



# Sovereignty, Parity, Equity & Datasharing

Presented by Marcia O'Leary, RN & Joseph Yracheta, MS

September 14, 2017

@ NIH - Tribal Advisory Committee



# Missouri Breaks Industries Research, Inc.

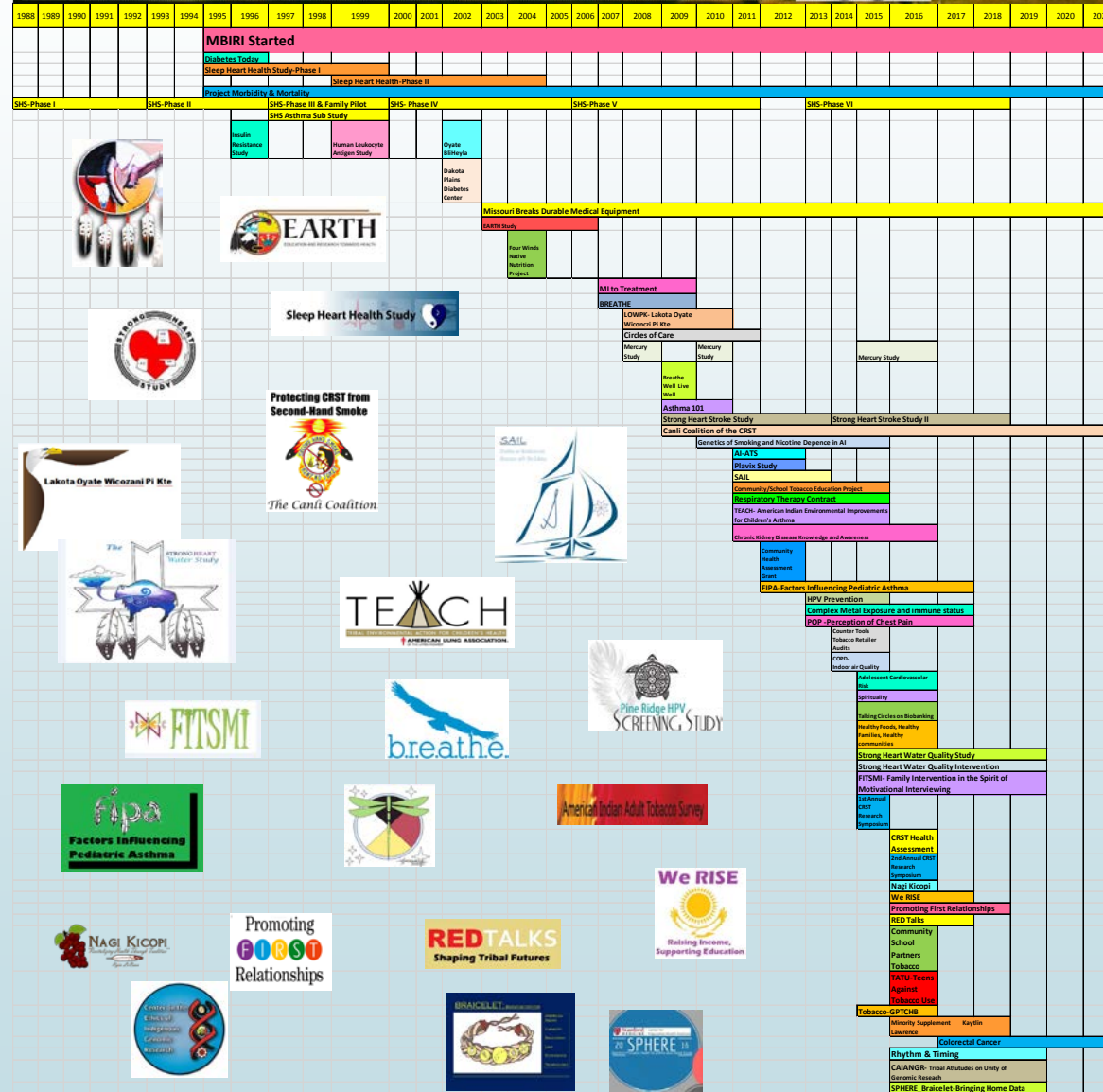
Promoting community health through research, education, & medical equipment...

Home of the Strong Heart Study!

Serving the Cheyenne River, Oglala, Rosebud,  
Standing Rock, & Spirit Lake Nations



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Telephone: 605-964-3418





## Home of the Strong Heart Study!



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1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021																	
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SHS-Phase I						SHS-Phase II				SHS-Phase III & Family Pilot				SHS- Phase IV						SHS-Phase V							SHS-Phase VI																							
							SHS Asthma Sub Study																																											
							Insulin Resistance Study				Human Leukocyte Antigen Study				Oyate BliHeyla																																			
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Sleep Heart Health Study

Protecting CRST from  
Second-Hand Smoke



The Canli Coalition



Missouri Breaks Durable Medical Equipment

EARTH Study

Four Winds  
Native  
Nutrition  
Project

MI to Treatment

BREATHE

LOWPK- Lakota Oyate  
Wiconci Pi Kte

Circles of Care

Mercury  
Study

Mercury  
Study

Mercury Study

Breathe  
Well Live  
Well

Asthma 101

Strong Heart Stroke Study

Strong Heart Stroke Study II

Canli Coalition of the CRST

Genetics of Smoking and Nicotine Dependence in AI

AI-ATS

Plavix Study

SAIL

Community/School Tobacco Education Project

Respiratory Therapy Contract

TEACH- American Indian Environmental Improvements  
for Children's Asthma

Chronic Kidney Disease Knowledge and Awareness

Community  
Health  
Assessment  
Grant

FIPA-Factors Influencing Pediatric Asthma

HPV Prevention

Complex Metal Exposure and immune status

POP - Perception of Chest Pain

Counter Tools  
Tobacco Retailer  
Audits  
COPD-  
Indoor air Quality





Adolescent Cardiovascular Risk					
Spirituality					
Talking Circles on Biobanking					
Healthy Foods, Healthy Families, Healthy communities					
Strong Heart Water Quality Study					
Strong Heart Water Quality Intervention					
FITSMI- Family Intervention in the Spirit of Motivational Interviewing					
1st Annual CRST Research Symposium					
CRST Health Assessment					
2nd Annual CRST Research Symposium					
Nagi Kicopi					
We RISE					
Promoting First Relationships					
RED Talks					
Community					
School					
Partners					
Tobacco					
TATU-Teens Against Tobacco Use					
Tobacco-GPTCHB					
Minority Supplement Lawrence					
Kaytlin					
Colorectal Cancer					
Rhythm & Timing					
CAIANGR- Tribal Attitudes on Unity of Genomic Research					
SPHERE_Bracelet-Bringing Home Data					

