
Biological	Vulnerability Mechanisms	Caregiver-Child Interaction Family Microbiome	Infectious Disease Prevalence Herd Immunity	Sanitation Immunization Pathogen exposure
Behavioral 5	Health Behaviors Coping Strategies	Family Function School/Work Function	Community Function	Welfare Immigration Language access
Physical Environment	Personal Environment	Household School Work	Community Environment, Resources	Government Education Housing
Sociocultural Environment	Sociodemographic Cultural Identify Discrimination	Networks Family/Peer Discrimination	Community Norms Discrimination	Societal Norms Structural Discrimination
Healthcare System	Access Limited English Proficiency	D/P Relationship Collaborative care	Availability Health Services	Quality of Care Health Care Policies
Health Outcomes	Individual Health	Family Health	Community Health	Population Health





Inclusion of Diverse Participants

- All disparity populations are historically underrepresented in biomedical research
- Inclusion of minorities in clinical studies is an important and separate domain from research
- Inclusion is not to be confused with minority health or health disparities research
- Social justice, good science, and common sense mandate inclusion (40% US population)





We Have to be at The Table

- Yes, it is harder to recruit minorities and it usually takes more resources and different skills
- More face time and personal messages
- Minority scientists are generally better at it
- We need greater granularity (SES, birthplace, language) and accountability
- End myth that barriers are insurmountable







Workforce Diversity is an Urgent Issue

- About 5% of all NIH R01 grants are awarded to African American and Latino Pls
- Apparent bias in funding: less re-submission, mentoring, "low success" topics
- Medical school graduates in 2014: 5% Latino, 6% African American, <1% American Indian
- See more uninsured and Medicaid patients, greater intent to work in underserved areas



NIMHD Priorities

- Define the science of health disparities and minority health and develop an NIH Strategic Plan
- Promote innovation from extramural scientists in these sciences that lead to R01 applications and awards
- Collaborate on research MH/HD topics with other Institutes
- Promote diversity in the workforce



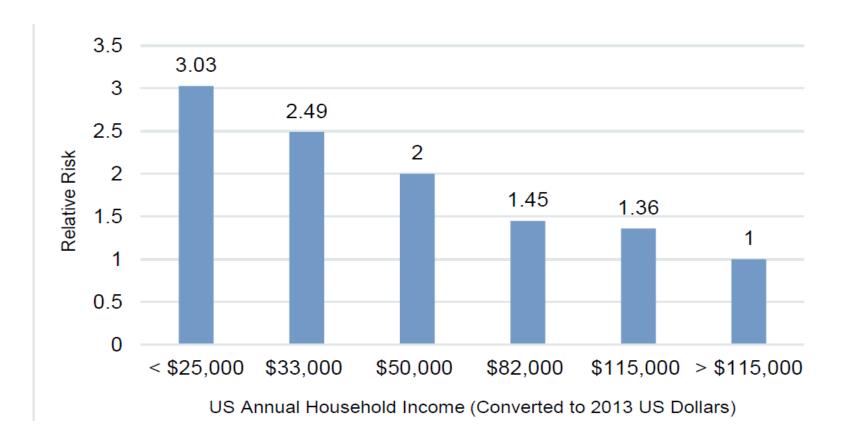


NIMHD Scientific Programs

- Clinical and Health Services
 Research
- Integrative Biological and Behavioral Sciences: Mechanisms and Etiologies
- Community Health and Population Health Sciences



Relative risk of All-Cause Mortality by US Annual Household Income Level





Life Expectancy in the U.S., 2014

	Men	Women
Whites	76.5	81.1
Blacks	72.0	78.1
Latinos	79.2	84.0
AI/AN and NH (2007-09)	68.0	74.3

Arias E, NCHS, CDC, 2016





Place, Income and Life Expectancy

- Tax records for pretax household income and death registry in SSA
- Richest vs. poorest 1% live on average:
 10.1 y (women) and 14.6 y (men) longer
- Inequality in 5% increased by 2 y for men and 3 y women over time
- Bottom quintile in some local areas live an average 4.5 years longer than others

Chetty R, et al, JAMA. Online April 10, 2016





Rural Residence is a Health Disparity

- National Vital Statistics compare mortality for leading causes of death by urban/rural
- Heart disease, cancer, COPD, accidents and stroke
- Compared with metropolitan areas, nonmetropolitan areas have higher ageadjusted death rates and greater percentages of potentially excess deaths from the five leading causes of death.

