



# **IHS Annual Research Conference**

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## ***IHS Research Program, Policy, and Priorities***

by

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Good Morning. It is a pleasure to be speaking here today at this conference. Recently, I have attended and presented at several international conferences on the health of Native peoples around the world, where the subject of health research and health information technology 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, coupled with competent health data collection and processing systems, are essential in guiding the future of health delivery and wellness efforts in any population.

Since I strongly believe that the Indian Health Service (IHS) has been a leader in this area, I was pleased to be able to share our successes, and even what we have learned from our failures, with others in the international community who may be facing similar challenges in serving the health needs of Native communities.

One thing I was proud to share with health professionals from around the world was how far the IHS has come in the past 50 years since we were officially established as an agency.

Due to aggressive immunization, disease prevention, primary care access, and sanitation improvement efforts, and the incredible dedication and hard work of many IHS, Tribal, and Urban program employees and researchers over the years, the health status of American Indian and Alaska Native people has improved dramatically.

The proof of this can be seen in the significant reductions in American Indian and Alaska Native mortality rates over the years. We have been successful in dramatically decreasing many causes of mortality among Indian people. For example, deaths due to accidental injuries have declined by about 60% since 1973; maternal deaths have declined by 64%, and infant deaths have declined by 66%. Tuberculosis, once the major cause of morbidity and mortality among Indian people, and in some respects the reason the IHS was established in 1955, has declined over 80% since 1973.

And what does this mean in human terms?

It means that, in 1955, an Indian child had over twice the chance of dying in infancy as a non-Indian child in the United States. He was 22 times more likely to die of tuberculosis before age 4 than a non-Indian child; 13 times more likely to die of gastrointestinal disease, and over 7 times more likely to die of influenza or pneumonia. Even if he survived all this, he had a life expectancy of only about 60 years.

But we have come a long way . . . an Indian child born today has less than 1 percent chance of dying in infancy; less than one-half percent chance of dying of pneumonia, influenza, or gastrointestinal disease, and almost no danger at all of dying of tuberculosis.

I hope this makes you realize the importance of the work you do. Each of you here today has made a difference, and continues to make a difference, in the health status of American Indian and Alaska Native people across the nation.

However, there is still much to be done.

Despite all our advances, significant health disparities still exist in the American Indian and Alaska Native populations. Most of today's health challenges involve chronic diseases, such as diabetes, cardiovascular disease, and injuries, which are heavily impacted by lifestyle issues, and which require a holistic, multi-disciplinary approach to health care provision.

In order to better address these current pressing issues in Indian health care, the IHS has established 3 focus areas, or Director's initiatives. These are:

- Health Promotion/Disease Prevention
- Management of Chronic Disease, and
- Behavioral Health

These initiatives are linked together, and seek to address the underlying causes of poor physical and mental health, rather than just treating the symptoms. And they stress the empowerment and full engagement of individuals, families, and communities in health care. Addressing all the diverse elements that contribute to good health demands, among many other things, a strong research program to help guide our health care efforts.

And that brings us to our main topic here today, the IHS research program, policy, and priorities. One of the main priorities of the 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. We are well underway on that process, thanks to the work of many of you here.

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.

There were some early exceptions to this, such as the long and productive relationship between the White Mountain Apache Tribe and the Johns Hopkins School of Public Health, which has generated important information and improved the prevention of bacterial disease among the Apache. 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. Formally stated, the goals of the IHS research program are:

1. To perform and sustain careful and socially responsible scientific inquiry in the health sciences involving American Indian/Alaska Native people and communities, with maximum tribal involvement in and control over that research.
2. To optimize community involvement in and control over research, to protect volunteers and communities from excessive risks of research, and to maximize its benefits to them, and
3. To increase the capacity of Indian communities and individuals to do research in health sciences that is important and useful to them.

This means we are actively working to develop the capacity for research in Indian communities by increasing the number of qualified Indian researchers and increasing federal funding for research that directly benefits Indian people, based on priorities they themselves have set. 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, terms of conduct, approval, and cultural issues (for instance, in the treatment of human remains or tissue specimens). Related to this goal, we are also supporting the education of Indian leaders and communities about health research to help build trust between researchers and Indian communities.

We are also concerned with the importance of ensuring that the results of research are brought back to the community. 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 this annual IHS research conference to share information and generate ideas among IHS and tribal participants. The second is our human subjects protection program, or Institutional Review Board (IRB), that 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 two-tiered approach with Headquarters and the Areas.

And we are continuing to build liaisons and partners with other Federal agencies, foundations, academic centers, etc. This conference is in fact mostly the result of the efforts of the Native Research Network, one of our very successful partnership efforts.

Another important component is the Native American Research Centers for Health (NARCH) Program, a partnership between the IHS, the National Institutes of Health, and other federal research agencies. The NARCH program funds research partnership efforts between universities and Tribes and tribal organizations. The purpose of these partnerships is:

1. To develop a cadre of American Indian and Alaska Native scientists and health professionals engaged in biomedical, clinical, behavioral, and health services research who will be competitive in securing federal funding;
2. 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
3. To encourage competitive research linked to the health priorities of tribal organizations and to reducing health disparities.

These purposes are being achieved by supporting student development projects, faculty/researcher development projects, and research projects developed by each NARCH partnership. 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 projects for NARCH grants.

In support of our research and health delivery efforts, the IHS continues to strengthen our health information technology systems. The IHS has developed and continues to enhance an innovative, state-of-the-art health information technology system — the Resource and Patient Management System (RPMS). The RPMS facilitates ongoing sharing of information on effective monitoring, prevention, and treatment programs that have reduced morbidity and mortality. The collection of reliable data helps guide health care delivery decisions and set research priorities.

Just having good health data is not enough, however, and IHS has embarked on a project to help Tribes develop a network of tribal epidemiology centers to actually do something with the data. These tribal epidemiology centers are operated by tribal organizations, such as regional Indian health boards. They are located throughout the U.S. Their mission is to provide essential public health services. They collect, analyze, interpret, and disseminate health information to Tribes and to potential funding sources. They also assist Tribes in identifying key local health issues through the development of community health profiles. In addition, they respond to community health needs, such as outbreak control or implementation of health interventions.

In recognition of the need for change in the way research is conducted in Indian Country, the IHS has been working with the Department of Health and Human Services (HHS) on an official American Indian/Alaska Native Health Research Advisory Group to provide a formal avenue through which the Department can gather specific information on health research matters.

This initiative establishes a group of tribal leaders to provide input on the specific health research priorities and needs of American Indians and Alaska Natives. The Advisory Council will serve three main functions:

1. Obtain input from tribal leaders on health research priorities and needs for their communities to assist in the development of an HHS-wide Indian health priority research agenda.
2. Provide a forum through which HHS agencies can better communicate and coordinate the work their respective organizations are doing in Indian health research.
3. Provide a conduit for disseminating information to Tribes about research findings from studies focusing on the health of Native populations.

Another tool for American Indian and Alaska Native health researchers is the Native Research Network (NRN) Listserv, an online list of email addresses of their members. The NRN 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 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.

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.

Thank you for inviting me to speak here today. I look forward to continuing our work together on behalf of American Indian and Alaska Native people.