# GROWING OUR OWN: *STEERING & DEVELOPMENT CAPACITY*



**Researching, Restoring  
& Rebuilding Our Oyate  
for a Longer Life**

**A Research  
Symposium for  
Cheyenne River**





# GENOMICS AND SOCIETY

Expanding The ELSI Universe - #ELSICON



**Center on  
American Indian  
and Alaska Native  
Genomic Research**

**Principal Investigators:**



Dr. Paul Spicer  
Professor  
Department of Anthropology



Dr. Amanda Cobb-Greetham  
Professor/Director  
Native American Studies



Dr. Cecil M. Lewis, Jr.  
Associate Professor  
Department of Anthropology

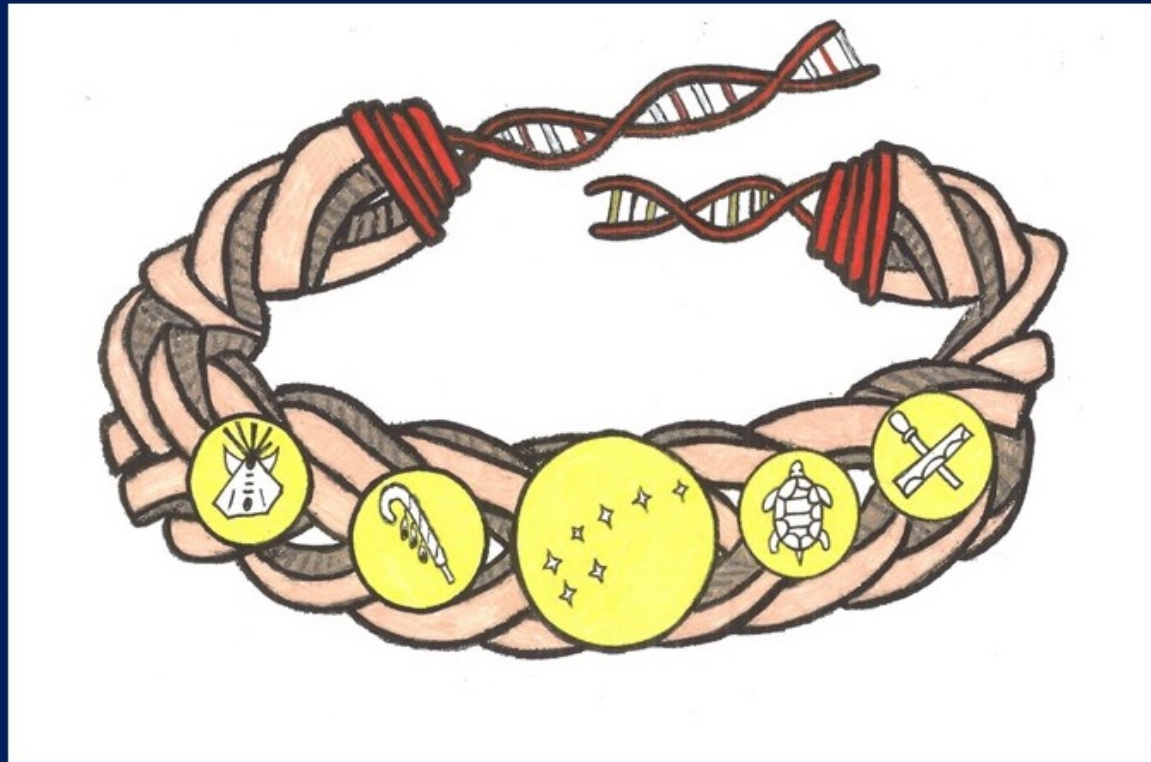


**UConn  
HEALTH**

National Human Genome  
Research Institute

# SPHERE & B.R.A.I.C.E.L.E.T

## BRAICELET: BIOREPOSITORY FOR



AMERICAN  
INDIAN

CAPACITY

EDUCATION

LAW

ECONOMICS

TECHNOLOGY





**Stanford**  
MEDICINE

**SPHERE**

*Stanford Precision Health  
for Ethnic and Racial Equity*

### **What is Precision Health**

Precision Health is a way dealing with disease prevention and treatment that takes into account people's individual differences in genes, environment and lifestyle.

(Adapted from the US Precision Medicine Initiative)

### **Stanford's Work on Precision Health**

1. Advanced and extensive experience in genetic research and their relationship to both disease and treatment.
2. Research on social, economic, and biological impacts of health.
3. Outstanding analytic and high-performing computing capabilities.

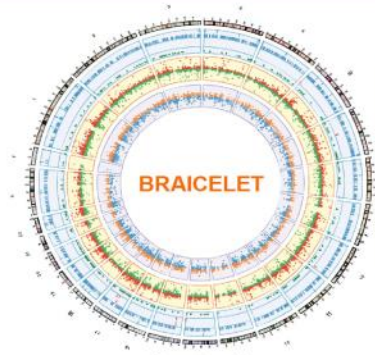


### **SPHERE Goals**

1. Expand our precision health research focusing on differences between ethnic and racial groups, known as health disparities.
2. Develop and expand relationships with our community partners to make sure they are included in our work.
3. Conduct three precision health research projects focusing on different population groups.
4. Learn how to use knowledge of genetic and biologic information to reduce ethnic and racial health disparities.