MMWR Surveillance Summary, January 13, 2017, Vol 66, No 1



Trends in Premature Mortality

U.S. 1999-2014, age 25-64

- Death certificates from NCHS and Census data using age-period cohort models
- Increase in Whites and Al/AN from accidental OD, CLD/cirrhosis, suicide
- Women at age 30: +2.3% W; +4.3% Al/AN
- Marked decreases in Latinos (-3.2%),
 Blacks (-3.9%) and Asian/PI (-2.6%) from decline in HIV, cancer and heart disease
- Al/AN highest mortality; Blacks second

Shiels MS, et al, Lancet. Online January 25, 2017





Trends in Suicide Rates

Age-adjusted Incidence, 1996-2013, age 10 y and older MMWR, March 17, 2017, 66: 270-273

	1999-07	2008-15
Whites	14.9	18.1
Blacks	6.3	6.5
Asians/PI	6.5	7.0
AI/AN	15.8	20.0
Latinos	6.7	6.8



U.S. Infant Mortality Rates, 2005 & 2013 (per 1000 live births, by race and Latino origin of mother)

Race/Ethnicity	2005-07	2012-14	% change
All races	6.86	5.96	-13%
White	5.76	5.06	-12%
Black	13.63	10.93	-20%
AI/AN	8.06	7.59	-6%
API	4.89	3.86	-21%
Latino	5.51	5.04	-9%
Mexican	5.43	4.92	-9%
Puerto Rican	8.00	6.68	-17%
Cuban	4.90	3.95	-19%
CA/SA	4.59	4.23	-8%



Childhood Measles, Mumps and Rubella Vaccination Rates, U.S., Aged 19 – 35 months

Race and Ethnicity	Percent of Vaccination Rates*
U.S. National	91.5 (+/- 0.9)
American Indian/Alaska Native	96.5 (+/- 3.7)
Asian	95.7 (+/- 2.4)
Black/African American	90.3 (+/- 3.0)
Latino/Hispanic	91.9 (+/- 2.0)
Native Hawaiian/Pacific Islander	95.7 (+/- 4.7)
White	91.2 (+/- 1.1)
Multiple Race	90.5 (+/- 4.5)

^{*} Estimates presented as point estimate (%) ± 95% Confidence Interval (CI)





Source: CDC/NIS, 2014

Breast Cancer Screening, 2015 among women age 50-74, NHIS

	Up-to-date on Mammography
White	71.8%
Black	74.3%
Asian	66.1%
AI/AN	56.7%
Latina	72.1%

Education Level	Up-to date on Mammography
< High School	60.3%
High School / GED	68.3%
Some College / Tech	71.0%
College Graduate	78.9%

BRFSS. MMWR July 9, 2010 / 59(26);813-816



Prevalence of Colorectal Cancer Screening, 2015

in adults age 50-75, National Health Interview Survey, CDC

	Screened for CRC
White	63.7%
Black	59.3%
Asian	52.1%
Am Indian / Alaska Native	48.4%
Latino	47.4% (Mexicans 36%)

Educational Level	Screened for CRC
< High School	46.7%
High School / GED	58.2%
Some College / Tech	63.5%
College Graduate	70.7%

White A, et al. MMWR March 3, 2017/66 (8): 201-206



American Indian/Alaska Native Research at NIMHD: FY 2015

- NIMHD had 78 Projects and subprojects
- \$18,901,522 or about 9.8% of NIMHD
- Centers: COE and TCC
- R01, R24, R43, T37
- Content analysis to identify needs

