



HHS American Indian/Alaska Native Health Research Advisory Council Meeting

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Overview of Indian Health Service and American Indian/Alaska Native Research Priorities

by

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Good afternoon. It is a pleasure to be here today to meet with all of you to discuss the status and future of health research in Indian communities. Recently, I attended and presented at several international conferences on the health of Native peoples around the world, where the subject of health research came up repeatedly. The point has certainly come home to me, and I think to many in the international community, that effective, culturally sensitive research efforts are essential in guiding the future of health delivery and wellness efforts in any population.

One of the main priorities of the Indian Health Service (IHS) research program is putting Native people in charge in the research arena. Past abuses, real and perceived, have contributed to a general distrust of research in the Indian community. Contributing to this distrust were issues such as the lack of communication with communities after research is completed; research being conducted on topics that are not of concern to the local community; and special cultural considerations being ignored or trampled upon.

All of these wounds can be healed only when the community gets intimately involved in the process of research, from beginning to end.

The old model of research in Indian Country was what we now refer to as “helicopter research.” This was where faculty from some university would descend on the reservation to do research on Indians that might or might not address any needs of the tribal community, then fly away, never to be seen again — with only a publication in some journal leaving tracks of their brief visit.

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There were some early exceptions to this, such as the long and productive relationship of over 25 years between the White Mountain Apache Tribe and the Johns Hopkins School of Public Health, which generated some important health information and resulted in improved prevention of bacterial disease among the Apaches and other people worldwide. This work exemplified research done *for* and *with* Indians –rather than *on* Indians – and led to important improvements in health care for American Indians and Alaska Natives.

The IHS recognizes and supports “good” research among Native Americans. We believe that good research discovers important new knowledge and answers questions to pressing and serious health issues. And we believe that good research should address an identified need in Indian Country, and should be acceptable to Indian communities and people. It should be conducted in partnership with the community.

The IHS research program attempts to go one level further, in that we are trying to generate, support, and improve research conducted *by* American Indian and Alaska Native researchers. The IHS is actively working to develop the capacity for research in Indian communities by increasing the number of qualified Indian researchers and increasing access to the federal funding for research that directly benefits Indian people, based on priorities they themselves have set.

This means we must increase the number of the partnerships between Tribes and academic institutions that are skilled in doing research, in order to build a long-lasting research infrastructure. And we are focused on finding ways to ensure that Tribes and communities have appropriate involvement in making decisions about issues related to research, including research topics, design, terms of conduct, approval, and consideration of cultural issues— as in the handling of human remains or tissue specimens.

Related to this goal, we support the education and training of Indian leaders and communities about health research to help build trust between researchers and Indian communities. We are concerned about the research data ownership and the importance of ensuring that the results of research are brought back to the community and discussed with the participants. And we are dedicated to ensuring the appropriate protection of human subjects of research. This includes guarding the privacy of individuals and communities; increasing local capacity for research review; and promoting integrity in research.

The IHS Research Program has several components that address these goals. The first is the annual IHS national research conference held each year in April, which serves as a means of sharing current information and generating ideas among IHS and tribal participants. Next year’s 19th annual conference will be held in Phoenix, Arizona.

The second is our human subjects protection program, the Institutional Review Board, or IRB, which works to ensure extra protection for American Indian and Alaska Native research subjects that goes beyond the minimum required by Federal regulations. The IHS research program is working to improve the function of the IRB through a multi-level approach. All research protocols, after being endorsed by the appropriate tribal leadership, would be approved at the local level by an IHS Area or Tribal IRB. In some cases, a protocol would also need to be submitted for approval by the national IRB.

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Another important component of the IHS Research Program is the Native American Research Centers for Health, or NARCH, Program, which I will speak more about in a moment. And we are continuing to build liaisons and partnerships with other Federal agencies, public and private foundations, academic centers, etc.