## SPHERE: Stanford Precision Health for Ethnic and Racial Equity

### BRAICELET (Snyder & Li-Pook-Than)



Partnering with Lakota for precision medicine research.

### GOALS (Robinson)



Using data from previous research to determine genetic risk for obesity among Latino children.

### Breast Cancer (Periyakoil)



Communicating cancer genetic information to Latina, Chinese, and Caucasian women.

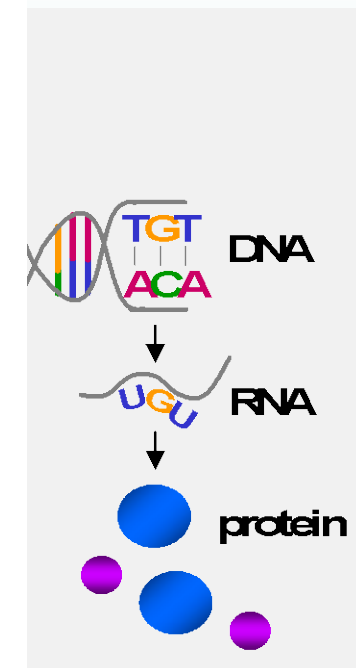
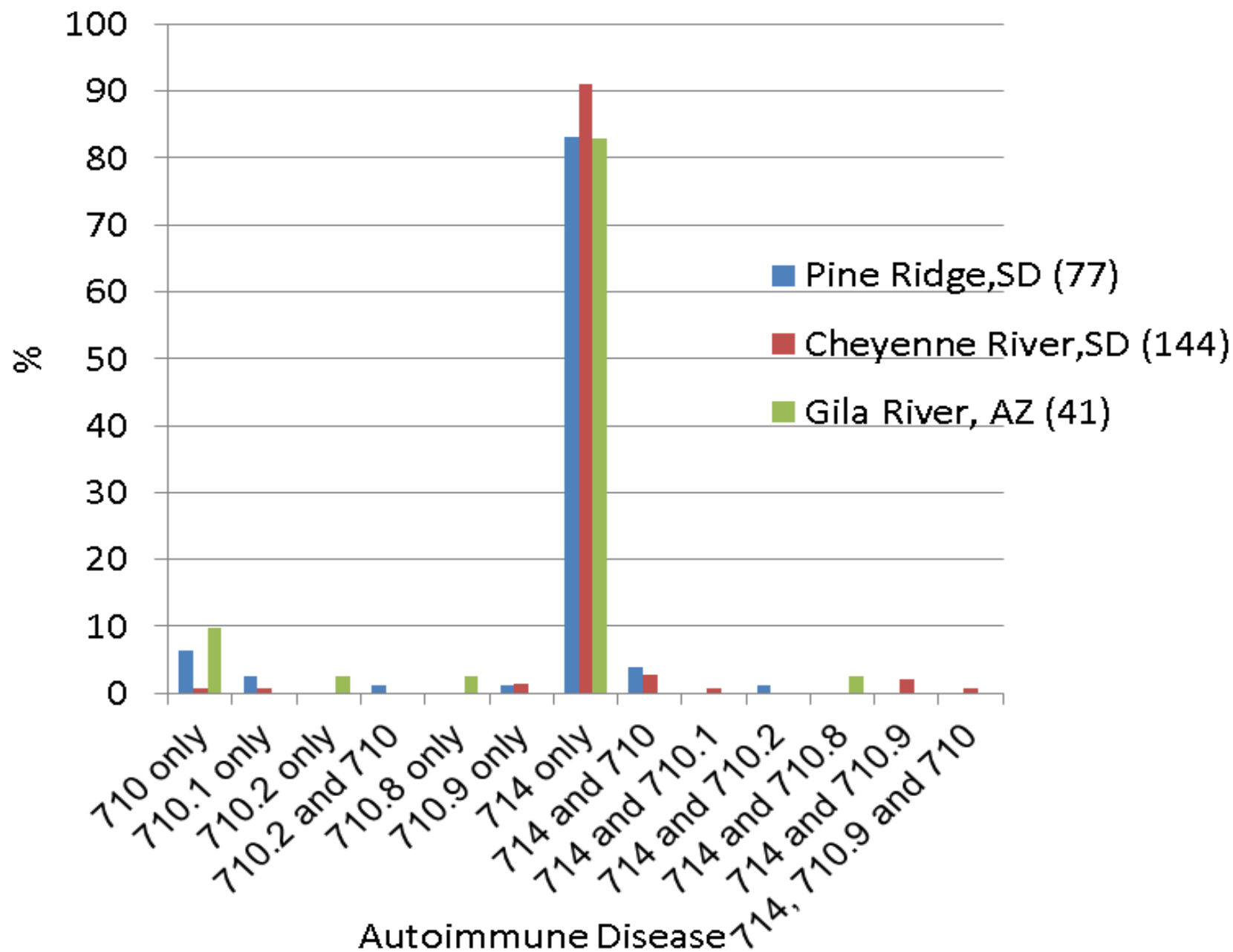
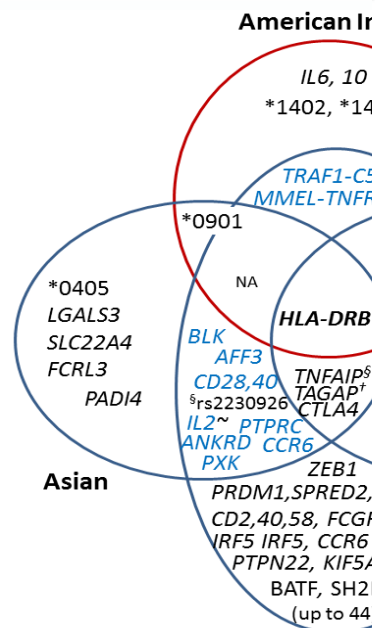
### Stanford Team for the BRAICELET Project

