# Reflect, Connect, Inspire

Amy Elliott, PhD Sanford Research







## **Foundation**

Transdisciplinary

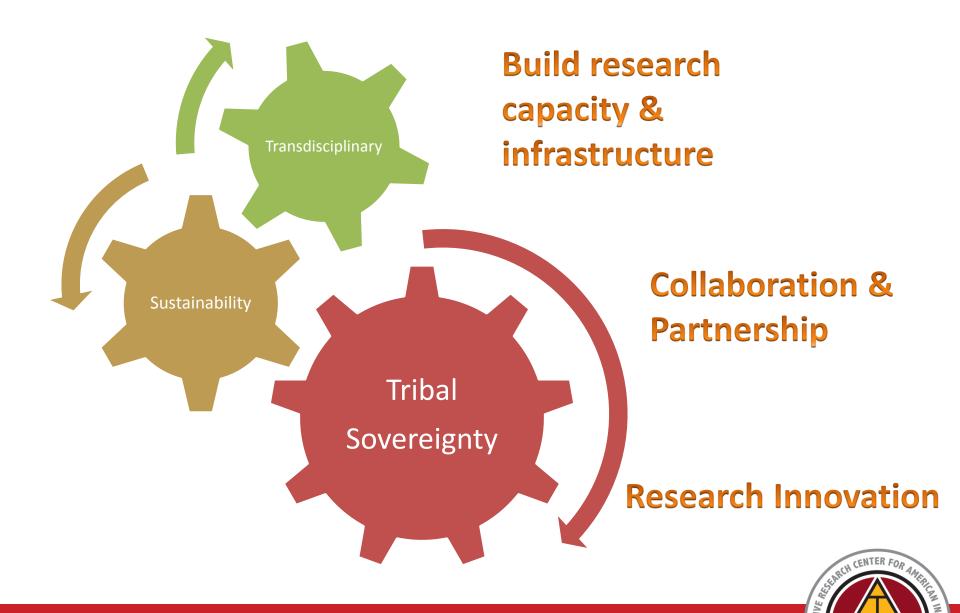


Sustainability

**Values** 

Tribal Sovereignty





# **CRCAIH Organizational Partners**

**Tribal Partners** 

North Dakota

Minneso

South Dakota

**Tribal Organizations** 



**Academic Institutions** 



**Healthcare Entities** 



# "Don't tell me what you value, show me your budget" - Joe Biden



# "Don't tell me what you value, show me your budget" - Joe Biden

68-72% of grant budget went outside of CRCAIH core services to support partners & projects







## **Building Tribal Research Infrastructure**

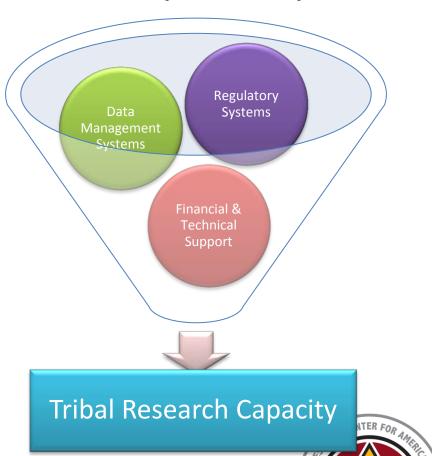
Why? (The Need)

