Research Partnerships with Natives: Major Challenges, Proven Solutions

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Hy’shqe siam -
Thank you, respected teachers

- Community Institutional Review Board (IRB) members
  - Sam Deloria, Lisa Preston, Kathleen Alexis, Dave Oreiro, & others

- IRB members
  - Dr. Francine Romero, Dave Oreiro, & others

- IRB staffs
  - Helen McGough, Moira Keane, and others

- Participants in research projects

- Researchers

- Wife - Carolyn Robbins
Problematic Research: alcoholism in Alaska – Barrow Alcoholism Study

- 1970s, researchers from northeastern US
- “All adverse impacts of drinking in Barrow.”
- Announced findings in press conference
  - held at their university in the northeastern “lower 48”
- Barrow’s Wall Street bond rating adversely affected
- Internal stigmatization of all Alaska Native people living in or near Barrow
- Impact of research results?
  - no positive change in/by Barrow
- Problems: Purpose & Dissemination (publication)
Good Research: alcoholism in Alaska – People Awakening Project (PAP)

- Mid 1990s
- “What strengths & resiliency do AN people have re: alcohol & alcoholism”
- People who had never drank or “in stable recovery”
- People interviewed for their life history
- Patterns of individual, family, & village/community strengths & resiliency
- Led directly to an intervention now proven effective
- Align Purpose, Dissemination, Future Use, Values
Problematic Research: BC, CAN – Nuu-chah-nulth Arthritis Study

- Early 1990s
- Cause of arthritis highly prevalent in First Nation
- Included genetic analysis of specimens from people
- Geneticist took specimens with him to study population genetics – not part of research proposed to or approved by Nuu-chah-nulth Council
  – Reported from where & when Nuu-chah-nulth came
- Big scandal in British Columbia & all Canada
- Problem: Future Use
Problematic Research in Arizona – different values

- *Havasupai* (“Not again!” Not really - please stay 😊)

- “DNA is a waste product. We shed it all the time. It carries our personal information which can identify us but provided it is anonymised, no harm is done. If a scientist collects it and can do something useful with it, we should celebrate their achievement.”  
  *(Jeremy Laurance, UK scientist, said Apr 23, 2010 in response to legal settlement)*

- "Their spirits will no longer be locked in a cooler," Ms. Tilousi said. "We are going to take them back down to Supai Canyon so they can rest in peace."

- **Problem: Values**
Problematic Research in Arizona – Were they really different values?

• Returning the specimens to 2 other Tribes in similar circumstances was a **HIGH** priority for them, too – to give the specimens proper respect and care
  – bloods came from **people** (for Havasupai, even from young children!)
  – some people were still with us, others passed on
  – **all with families**

• **M.I.A. (Missing-In-Action) remains for the USA**

• **Perpetual cell lines of “Amy” and “Mary”**

• **Mainstream Values are Havasupai Values**
Good Research with American Indian / Alaska Native TCUs / Tribes – SUMMARY

• Purpose,
• Dissemination,
• Future Use,
• and Values

ALL ARE ALIGNED AND CONGRUENT between TCUs / tribes and researchers
Data and Material Sharing and Ownership Agreements

• “DMSOAs”

• Formal, legal, agreements between institutions
  – Not just TCU/tribe with researcher
  – Must include researcher’s institution. Why?
    • Longevity, authority, & responsibility of institution
    • Institutions prohibit / do not honor such agreements

• Covers all major, potentially problematic, aspects
  – Purpose, dissemination, future uses, & values
Sample DMSOA: Basic Characteristic

• “Collaborative Multi-Center Research” (MCR)
  – 2+ PIs, their research teams, & their institutions
  – All are bound by & follow the MCR Agreement
    • Identical protocol for all
    • Publications by entire group, not just by individual PI
  • MCR with “community” & “academic” researchers
    – Each TCU/tribe is a Center – a local research institution
  • TCU’s/Tribe’s researchers:
    – collaborating scholars with special expertise
    – full members of the research team
      • like biostatisticians & qualitative research specialists
Sample DMSOA: Multi-Center Research (MCR)

- **DMSOA is a legal agreement for a MCR project**
- **Research Centers are institutions of the participating TCUs/tribes and outside researchers**
- **As with many MCR projects:**
  - Each research Center appoints its own researchers
  - DMSOA requires (or expects) all researchers in all Centers to participate in drafting & finalizing analyzes, reports, presentations, & publications
  - DMSOA Items 11), 12), 13), & 14)
Sample DMSOA: Purpose

- The nature and Specific Aims of the research are stated in the DMSOA – the scope and limits of research and activities the DMSOA permits and research team agrees to.
- Researchers have full “academic freedom”
- but only within nature & Specific Aims of the research approved by the TCU/tribe.
  - DMSOA p. 1, and Item 2)
Sample DMSOA: Dissemination

- Like most MCR Projects, DMSOA has a “Publications Committee”
- Like many MCR Publications Committee:
  - DMSOA’s Publication Committee requires unanimous consent of all researchers to publish or disseminate results
  - Unanimous consent of TCU/tribe-appointed researchers
    - DMSOA Items 11), 12), 13), & 14)
Sample DMSOA: Future Use

• DMSOA gives a researchers a “royalty-free, non-exclusive license” within the Specific Aims

• TCU/tribe controls, & must give prior approval for, all current changed uses (of nature or Specific Aims or researchers), and all future uses

• Control continues even after DMSOA is terminated

• Each researcher agrees to comply with DMSOA
  • DMSOA Items 1), 12), 13), 14), 15) 16), & 20)
Sample DMSOA: Respect Values

- Include immediate “ancillary benefits” to TCUtribe
  - Increase capacity of all partners, not just TCU[s]/tribe[s]
  - Co-teach students in TCU[s]/tribe[s]
  - Non-TCU/tribal partners stay present & be allies

- “You gain respect by giving respect”
  - (Said by a respected Lummi Elder to Lummi youth.)

- Suggestion: Each “side” try to imagine circumstances in which its values are similar to those espoused by the “other side”

- We are peers – co-researchers, co-scholars – working together.
  - DMSOA Items: Purpose & Aims, 1), 2), 11), 12), 13)
Sample DMSOA: Other issues

- The TCU/tribe receives a copy of all (de-identified) data & material at end of study
  - De-identified to person, unless person consented
  - In MCR with 2+ TCUs/tribes, de-identified to TCU/tribe, unless all TCUs/tribes consent
    - DMSOA Items 5) & 9)

- Researchers do not have to destroy all data
  - “Virtually” impossible to do

- TCU controls & owns/co-owns all data+materials
  - Ownership within limits imposed by grant or law
    - DMSOA p. 1, & Items 1), 13), 14), 15.D), 16), & 20)
“Other issues”: TCU/Tribe/Community values & concerns in research

- Protect and benefit the Tribe/community
- Respect elders & knowledge of Tribe/community
- Respect Tribe/communities, strengths, and survival
- Incorporate traditional spirituality into the project
- Promote resiliency, assist Tribe/community in its activation and problem finding/addressing/solving
- Have pride in community’s role in the project
- Have ownership in/of the research project
- Respect/promote Tribal sovereignty/community power
- Express hope for the Tribe’s/community’s future