Looking Back on Research: Successes and Lessons Learned and Panel discussion/Q&A

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American Indian/Alaska Native Health Research Advisory Council

• In November 2005, HHS solicited nominations from tribal leaders to develop the HRAC.

• The HRAC’s role is to facilitate communication between HHS and tribes regarding health research priorities and needs in AI/AN communities.

• Members of the Council are elected or appointed tribal officials, and include one delegate and one alternate from each of the 12 HIS areas as well as four national at-large members.
Obtain input from tribal leaders on health research priorities and needs for their communities;

Provide a forum through which HHS operating and staff divisions can better communicate and coordinate AI/AN health research activities; and

Provide a conduit for disseminating information to tribes about research findings from studies on the health of AI/AN populations.
Tribal Governance

• Today the 567 federally recognized tribal governments have constitutions:
  ➢ Each and every tribe has their OWN constitution
• Elections are held to elect tribal leadership
  ➢ Election governance is guided by EACH tribe’s constitution
    ➢ Some elect every year
    ➢ Some have staggered terms
• Each tribal government is directly responsive to their individual members
• Researchers MUST respect TRIBAL GOVERNANCE
Tribal Governance

• Ownership, control, access, and possession of data from tribal populations is controlled solely by each respective tribe.
  ➢ This applies to all research, evaluations, assessments, monitoring and surveillance, surveys, videos, cultural knowledge, and presentations.
  ➢ Basically all aspects of information, including its creation and management.

• Generally, a “data sharing agreement” is used by researchers to ensure the tribe has control (in writing) of what, who, when, methods, duration, and involvement of stakeholders.

• Generally, a TRUE model of Community Based Participatory Research is where the stakeholders are the “drivers” of issues, involvement, and expected results.
Where Research has Gone Wrong

• The gathering of information and its subsequent use has been inherently political and at the mercy of the agenda of individual researchers – not the stakeholders.

• Historically, AI/ANs have not been consulted about what information should be collected, who should gather the information, who should maintain it, and who should have access to it.

• The information gathered may or may not have been relevant to priorities or concerns of the stakeholders, but rather personal agendas from “outside” researchers.

• Researchers have a history of essentially pre-empting meaningful community involvement by presenting completed research designs, often already funded, for community approval rather than collaborating from the start.
An Example of Research Gone Wrong

The Havasupai Indian Tribe Case — Lessons for Research Involving Stored Biologic Samples
Michelle M. Mello, J.D., Ph.D., and Leslie E. Wolf, J.D., M.P.H.

April 20, 2010, Arizona State University agreed to pay $700,000 to 41 members of the Havasupai Indian Tribe to settle legal claims that University researchers improperly used Tribe members’ blood samples in genetic research.

• Suit stemmed from a 1990 diabetes study, ASU researchers collected more than 200 Tribal blood samples using a;
• consent form described as studying “the causes of behavioral/medical disorders.
• Researchers used the samples in multiple studies unrelated to diabetes, sharing them with other investigators, such as:
  • evaluating the genetic basis of schizophrenia, inbreeding, and evolutionary-genetics.
COMMUNITY INVOLVEMENT?
RESEARCHERS' TYPICAL, DEADLY COMMUNITY PRESENTATION ...
Samples of Current Universities offering American Indian Research

American Indian Studies Center – UCLA
• facilitate and disseminate research about indigenous peoples;
• strengthen graduate and undergraduate education;
• seek extramural funds to support student and faculty research; and
• carry out university and public service programs related to the Center's mission.

American Indian Studies Research Institute – Indiana University
• Provides the institutional structure necessary to carry out research and educational projects, most of which are funded by outside sources including the National Science Foundation, the National Endowment for the Humanities, and American Indian tribal organizations.

University of North Dakota – Center for Rural Health
• Resource Center on Native American Aging, which works with tribes nationwide on community-based participatory research. CRH faculty conduct research on behalf of foundations, North Dakota state government agencies, and through support from a variety of federal programs.
Advancing American Indian Nutritional Health Research Project

• In November 2015, the Shakopee Mdewakanton Sioux Community (SMSC) announced the details of its $1 million Seeds of Native Health gift to the University of Minnesota. Three groundbreaking projects will make major contributions in the fields of nutritional science, public health, and food production. The Project includes:

• A series of annual national conferences focused exclusively on American Indian nutrition and food access, to be jointly convened by the University and the SMSC;

• A publicly accessible, comprehensive, multi-disciplinary bibliography relating to American Indian nutrition and a publicly accessible, searchable database of leading experts in relevant fields;

• A study analyzing the obstacles between Western academic research and American Indian traditional knowledge and experience relating to food and nutrition.
The University of Minnesota, as a leading predominate University, has limitless opportunities to venture into uncharted educational and service collaborations that are critically needed to STOP the continued decline of health status of American Indians.