Tribal sovereignty

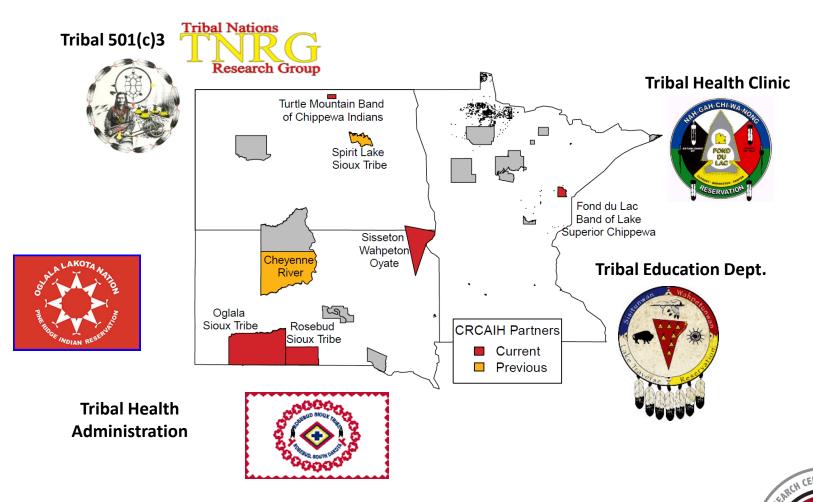
Protect & benefit tribal members

Respect culture/tradition

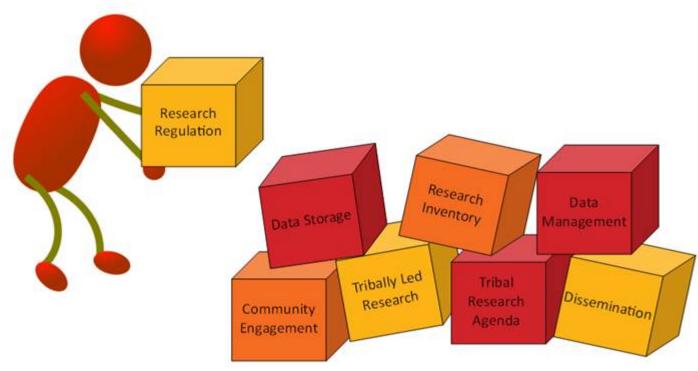
How? (The Tools)



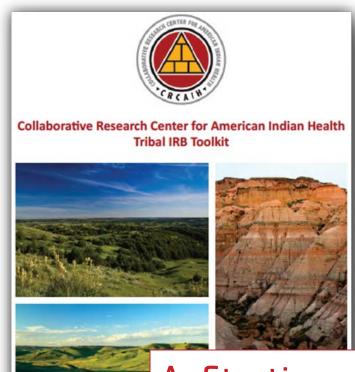
## **Tribal Partners**



# **Capacity Building**



## **Tribal IRB Toolkit**



	CONT	

Α.					

- 1. Foreword
- 2. Why Establish an IRB?

#### B. Starting an IRB

1.	Obtaining Tribal Approval	
2.	Policies and Procedures	
3.	Selection and Recruitment of IRB Members	. 1
4	Orientation and Training of IDP Mambars	

#### C. IRB Administration Tools

1.	Submission Process Flow Charts	1
2.	Investigator Submission Forms	
	Pre-Review Tools	
4.	Letter Templates	
5.	Review Process Tools	

#### D. Research Review Checklists

1.	Initial Review	63
2.	Continuation Review	67
3.	Publications Review	70
4.	Informed Consent	71
5.	Research with Pregnant Women	74

How to use the CRCAIH IRB Toolkit

A. Starting a Tribal IRB

**B. IRB Administration Tools** 

C. Research Review Tools

ibal IRB. It is recommended that or habetical order, A-E. Thereafter the . In the electronic version of the We provide many template ustomization of these resources by lat you acknowledge the source



# Data Management



Community Engagement

American Indian History al Culture, Past and Present

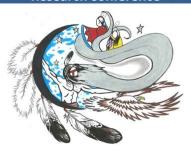


Cheyenne River Sioux Tribe Research Symposium



"Researching, Restoring, & Rebuilding Our Oyate for Longer Life" March 18, 2015

Oglala Sioux Tribe Research Conference



"No Longer Dreaming: Your Role in Native American Research"

May 7, 2015

## **How We Connect**



## What about the data?

#### 1. Health Index

Assesses the health and health disparities by county in South Dakota, North Dakota, and Minnesota, over the 5 years before CRCAIH was implemented.