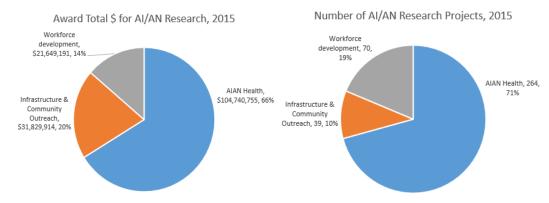




Summary Table of NIH AI/AN Research Investment by Emphasis Area

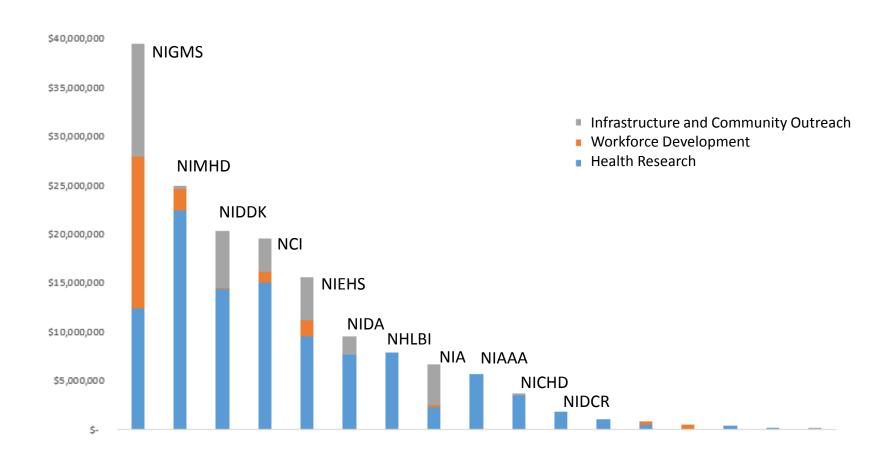
Research Emphasis	Funding, 2015 Millions (pct)	No. Al/AN Research Projects (pct)
Health Research	\$104.7 (66.2%)	264 (71.0%)
Workforce Development	\$21.6 (13.7%)	70 (18.6%)
Capacity Building and Community Outreach	\$31.8 (20.1%)	39 (10.4%)
Totals*	\$158.2 (100.0%)	373 (100.0%)

Awarded dollars and projects for AI/AN Research, 2015





Awarded \$ by Institute and Center and Area of Al/AN Research, FY2015









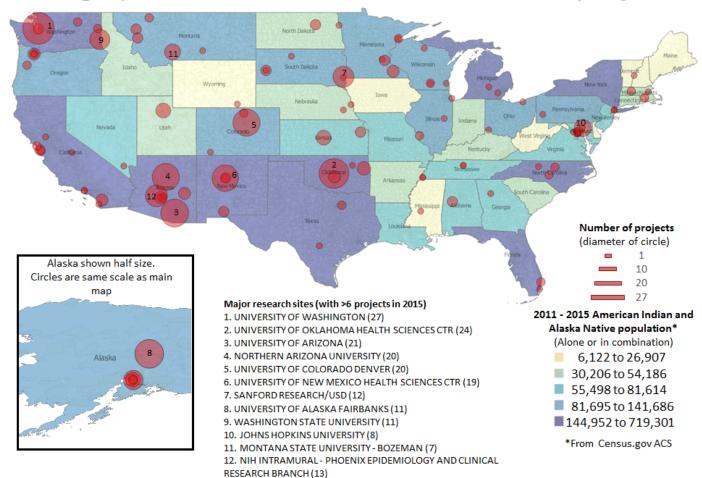








Geographic distribution of AI/AN Research projects





NIMHD Hosted Blogs from Native investigators in honor of Native American Heritage Month—November 2016

(http://nimhd.blogs.govdelivery.com/2016/11/)





"Hope and Healing Through Living Kidney Donation and Transplant"

Principal Investigator: Nancy Fahrenwald, PhD (U54MD008164)

https://www.youtube.com/watch?v=YHV3QY9qIAk&feature=youtu.be

Al/ANs have highest prevalence of Type 2 diabetes of any U.S. racial Minority and high rate end-stage renal disease

Living kidney donation and transplantation (LKDT) could save lives, but there are many cultural, geographic, and economic barriers to learning about it.

Project uses an interpersonal approach and story-telling to present LKDT information.

Target audience is Al/AN people on renal dialysis, eligible for transplant.





Bias in Emergency Department Clinicians Caring for American Indian Children

Puumala, SE; et al (2016). The Role of Bias by Emergency Department Providers in Care for American Indian Children. Medical Care **54**(6): 562-569. (U54MD008164)

American Indian children have high rates of emergency department (ED) use and face potential discrimination in health care settings.