- Mark Cullen, Co-Principle Investigator for SPHERE
- Bonnie Maldonado, Co-Principle Investigator for SPHERE
- Mike Snyder, Project Lead, BRAICELET
- Jennifer Li-Pook-Than, Project Coordinator, BRAICELET
- Rhonda McClinton-Brown, Consortium Core Lead
- Lisa Goldman-Rosas, Implementation Core Lead
- Jill Evans, Program Director for SPHERE



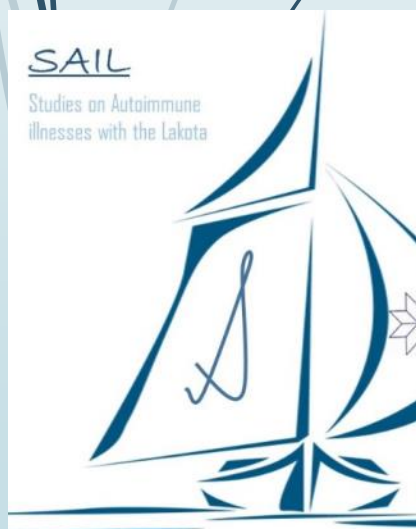


# SAIL- Studies of Autoimmune Illnesses with the Lakota



Inflammatory

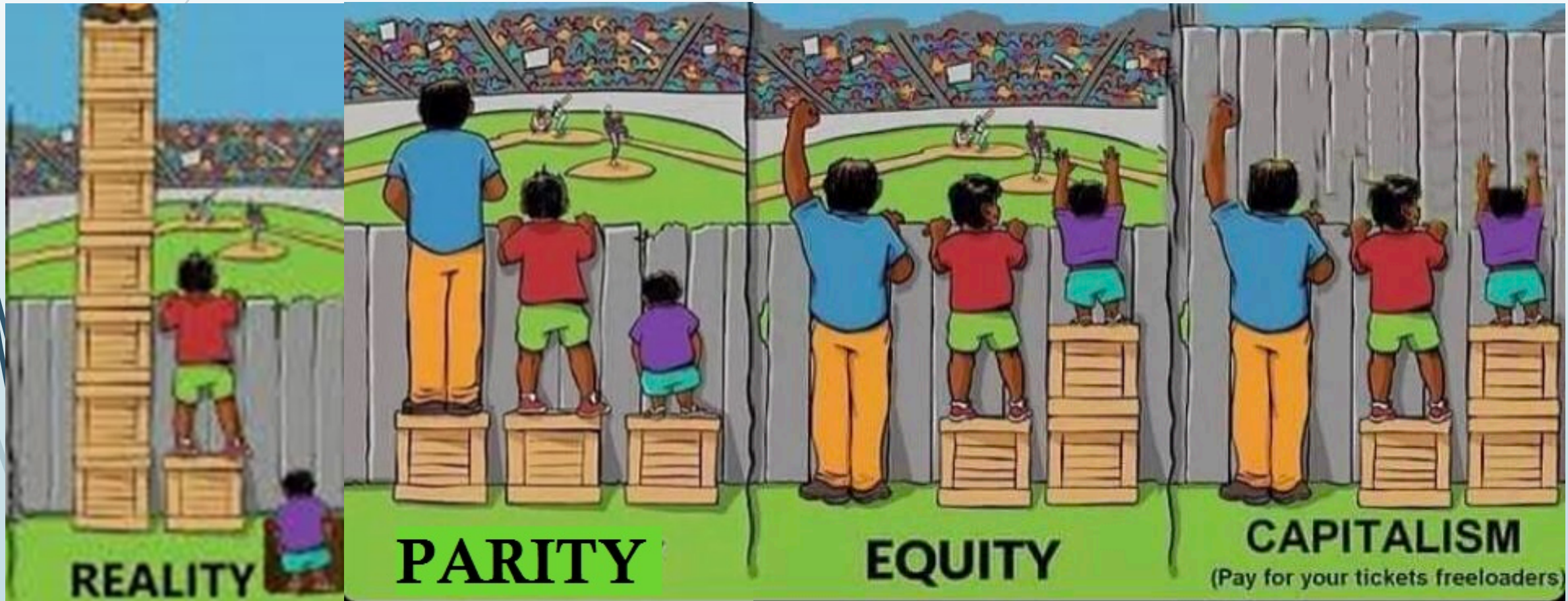
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**Parity** : Striking a reasonable balance between social strategies and social ideals (e.g. quotas)