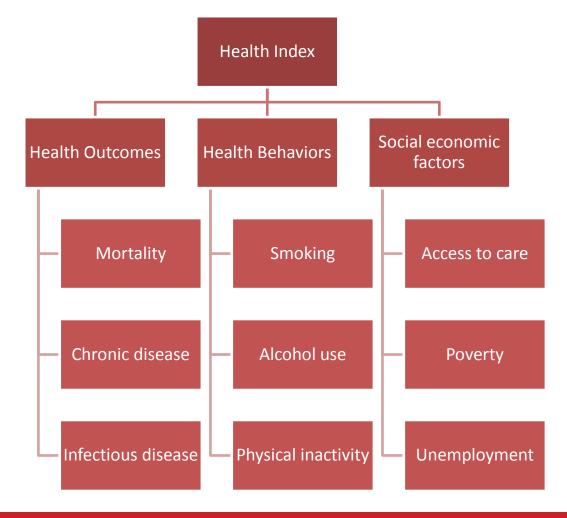
## 2. Social Network Analysis

Highlights the fruition of CRCAIH's aim to create a platform that brings together tribal communities and health researchers of many disciplines to combat American Indian health disparities.

## WHAT ABOUT THE DATA?

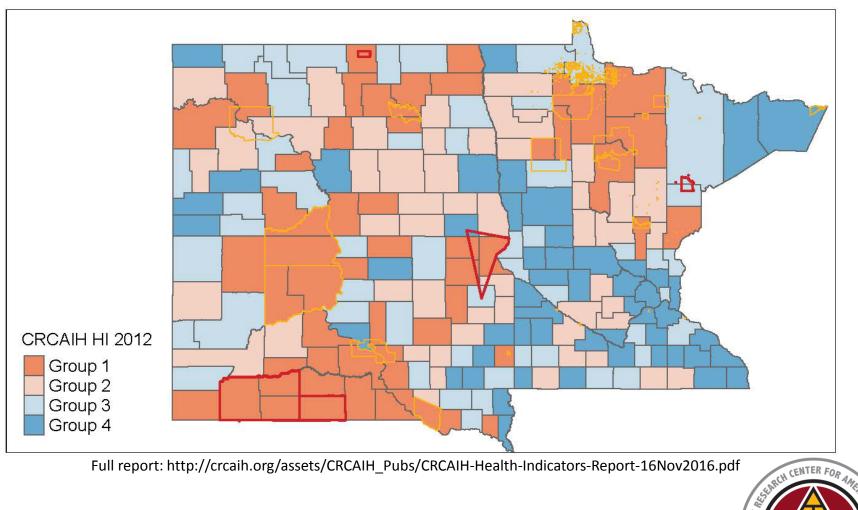


## **Health Indicators**



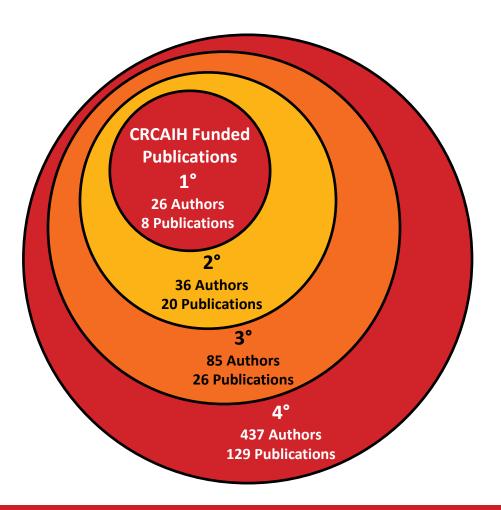


# Health Index Map



Full report: http://crcaih.org/assets/CRCAIH Pubs/CRCAIH-Health-Indicators-Report-16Nov2016.pdf

