The Good, the Bad & the Ugly: The Path Ethical to Research in Indian Country

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Research Distrust

- U.S. Army Research
- Indian Health Service
- Helicopter Research

Samples used in unapproved ways
Results reported to public before tribal community was informed causing harm to the community
Community-identifying information revealed in publications causing harm to community.
What were the good, the bad, & the ugly in AI/AN research—and how to avoid the bad & ugly?

- Research with AI/AN people/communities/tribes is not listed in the catalog of problematic research
- A common feeling among many tribal people: research has harmed AI/AN people
- What is behind that feeling?
Older & current good history/research

**Tuberculosis** was a killer, major cause of AI/AN death

- last half of 19th & first half of 20th centuries
  - Clinical trial of INH [isoniazid] in the Navajo Rez in early 1950s proved INH was an effective treatment, saved many AI/AN lives

**Diabetes** is a killer

- Diabetes Prevention Program [“DPP”] proved that intense counseling for lifestyle change could prevent type 2 diabetes (reduce calories, especially fats; moderate exercise 30 minutes a day, 5 times a week; reduce weight by 7%)
Older & current good history/research

**Community-Based Participatory Research**

- Kahnawa:ke Schools Diabetes Prevention Project

- People Awakening Project with Alaska Native groups, about resiliency and strengths in dealing with alcoholism
Current bad research – 1

Nuu-chah-nulth First Nations [western Vancouver Island, BC, Canada], severe unusual arthritis

- Early 1980s, UBC rheumatology & genetic researchers studied their problem, took blood specimens
- Geneticist kept specimens with him (UBC -> U Utah -> Oxford U), report migration genetic research results

Community found out 10 years ago

- Major adverse publicity across Canada

Community wanted the specimens back to finish the arthritis research

- Geneticist died early 2004, specimens were returned
Older bad history

Research with radioactive iodine (I131)

Early 1950s, USAF

"Do ANs survive the cold by having higher metabolism?"

Gave I131 to Alaska Native people

Same amount as then used for thyroid scan

Almost all ANs did not speak English

Three AN women in research were breast-feeding children!

Long-term effects of thyroid scan not then known

(ANs: not higher metabolism; know how to dress & eat)

Involved radiation—a feared modern hazard
Implications of older bad history

- \textit{I131 and a few other older problematic studies had complex issues}.
- Children who were breast-feeding may not have been followed up.
- \textit{The problem was basic protocol design}.
Examples

Community Harms of Research

- Results of a study on alcoholism in an Alaskan community were revealed at a news conference in Pennsylvania.
- Epidemiological study on syphilis in a Southwestern Indian tribe.
- Research on the genetics of diabetes among the Havasupai Tribe.
- Research on severe atypical arthritis among the Nuu-chah-nulth First Nations people in Canada.
Recent bad history-1

- Barrow, Alaska study on alcoholism
- 1970s, researchers from northeastern U.S.
- Announced findings in press conference held at their northeastern university
- Internal stigmatization by people from Barrow & nearby communities
- Bonds on Wall Street adversely affected
- Impact of research results?
- No positive change in/by Barrow
Recent bad history - 2

- **Congenital syphilis epidemic, 1980s**
  - Rez not named in publication
- **Rez children taunted** ("Your mama's ...")
- **Gas stations refused to let Rez people use restrooms**
Recent good & bad history

Hantavirus, summer 1993
50% of infected people died

- First recognized on the Navajo Rez
- CDC found cause < 10 days—a virus from deer mice

**Good:** helped NNDOH develop prevention programs

**Bad:** First two articles CDC named the Navajo Chapters
- Where the people lived who were infected first
- Where the deer mice and other animals were trapped

NNDOH asked CDC not to give Navajo place names in scientific articles
Implications of recent bad history

- Major community harm was disruption
- Major individual harm was “internal” self-stigmatization
- All subsequent research in many of those communities was adversely affected
- The problem was publication-dissemination
Current bad research – 2

Havasupai

Early 1990, tribe approved a diabetes study including genetic analysis by ASU researchers
No NLM-listed journal articles on genetic analysis of T2DM among Havasupai, one article on nutrition
HLA, inbreeding, & migration genetic research also done using the specimens

Sources:

Pubmed: Havasupai OR Markow T[Author] OR Martin JF [Author] OR Benyshek D[Author] OR Zuerlein K[Author]
Paul Rubin [personal communication]
Implications of current bad history

The old NIH policy and researcher practice of sharing genetic specimens [usually anonymized for identity of the individual] is no longer appropriate

“Tribal approval of research” extends to future uses

- of genetic & biological specimens and
- of data

Tribes vary about their degree of favorable or unfavorable attitude toward research in general

- Extent to which they see research as an enemy, or a friend, of the tribe’s future physical and cultural survival

The values and relationships of the tribes and researchers are changing
Current ugly research

Havasupai [there is more]

concurrently with T2DM study was schizophrenia study
apparently researchers told neither tribe nor individuals
apparently research team obtained information from clinic
charts surreptitiously, after hours, with no approval
apparently the ASU IRB did not comply with own
procedures & requirements

Was this “amateur night”?

Now prime example of ugly research in Indian Country

major adverse publicity in Arizona, major law suit by
Havasupai

More self-discipline by researcher and institution
could have prevented this!
“Kennewick Man” is an example of bad practice
skeleton found 08/96, 1st scientist said was “caucasoid”

*Kwaday Dan Ts’inchí - “Long Ago Man Found”*
Champagne-Aishihik First Nations [FN], d. 1415-1445
Glacier in Tatshenshini-Alsek Park, British Columbia [BC]
Body found 08/99, plan developed, studied to 12/2000
Returned to the Champagne-Aishihik
Cremated, potlatch, ashes scattered where found 07/2001
Head found 08/2003, studied, laid to rest 10/2004
Final ceremonies were planned and carried out 2005

FN community + BC government set up a joint
group to oversee the research within cultural limits

*“People Awakening” Project*
With Thanks to all of my Elders & Teachers and the Wisdom They have passed on to All of us
Wado!
Questions?
Discussion?
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