**Equity** : Attempt to make things fair often by applying mutually agreed upon rules and processes



# History of "Parity" & "Equity"

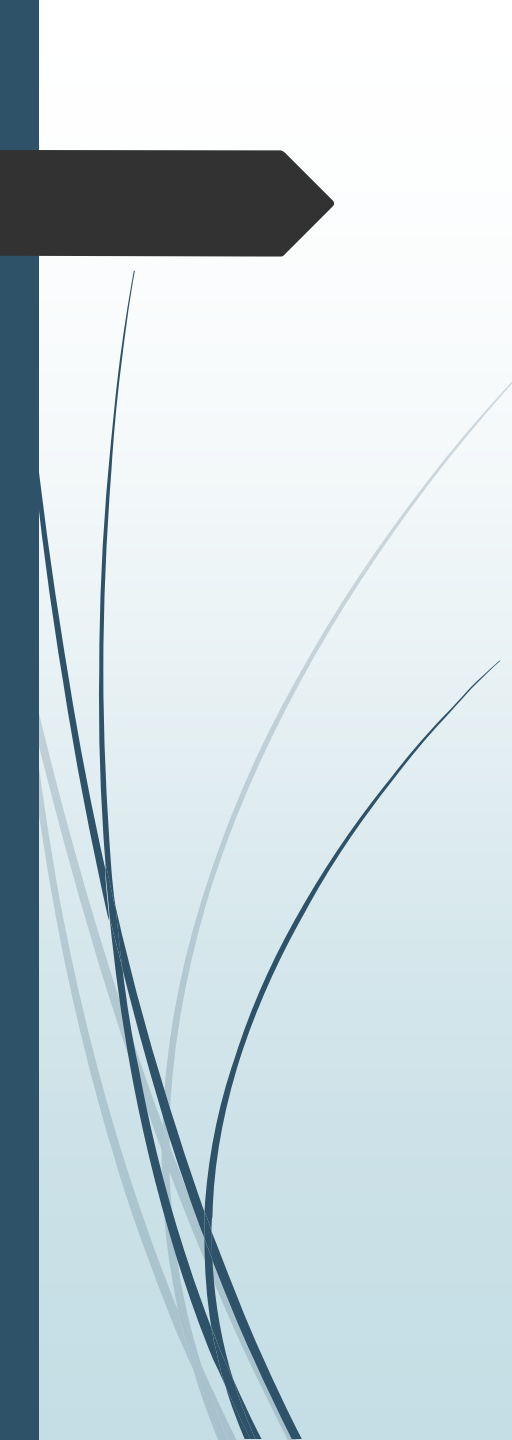
- Treaty of Fort Laramie (1868) – Abrogated in 1877 for Gold in Black Hills – **"Sell or Starve"**
- 1.4 Billion but estimated at 340 billion owed  
(74 billion in Gold )
- Dawes Act 1887 – Allotted communal land to individual Indians. 90 million acres lost (2/3rds) due to tax liability and sold to whites
- Cobell vs Salazar – 3.4 billion , estimated 176 billion owed

# OCAP-MAT-PIC Works for Both Sides

OCAP – Ownership, Control, Access, Possession,  
MAT – Mutually Agreed Terms  
PIC – Prior Informed Consent,

- Consistency -Homogeneity of Data
  - Region, Climate, Lifestyle, Health Care access, cultural commonalities
- Predictability of Approval & Analytic processes
  - Intertribal agreements
  - Expedited Timelines that more closely match Federal Timelines
  - Increased Efficiency of Infrastructure
- Reliability of Partnerships
  - Set Criteria for Partnerships
  - Both sides trust process
  - Ability to Plan for Future projects
- Harmony of Data collection
  - Longitudinal, not Cross-sectional
  - Vetted and Adjudicated charting
  - Privacy and Anonymization standardize
- , Built-In Moral & Ethical Value (socially remunerative justice)