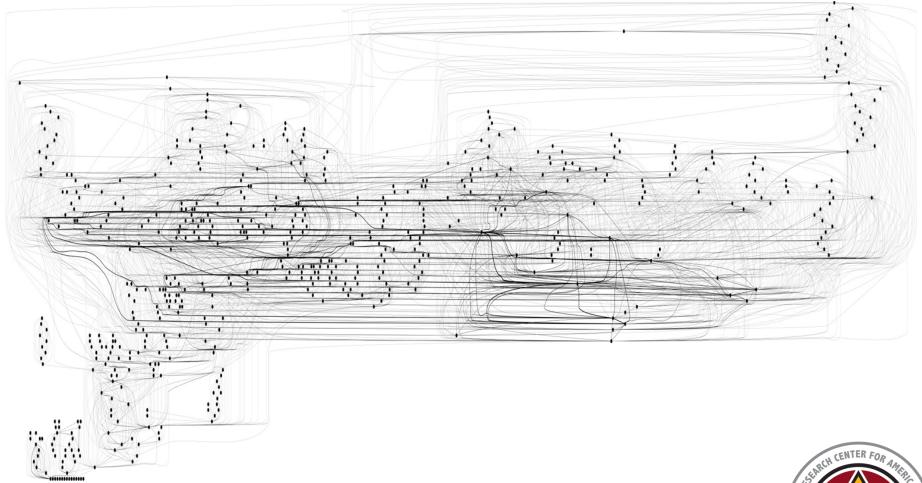
## **CRCAIH Social Network Analysis**



#### Totals:

- 584 Authors
- 184 Publications
- Location Statistics
  - 5% International
  - 95% USA
  - 12% CRCAIH States(SD, ND, MN)

# **CRCAIH Social Network Analysis**



# **CRCAIH - NCAI Partnership**



#### Collaborative Research Center for American Indian Health

Mission: Bring together tribal communities and health researchers, with a goal to build research infrastructure and transdisciplinary teams to improve health through focus on social and environmental influences on health.

#### National Congress of American Indians Policy Research Center

Mission: Provide tribal leaders with best available knowledge to make strategically proactive policy decisions in framework of Native wisdom that positively impacts future of Native peoples.



## Culture, Science & Bioethics Core

Mission: Facilitate ethical research that meets cultural and contextual needs of communities by bridging traditional, western/academic, and policy sciences.



# **CRCAIH - NCAI Partnership**

- Assistance with culturally-relevant report writing and dissemination
- Workshops Research that Benefits
   Native People: A Guide for Tribal
   Leaders
- Response to Notice of Proposed Rulemaking (NPRM) to revise the Common Rule
- Presentation on CRCAIH's work to Tribal Leaders at NCAI's Mid-Year Meeting



## **RESEARCH INNOVATION**



# Pilot Grant Program





Pl Applications by state (2013-2016)





PI Awardees by state (2013-2016)



South Dakota





North Dakota



Washington



Colorado



New York



# Who were the pilot grant awardees?

## **2013**

John Gonzalez, PhD Jessica Hanson, PhD Alicia Mousseau, PhD Soonhee Roh, PhD Bruce Vogt, MD, & Jay Memmott, PhD

## **2014**

Emily Griese, PhD MaryLou Mylant, PhD Daniel Petereit, MD Heather Peters, PhD Ursula Running Bear, PhD

### **2015**

Sara DeCoteau, BA, & Bonny Specker, PhD Amanda Fretts, PhD Tai Mendenhall, PhD, & Kathy Denman-Wilke, MEd

## **2016**

Jacqueline Gray, PhD Lacey McCormack, PhD, & Rae O'Leary, RN

Pilot Grants Awarded having an American Indian PI or Co-PI

47%

Pl Organization is Tribal/Tribal Academic

27%



# 5-year, Large-Scale Research Projects

- Factors Influencing Pediatrics Asthma
  - PI: Lyle Best, MD
- Culturally Targeted Education on Living Kidney Donation
  - PI: Nancy Fahrenwald, Ph.D.
- Emergency Department Use & Care in American Indian Children
  - PI: Susan Puumala, Ph.D.