Of course, one of our most important research partnership efforts is with the Department and the American Indian/Alaska Native Health Research Advisory Council. Together with your help, we will address the need for change in the way research is conducted and supported in Indian Country. This Advisory Group provides a formal avenue through which the Department can gather specific information from Tribal Leaders on the health research priorities and needs of American Indians and Alaska Natives.

This information can be used in the development of an HHS-wide Indian health priority research agenda that can help guide the direction of national research activities conducted by our sister agencies. This may allow for greater participation of Indian people in many of the national projects that have not included this population group in the past. Since many of the health services research projects are directed at health disparities, the results of this research can provide key information to assist us in fulfilling our mission of improving the overall health status of Indian people everywhere.

Also, studies that seek to adequately and completely identify health problems in rural areas need to include the Indian community, since they represent a largely rural population. One important tool for Native health researchers that I think is worth mentioning is the Native Research Network, or NRN, Listserv. This is an online list of email addresses of NRN members. The NRN, which I am sure many of you here are familiar with, is a network of over 160 members from the U.S., Canada, and South America who share information on Native research efforts, providing a valuable communication tool for those interested in or involved in Native health research efforts.

The composition of the NRN is very diverse, including members who work or teach in academic institutions, hospitals, clinics, and tribal programs. They all have one thing in common, however — an interest in improving the health of Indian people through quality research, and increasing the number of skilled Indian professionals available to work in Indian communities.

The NRN provides an excellent forum for networking and mentoring opportunities, sharing research expertise, sponsorship of research events, assistance to communities and Tribes, and enhanced research communication. NRN members have benefited from the listserv by responding to announcements of conferences, employment opportunities, calls for collaboration, and grant funding.

Another important activity related to ongoing research in Indian communities, as I mentioned earlier, is the partnership represented by the NARCH program. This is the result of a collaboration between the IHS and NIH to fund research partnership efforts between universities and Tribes and tribal organizations. The NARCH partnerships serve three main functions. The first is to develop an active cadre of Native scientists and health professionals engaged in biomedical, clinical, behavioral, and health services research who will be competitive in securing

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federal funding. The second goal is to increase the capacity of both universities and Native organizations to work in partnership to reduce distrust by Native communities and people toward research. And the third function is to encourage competitive research linked to the health priorities of tribal organizations and to reducing health disparities.

These purposes are being achieved through the support of American Indian and Alaska Native student training and development projects, faculty and researcher development projects, and research projects developed and implemented by each NARCH partnership in their respective tribal communities.

Some examples of research project topics for NARCH grant awards include:

- Pneumococcal disease
- Attitudes of Indians toward research
- Social protective factors of Tribes
- Type 2 diabetes risk factors in youth
- Childhood obesity & dental caries
- Disabilities
- Telemedicine
- Maternal nutrition
- Alternative medicine
- Substance abuse & neglect

These projects obviously cover a wide range of health issues. Each grantee is partnered with an academic university so the opportunities for mentoring and learning are great.

In FY 2005, \$6.2 million was awarded for a total of 14 NARCH grants nationwide. These funds, received principally from NIH institutes, support student and faculty development at major universities, as well as the NARCH research projects. Over 450 Tribes are involved in some aspect of the NARCH program nationwide. Each NARCH is a 4-year cycle of funding – the grant award is received annually if progress is satisfactory. We are funding NARCH 4 this year and are starting planning for NARCH 5 and 6 funding cycles.

At present almost all funds for research in Indian communities come from outside the IHS, making the work of this Advisory Council very important to the future of Indian research. Since the IHS does not have a line item for research in our budget, we must depend heavily on the work of our sister agencies and other public and private research entities to help meet the health research needs in Indian Country. So your efforts to incorporate Indian health priorities into the HHS research agenda are of vital importance to the IHS research program, and to the health and wellness of American Indian and Alaska Native people.

Ultimately, the purpose of all our research efforts, and all our health care delivery efforts, is to improve the health and well-being of the people we serve, both today and far into the future. I look forward to working with all of you to help further this goal.