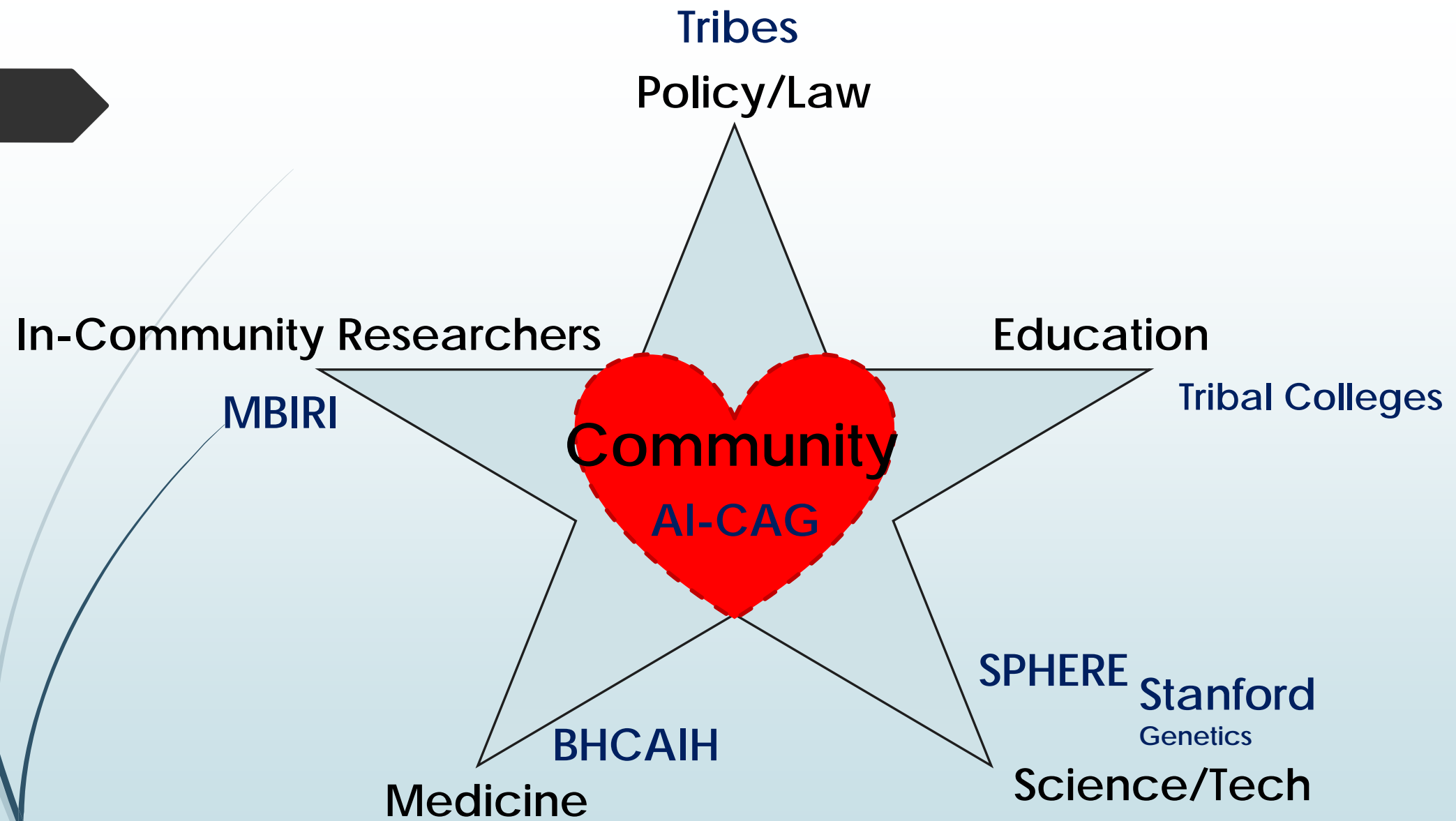
# Empowerment Via Data Types Collected

- Human Omics and Health Disparity Samples & Data
- Repatriated Samples & Data from 30 years of studies
- Repatriated Ancient Hominid Samples & Data ( may inform current Health)
- Repatriated Samples from Museums
- Non-human genomes from w/in tribal borders
- Non-human microbiome from w/in tribal borders (e.g. extremophile research)
- Non-Genomic Environmental samples & data
- Demographic Data (Social Determinants of Health)
- CRISPR Edited Cell Lines and Other Lines used in Model Systems w/ Data



# Acknowledgement That DataSharing Comes with Trade-offs

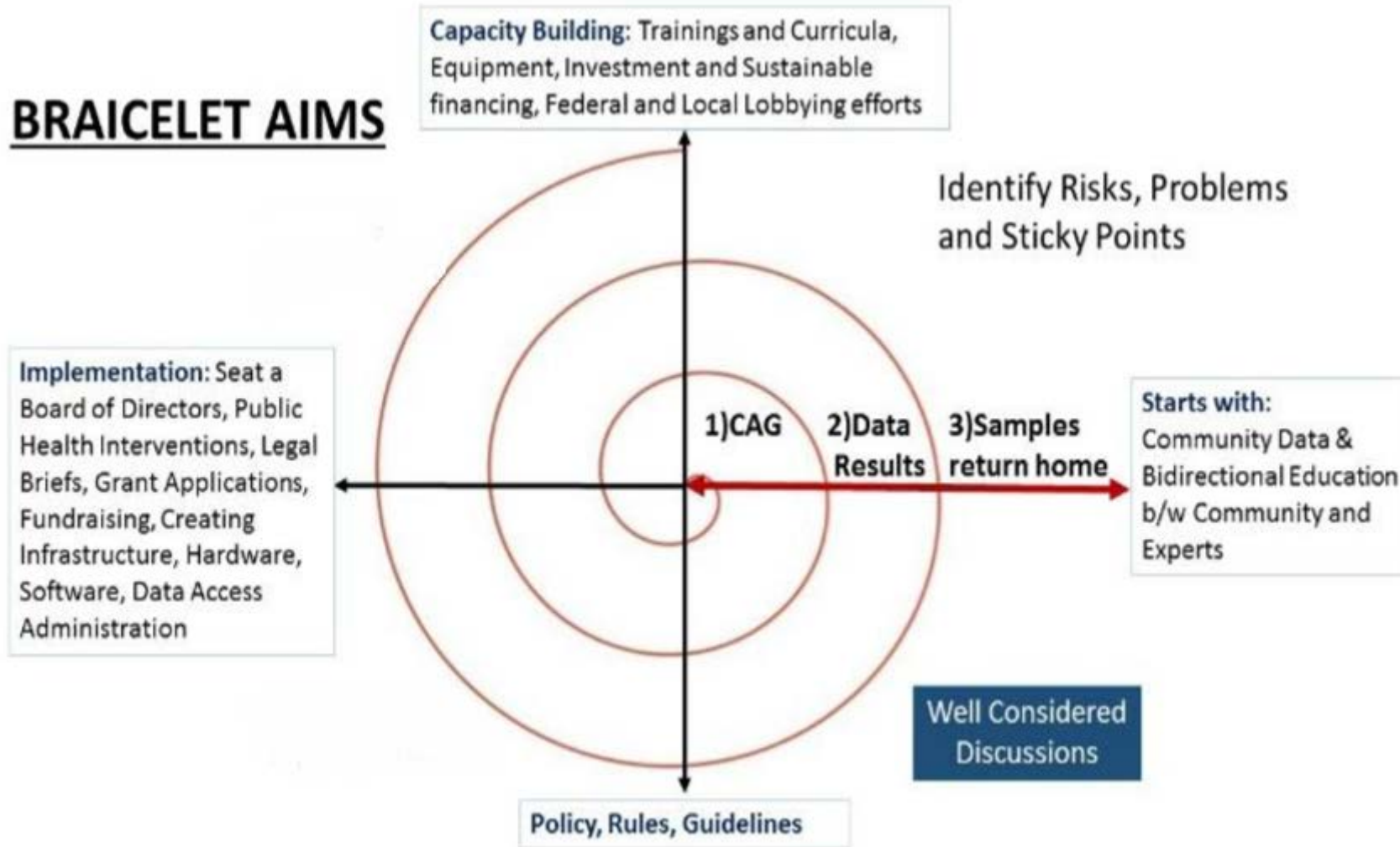
- **Must work towards Equity rather than Parity: Datasharing can Help**
- Data shared for Infrastructure & Capacity/Capabilities Building (IT and Analysis)
- Publicly Accessible Bio & Data Repository but under Local Control
- Datasharing increases robustness of findings or refined articulations of comparison
- Datasharing as a hedge against “bad actors”
- Datasharing as an “Olive Branch” and Sustainability tool for Research Efforts
- Datasharing as means for non-federal partnerships
- Datasharing for Implementation or Intervention efforts