- To assess both implicit and explicit racial bias, cross-sectional survey of clinicians at 5 hospitals; questions included American Indian stereotypes (explicit attitudes), clinical vignettes, and the Implicit Association Test. IATs created to assess implicit bias toward the child or the parent/caregiver.
- Agreement with negative American Indian stereotypes was 22%-32%; 84% of clinicians had an implicit preference for White adults or children. Older clinicians (>50 y) had less implicit bias.
- American Indian children were seen as increasingly challenging (P=0.04) and parents/caregivers less compliant (P=0.002) as the proportion of American Indian children seen in the ED increased.





Categories of Racism/Discrimination

- Interpersonal: Most work done, good measures developed, associations established, most common
- Structural: History, culture, institutions, and codified practices that perpetuate inequity; research or systems construct?
- Internalized: How discrimination (as above)
 effects individuals who are not aware or
 sublimate; accept cultural or biological
 inferiority





How Does Racial Inequity Harm Health

- Measures: major experiences or events, everyday discrimination (9-items), heightened vigilance scale – potential reality
- Effect on physical and mental health status of African Americans in cohort study
- Conceptualize as a form of chronic stress
- Effect of racism on physiological measures such as SBP or levels of inflammatory markers
- Link effects on mental health to heart disease
- Discrimination impacts health behaviors: smoking, problem drinking, substance use
- Data link to disease outcomes are less robust





Risk, Resilience, and Natural Recovery

Mohatt, G. V., et al. (2008). "Risk, resilience, and natural recovery: a model of recovery from alcohol abuse for Alaska Natives." Addiction **103**(2): 205-215. (R24MD001626)

The People Awakening (PA) study explored an Alaska Native (AN) understanding of the recovery process from alcohol abuse and consequent sobriety.

- Cross-sectional, qualitative research and community-based participatory research. State-wide convenience sample of 57 participants representing all five major AN groups: Aleut/Alutiiq, Athabascan, Inupiaq, Yup'ik/Cup'ik and Tlingit/Haida/Tsimshian. Participants self-identified as alcohol-abstinent at least five years following a period of problem drinking. Open-ended and semi-structured interviews gathered extensive personal life histories. Narratives analyzed using grounded theory and consensual data analysis techniques.
- AN participants recovery model describes recovery as a development process understood through five interrelated sequences: (i) the person entered into a **reflective process** of continually thinking over the consequences of his/her alcohol abuse; (ii) that led to periods of **experimenting with sobriety**, typically, but not always, followed by repeated cycling through return to drinking and sobriety; culminating in (iii) a **turning point**, marked by the final decision to become sober. Subsequently, participants engaged in (iv) Stage 1 **sobriety, active coping with craving and urges** to drink followed for some participants, but not all, by (v) Stage 2 sobriety, moving beyond coping to what one participant characterized as 'living life as it was meant to be lived.

The PA heuristic model points to important cultural elements in AN conceptualizations of recovery.





Sensation-seeking Predicts Daily Smoking Behavior

Spillane, N. S., et al. (2012). "Sensation-seeking predicts initiation of daily smoking behavior among American Indian high school students." <u>Addictive Behaviors</u> **37**(12): 1303-1306. (P60MD000507)

Sensation-seeking, defined as the tendency to seek novel and thrilling experiences, has been associated with smoking initiation in other groups but has never been examined in American Indian (AI) youth.

 Data were from the Voices of Indian Teens Project (VOICES), a longitudinal study of Al youth from seven high schools in four Al communities in the western United States. A sample of 764 non-smoker students completed baseline and annual surveys in school over a three-year period. Smoking initiation was defined as endorsement of daily smoking after baseline.

Participants were 353 males and 411 females aged 13 to 21 years at baseline.

- After adjusting for covariates, baseline sensation-seeking correlated with smoking initiation differently by sex.
- Sensation-seeking did not predict daily smoking in males. Among females, however, higher sensation-seeking scores at baseline predicted daily smoking in both the unadjusted (odds ratio=1.4; 95% Cl=1.1-1.8; p=0.005) and covariateadjusted (odds ratio=1.3; 95% Cl=1.0-1.6; p=0.04) models.

Gender-specific prevention programs may be warranted in addressing different risk-factor profiles in this high-risk population.



