

2008 ANNUAL SELF-GOVERNANCE CONFERENCE
20th Anniversary of Tribal Self-Governance: Celebrating Excellence
Riviera Hotel & Casino; Las Vegas, Nevada
Tuesday, April 29, 2008

BREAKOUT SESSION 9:
RESEARCH AND COLLABORATION – STRENGTHENING PARTNERSHIPS AND
COALITIONS IN AMERICAN INDIAN AND ALASKA NATIVE RESEARCH

Moderator: Heather McMillan, Policy Analyst, Division of Regulatory Affairs, IHS

Introduction of Panelists:

David Wharton, R.N., MPH, is the Preventive Health Informaticist and Institutional Review Board Administrator for the Choctaw Nation of Oklahoma

Mariddie J. Craig, Principal Investigator, White Mountain Apache Representative

Dr. Philip Smith, M.D., M.P.H., Director, Division of Planning, Evaluation and Research, IHS

Dr Raymond Reid, M.D., Center for American Indian Health, John Hopkins Bloomberg School of Public Health

Dr. Smith:

Noted that the HIS Research Program is the primary interface with other Federal, State, Public, and Private health organizations and programs on behalf of the AI/AN communities

Although there is no line item for research in the HIS budget, support is provided for research through support of training on research related activities through annual conferences & meetings – the next conference is to be held August 26-28 in Portland, OR.

Dr. Smith then addressed Key components in the monitoring and participation in research activities. One primary key to understand is the

Tribe's ability to participate in a research project and to say "no" if they do not wish to participate.

The **Native American Research Centers for Health (NARCH)** was next addressed. There are currently 14 NARCH grantees composed of tribes, tribal organizations, and academic institution partnerships.

There are many financial implications and benefits of conducting research, and that is one reason Tribes participating. For example, the Department of Agriculture currently has a healthy foods study being conducted that would greatly benefit the understanding of diets.

The goals of NARCH are threefold:

1. develop a cadre of Indian scientists & Indian professionals active in research
2. enhance interactive Tribal partnerships with academic research centers
3. promote research on health conditions of AI/AN people and subject matter which is of importance to the participating tribes(s)

Samples of NARCH research projects include:

- Suicide prevention
- Social protective factors of tribes
- Type 2 diabetes risk factors in youth
- Asthma

Finally, each of the NARCH projects has a summer student training component for high school undergraduate and graduate AI/students.

EPI centers were mentioned and it was noted that each Area has an EPI center.

With regards to community oriented primary care, it is important that communities have a chance to weigh in on any research project.

Any research should be community based research – the community should decide what to study. Trust is the foundation of any good research.

Research should be used to create change for “good” – develop a vision where Indian communities are networking doing the research.

Native Americans have a long history of participating in research/research projects.

Mr. David F. Wharton:

Began by stating that “strength in research comes from trust” and continued by providing a quick overview of the Choctaw Nation, and discussing the Tribe’s establishment of its IRB or Institutional Review Board.

If you are a Self-Governance Tribe should have and IRB in you plan and established to protect participants in any research projects.

Tribes can come together and establish an IRB for several Tribes, and Tribes need an active voice in the IRB. Indian heritage needs to be protected.

The Navajo & Cherokee Nations have had long standing IRB’s with the Choctaw establishing one in 2004, by executive order of the Chief.

The steps in the establishment of the CNIRB was highlighted as well as the role of the CNIRB – ongoing human subject protection, review all human subject research, provide approval for projects, and provide feedback when a project cannot be approved.

The make up of the CNIRB was discussed and it included nine members from the community and health specialties.

Mr. Wharton emphasized that all human subjects regardless of race or tribal affiliation who are involved in research that occurs within the organizational boundaries of, or within the jurisdictional control of the Choctaw Nation of Oklahoma.

The future steps for CNIRB are to improve the Tribal IRB standard procedures, work with the Cherokee and Chickasaw Nations and IHS OKC Area on joint jurisdictional projects issues, and improve knowledge of researchers on CNIRB existence and Procedures.

Ms. Mariddie J. Craig, and Dr. Raymond Reid co presented:

Ms. Craig stated that the White Mountain Apache Tribe (WMA) works in partnership with Johns Hopkins University to translate research into community interventions by making sure JH knows how WMA feels about research.

WMA ensures that any research protects their community members and community heritage. All research must be controlled by the community and any questions must be specific to WMA.

Ultimately, WMA want to continue to move forward with research addressing questions specific to the Tribe.

Dr. Reid discussed the relationship b/w JH and the WMA which has made contributions to the medical community worldwide. The primary goal is to ensure the research results in practical interventions

Dr. Reid then describe several research projects from the 1970's through the 1980's that have resulted in many local to global applications. For example, diarrheal diseases were ultimately addresses, with some treatments being established as the preferred treatment for US children with diarrheal dehydration. The WMA received an award from WHO, UNICEF, CDC, and USAID for these research contributions.

Behavioral health projects addressing family spirit, living in harmony, and celebrating life and empowering our spirits to reduce suicidal behavior among youth are current research goals of the WMA.

Finally, a primary goal of NARCH and the WMA is to build on a history of successful collaborations to launch a unified research and training effort to transfer expertise from JH University to Apache tribal health leaders and budding Apache health scholars to conduct health research, compete for federal research grant opportunities, and hone skills to lead future health research and public health delivery for the Tribe.