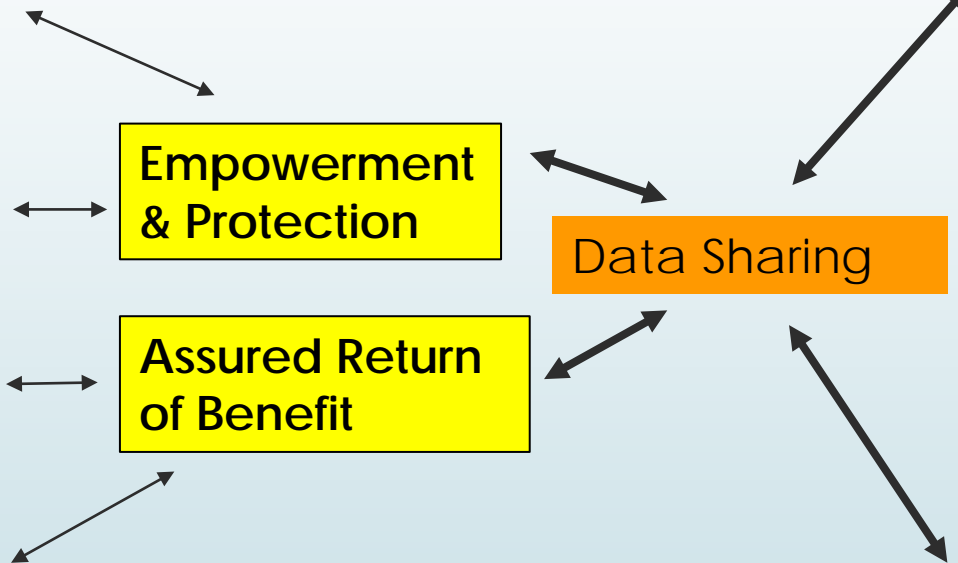
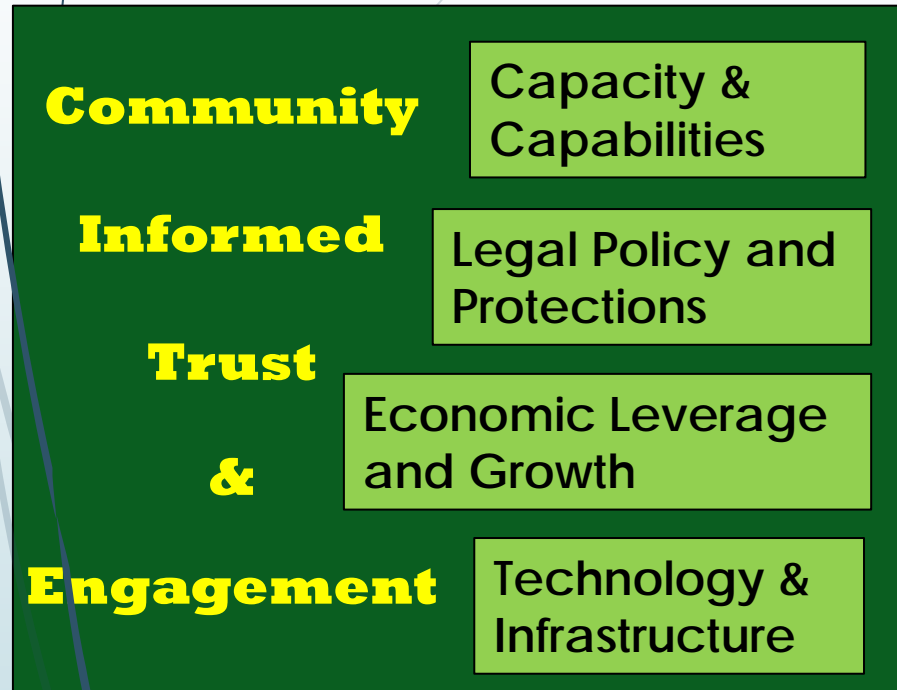


# Community Advisory Group (CAG) essential to trust, advocacy and control

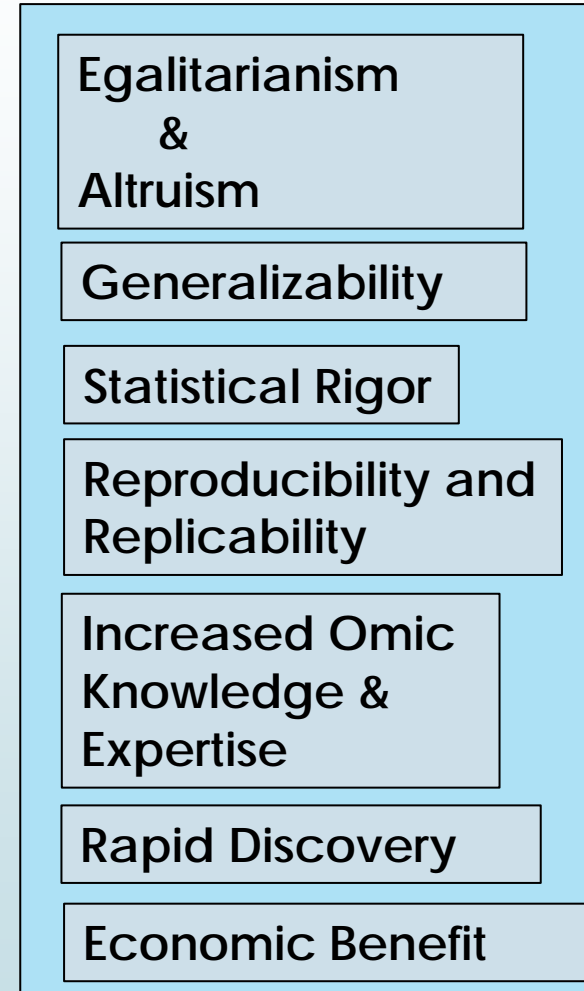
## BRAICELET AIMS



# Tribes



# NIH & External Partners



CENTER  
FOR  
ALASKA NATIVE  
HEALTH RESEARCH



Southcentral  
Foundation



**STRONG HEART STUDY**



University of Alberta -Edmonton





## 2018 AISES NATIONAL CONFERENCE



## Save the Date

May 17–19, 2018

[InterContinental Hotel](#)

900 Wilshire Boulevard  
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**Native Research Network**

Denver Sept. 18-19

Collaboration

Conference NNHRT



# 2017 SACNAS

## The National Diversity in STEM Conference

October 19 - 21, 2017 | Salt Lake City, Utah



SING

Summer Internship for Indigenous  
Peoples in Genomics

USA 2011

New Zealand 2015

Australia 2016

Canada 2018

Mexico?