Racial Disparities in Health Status: Diabetes among Al and US Adults

O'Connell, J., et al. (2010). Racial disparities in health status: a comparison of the morbidity among American Indian and U.S. adults with diabetes. Diabetes Care **33**(7): 1463-1470. (P60MD000507)

- American Indians and Alaska Natives are 2.3 times more likely to have diabetes; compare morbidity among American Indian and U.S. adults with diabetes.
- Demographic and health service utilization data for an adult American Indian population aged 18-64 years (n = 30,121) served by the Phoenix Service Unit from the Indian Health Service clinical reporting system. Comparison data for a U.S. population (n = 1,500,002) from commercial health insurance, matched by age and sex to the American Indian population, were drawn from the Market Scan Research Database. Diagnostic Cost Groups to identify treated medical conditions for which each individual was treated and to assign a risk score to quantify his or her morbidity burden
- American Indians with diabetes had **significantly higher rates of hypertension, cerebrovascular disease, renal failure, lower-extremity amputations, and liver disease** than commercially insured U.S. adults with diabetes (P < 0.05). All prevalence rates were 61.2, 6.9, 3.9, 1.8, and 7.1%, respectively. The morbidity burden among the American Indian with diabetes exceeded that of the insured U.S. adults with diabetes by 50%
- The morbidity burden associated with diabetes among American Indians far exceeded that of commercially insured U.S. adults.





Diabetes Related ESRD

Age-adjusted Incidence, 1996-2013, age 18 y and older MMWR, January 13, 2017, 66: 26-32

	1996	2013	%
Whites	12.1	15.5	+28
Blacks	52.2	42.7	-18
Asians	23.1	22.2	-4
AI/AN	57.3	27.5	-54
Latinos	40.1	34.2	-15



The Native Children Always Ride Safe (Native CARS)

Lapidus, J. A., et al. (2013). Trends and correlates of child passenger restraint use in 6 Northwest tribes: the Native Children Always Ride Safe (Native CARS) project. <u>Am J Public Health</u> 103(2): 355-361. (R24MD002763)

Compare children properly restrained in vehicles in 6 Northwest American Indian tribes in 2003 and 2009, and evaluated risks for improper restraint.

- 2009: conduct a vehicle observation survey in Oregon, Washington, and Idaho tribal communities. Estimate proportions of children riding properly restrained and evaluate correlates
- 1853 children aged 12 years and younger in 1207 vehicles; 49% rode properly restrained
- children aged 8 years and younger rode properly restrained 51% in 2009 c/w 29% in 2003 (P < .001); Only 25% of older booster seateligible children rode properly restrained in 2009
- American Indian children were more likely to ride improperly restrained than nonnative children in the same communities
- Other risk factors: riding with an unrestrained or nonparent driver, riding where child passenger restraint laws were weaker than national guidelines, and taking a short trip.

Proper restraint has increased, but it remains low. Tribeinitiated interventions to improve child passenger restraint use are being developed

NIMHD Scientific Workshops

- Use of Information Technologies in Minority Health and Health Disparities (NSF partner)
- Self-Identified Race and Ethnicity in Genomic and Biomedical Research (NHGRI partner); held October 2016
- Structural Racism and Cultural Competence: Impact on Minority Health and Health Disparities (OMH partner)





New Research Areas for FY 2017

- HIV Infected Youth and Young Adults from Health Disparity Populations in Treatment
- Immigrant Populations
- Disparities in Surgical Care and Outcomes
- Social Epigenomics
- Caribbean Initiative
- Sleep Disparities
- Chronic Liver Disease and Liver Cancer
- Research with Tribal Epidemiology Centers





NIMHD Health Disparities Research Institute August 15-19, 2016, NIH Campus, Bethesda, MD





Selected Lectures, Grant Tips, Mock Review, Meet with Program Scientists from NIMHD and Many ICs





2017 NIMHD Health Disparities Research Institute Online Application Is Now Open!

- TARGET AUDIENCE: Early stage research investigators.
 Applications will only be accepted from post-doctoral fellows, assistant professors, or individuals in similar early stage research career positions who are engaged in minority health and health disparities research.
- HOW TO APPLY
- The online application is **now open** on the <u>NIMHD Health Disparities</u> <u>Research Institute website</u>.

 The due date for submitting an application is May 12, 2017, 11:59pm (EST).





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