

# Journeys Along the Good Red Road

*Intersections of Culture, Science, Policy and  
Health Inequities in American Indians*

2015 Collaborative Research Center  
for American Indian Health Summit,  
Rapid City, SD

July 10-11, 2015

Jeffrey A. Henderson, MD, MPH  
President & CEO  
Black Hills Center for American Indian Health  
Rapid City, South Dakota

# Presentation Overview

- A legacy of health inequities among American Indians/Alaska Natives
- The Black Hills Center for American Indian Health
- Our Experience Partnering with Tribal Communities
- The blank sheet of white copy paper exercise – A best practices model for community-based participatory research

# Acknowledgements

- Our many Tribal partners
- National Institutes of Health
- Centers for Disease Control and Prevention
- Many other partners
- Dr. Patricia Nez Henderson and the wonderful BHCAIH staff

No Financial Conflicts



# AI/AN Health Inequities

- A long history of notable differences in health
- Despite profound change in disease causation
- As if AI/ANs have an inborn genetic predisposition to health inequities
- Profound geographic variation in cancer
- High rates of cardiovascular disease
- Leading rates of violence, abuse, self-harm, and abusive smoking and drinking
- Profound economic impoverishment

# BHCAIH

BLACK HILLS CENTER FOR AMERICAN INDIAN HEALTH

# Black Hills Center for American Indian Health

- Private, community-based 501(c)(3) organization
- Founded in 1998
- To conduct activities that will lead to the enhanced wellness of American Indian peoples, communities, and tribes
- Research, Service, Education, and Philanthropy

# Black Hills Center for American Indian Health

## *Research Portfolio*

- Currently home to 6 peer-reviewed health research grants and contracts totaling \$6 million (historical: 32 and over \$24 million since 2001)
1. Collaborative to Improve Native Cancer Outcomes (CINCO) CPHHD P50 – NIH/NCI/UW
  2. Native People for Cancer Control Community Networks Program – NIH/NCI/UW
  3. Native American Research Centers for Health: Lakota Center for Health Research – NIH/NIGMS/IHS



# Black Hills Center for American Indian Health

## *Research Portfolio*

4. Southwest Navajo Tobacco Education and Prevention Project (SNTEPP)– CDC/ANRF/AZ
5. Networks Among Tribal Organizations for Clean Air Policies (NATO CAP) – NIH/NCI
6. Center for Diabetes Translational Research (CDTR) – NIH/NIDDK/NCAI&Wash U
7. Strong Heart Study – NIH/NHLBI/MBIRI

# Black Hills Center for American Indian Health

## *Research Portfolio - Results*

- BHCAIH has consented more than 9,000 American Indians into its various studies in the past 8 years
- Injected more than \$5 million directly into impoverished Native communities
- Directly or indirectly hired more than 40 tribal members, primarily reservation-based
- 45 scientific publications, 4 book chapters and 1 DHHS guideline update monograph





# Journeys Along The Good Red Road

*Tribal Collaborations in Health Research*

## The BHCAIH Experience

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## *Tribal Collaborations in Health Research*

American Indians and Alaska Natives, too, have historical situations that have fostered mistrust

- Thyroid ( $I_{131}$ ) studies in Alaska in the 1950s
- Barrow alcohol study, 1970s
- Coerced sterilization of American Indian/Alaska Native women, 1970s
- Early use of Depo-Provera and Norplant, 1980s
- Recent situation involving ASU and the Havasupai Tribe, 2004





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## *Tribal Collaborations in Health Research*

American Indian and Alaska Native Tribes are unique in many ways

- Domestic, dependent nations with sovereignty
- Unique types and levels of approval, which vary by tribe, PLUS group consent in most cases
- Very different demographics
- DHHS/PHS/Indian Health Service beneficiaries

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## *Tribal Collaborations in Health Research*

American Indian and Alaska Native Tribes are unique in many ways

- Frequently lack typical supportive and easily accessible community resources (e.g., colleges and universities, social service agencies, grant-making bodies, etc.)
- Have such pressing needs that often health research falls far down the list of priorities
- Yet have tremendous assets



A photograph of a dirt road winding through a forest. The ground is covered in a thick layer of fallen red leaves. The trees are tall and thin, with some showing autumn foliage. The lighting is soft, suggesting a misty or overcast day.

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## *Tribal Collaborations in Health Research*

So What Can We do?

- Be there
- Involve tribal collaborators early and often
- Solicit broad input and feedback

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## *Tribal Collaborations in Health Research*

So What Can We do?

- Add value back to the community in explicit ways
  - Employment
  - Durable medical equipment
  - Diagnostic and therapeutic services
  - Enhanced skills
- Build training and employment opportunities into every grant
- Show that you are willing to think outside the box!





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## *Tribal Collaborations in Health Research*

The Blank Sheet of White Copy Paper Approach

# CONCLUSIONS

- AI/ANs have a long legacy of health inequities
- These inequities have their roots in profound social and economic inequities across generations
- Many influences on individual- and population-health
- Socioeconomic inequities have a profound impact on health status

# CONCLUSIONS

- Further research is needed to determine effective preventive interventions
- Successful interventions need to be replicated
- Ongoing surveillance of behaviors and conditions is essential to gauge progress
- Tribal/community, clinical, and national leadership and governmental financial support are essential
- Greater participation on the part of AI/AN Tribes, communities and people is essential to efforts to improve health

# Contact Me

Jeffrey A. Henderson, MD, MPH

Black Hills Center for American Indian Health

701 St. Joseph St., Ste. 204

Rapid City, SD 57702

(605) 348-6100; Email: [jhenderson@bhcaih.org](mailto:jhenderson@bhcaih.org)

[WWW.BHCAIH.ORG](http://WWW.BHCAIH.ORG)