# "Who You Gonna Call?" -Indigenomics Crew



**Shaawano Chad Uran**, *PhD Anthropology*  
*White Earth Anishinaabe*



**Kate McGlone West**, *PhD 3<sup>rd</sup> year student Public Health*  
*Genetics*  
*American*



**Joseph M. Yracheta**, *MS Pharmaceutics*  
*Purepecha & Raramuri (Mexican Natives:*  
*Tarascan & Tarahumara)*



**Keolu Fox**, *PhD 4th year student*  
*Genome Science*  
*Kanaka Maoli, Kingdom of Hawaii*



**Krystal Tsosie**, *PhD Genome*  
*Science and Ethics*  
*Dine'*



**Katrina Claw**, *PhD Genome Science*  
*Dine'*



**Nanibaa' Garrison**, *PhD Genome*  
*Science and Ethics*  
*Dine'*

# ***Legal***

## **Ron Whitener, Squaxin**

*Genetic Samples and Native Americans: Can Federal Data Sharing Mandates and Tribal Authority Be Reconciled?*, Lewis and Clark Law School, Emerging Indian Law Scholars Roundtable, Jul. 2007

## **Rebecca Tsosie, Yaqui**

[\*Indigenous Peoples and Epistemic Injustice: Science, Ethics, and Human Rights\*](#), 87 WASH. L. REV. 1133 (2012)

## **PILLAR OSSORIO, MEXICAN**

*Reflections on the cost of "low-cost" whole genome sequencing: framing the health policy debate.* [PLoS Biol.](#) 2013 Nov;11(11):e1001699. doi: 10.1371/journal.pbio.1001699

## **Preston Hardison, Tulalip**

*Taking UNDRIP Seriously: Indigenous peoples have the right to maintain, control and develop their cultural heritage.*

# ***Societal, Cultural, Ethical***

## **Kim Tallbear, Sisseton**

Reardon, Jenny and Kim TallBear. "[Your DNA is Our History." Genomics, Anthropology, and the Construction of Whiteness as Property.](#)" *Current Anthropology* 53(S12) (April 2012): S233-S245.

## **Shaawano Chad Uran, Anishinabe**

“Idle Know More.” Invited public presentation at the Elwha Klallam Heritage Training Center. Port Angeles, WA, May 16, 2013.

## **Jessica Kolopenuk, Nehiyaw Cree**

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## **Jessica Bardill, Eastern Band Cherokee**

"Genetic Ancestry Testing," in *International Encyclopedia of Social and Behavioral Sciences*, 2nd edition. Co-authored with Nanibaa' A. Garrison. Graciela Cabana, section ed. Accepted, 2015.



## ***Education***

**Lee Bitsoi', Dine', EdD, Genetics**

(2012). [\*Enhancing Scientific Research in Genomics Through A Native Lens, NCAI Genomics Resource Guide\*](#), National Congress of American Indians, Washington, DC.

**Francine C. Gachupin, Pueblo, PhD, Public Health**

[\*Cancer patient perceptions about biobanking and preferred timing of consent\*](#). Biopreserv Biobank 2014 Apr;12(2):106-12

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**Donald Warne, MD, MPH, Oglala Sioux**

[\*Policy Issues in American Indian Health Governance\*](#), *Journal of Law, Medicine, and Ethics*, Spring 2011

**Ralph Forquera, Juaneño & Maile Taulii, Kanaka Maoli**

Taulii, M., Bush, N., Bowen, D. & Forquera, R. (in press). Adaptation of a Smoking Cessation and Prevention Website for Urban American Indian/Alaska Native Youth. Journal of Cancer Education. Project Title: Web-based Smoking Intervention for Urban Indian Youth. Region: Northwest.

# ***Genomic***

## **Nanibaa' Garrison, Diné**

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## **Rosalina James, Lummi**

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## **Katrina Claw, Diné**

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## **Wilfred Denetclaw, Diné**

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## **Keolu Fox, Kanaka Maoli**

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## **Alexandra Obregon-Tito, Chilean**

*Insights from Characterizing Extinct Human Gut Microbiomes*. *Plos One*, December 12, 2012 DOI: 10.1371/journal.pone.0051146

# Jennifer Li Pook-Than in Mike Snyder's Lab (Snyderome)





# Mark Cullen and Bonney Maldonado



**Stanford**  
MEDICINE



## **Health disparities research center launched with \$11.5 million grant**

The Stanford Precision Health for Ethnic and Racial Equity Center will be one of the first national centers focused on using precision-medicine tools to improve the health of underserved ethnic and racial groups.

# Dr. Jeff Henderson and Dr. Lyle Best







Missouri Breaks Industries Research Inc

@MissouriBreaksIndustrie  
sResearchInc

Home



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Consider Quitting Today !!!

You Get To Choose How Your Generation is Remembered  
#FirstTobaccoFreeGeneration



#FirstSmokeFreeRezSD



# Acknowledgements

## ► Missouri Breaks Staff

Guthrie Ducheneaux

Alli Moran

## Dakota Center

Lyle Best

## Black Hills Center for Am Ind Health

Jeffrey Henderson

## Cheyenne River Sioux Tribal Health Committee and Community Advisory Group

National Institutes of Health: 1U54MD010724-01

## Stanford Partners

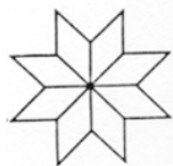
Rhonda McClinton

Lisa Goldman-Rosas

Jill Evans

Yvonne Maldonado

Mark Cullen



**Missouri  
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**MEDICINE**



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