## **SUSTAINABILITY?**



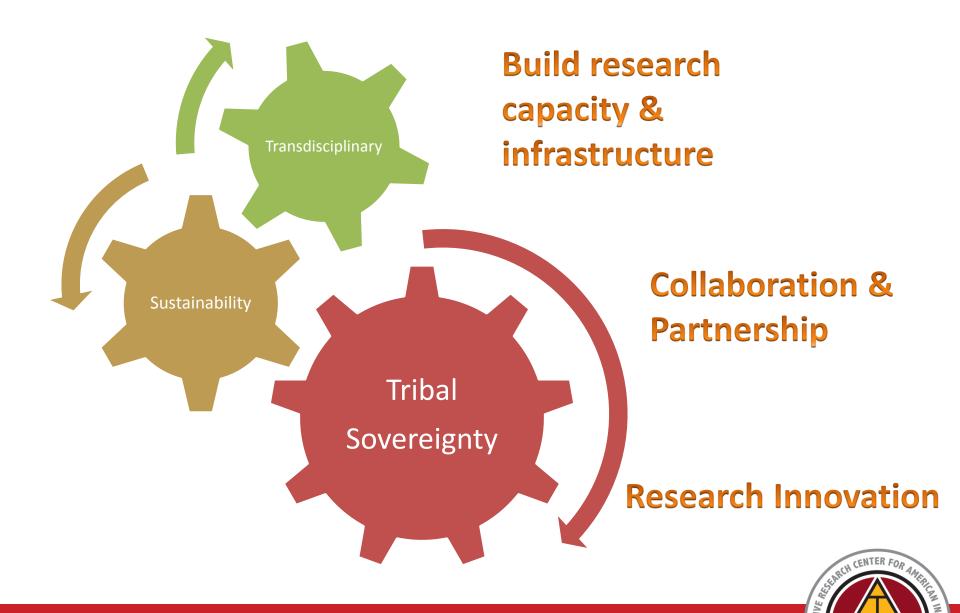
# **Additional Funding**

- Initial CRCAIH grant \$13.5 million
- CRCAIH researchers and tribal partners have brought in over 30 grants (and counting!)



Subsequent grants awarded (all partners combined) \$13.8 million (and counting)









## **CRCAIH Partners**

#### **NIMHD**

Rick Berzon, PhD Dorothy Castille, PhD Derrick Tabor, PhD

#### **External Advisors**

Bonnie Duran, PhD
Spero Manson, PhD
Leander "Russ" McDonald, PhD
Tassy Parker, PhD
Daniel Petereit, MD
Jacque Gray, PhD
Don Warne, MD, MPH
Gerald Yutrzenka, PhD
Kris Rhodes, MPH

#### **Administrative Division**

Amy Elliott, PhD DenYelle Kenyon, PhD Jessica Heinzmann, BA

#### **Tribal Partners**

Delores Pourier, MSAS Kathryn Blindman Sherry Johnson, PhD Heather Larsen. MEd Anita Frederick, MS Rhonda Gustafson, MBA Ashley Parisien, MBA Paula Carter, PhD Carol Davis, PhD Carty Monette, PhD Evelyn Espinoza, MA Simone Bordeaux, LPN Jennifer Dupuis, MBA Marilyn Grover, MBA Nate Sandman, BAS Patti Dufault, MBA

#### Research Project Pls

Lyle Best, MD Susan Puumala, PhD Nancy Fahrenwald, PhD

#### **Community Engagement & Innovation**

Victoria Grey Owl, PhD Melissa Buffalo, MA

#### Regulatory Knowledge Core

Jyoti Angal, MPH Michaela Sieber, MPH Temana Andalcio, BA

#### Culture, Science & Bioethics Core

Deana Around Him, DrPH Sarah Pytalski, PhD

#### Methodology Core

Jessica Hanson, PhD Jing Zhao, PhD Morgan Nelson, MS Tess Weber, MPH





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