Journeys Along the Good Red Road

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

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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
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- 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
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
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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
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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
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Tribal Collaborations in Health Research

The BHCAIH Experience
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
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
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
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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
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