



# Indian Health Service Research Agenda

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## Message from the Interim Director, IHS



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*The Indian Health Service (IHS) Research Agenda is attached for consideration by the Research Coordination Council. I will be discussing this agenda at the April 22 Research Coordination Council meeting.*

*The IHS mission is to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives (AI/ANs) to the highest level. Our research priorities reflect the health issues that currently impact our achieving this mission. Health statistics illustrate consistently the health status disparities between AI/AN people and other Americans. The IHS recognizes the need to develop and evaluate new and innovative approaches to eliminating health disparities and to improving AI/AN access to quality health care.*

*The IHS recognizes the need to partner with other Federal agencies to reduce the prevalence and severity, as well as the social and economic burden, of particular diseases and disabilities that disproportionately affect AI/ANs. The IHS also recognizes the need to continue to develop and identify best practices for prevention and health care delivery. We are committed to ensuring that, once identified, these best practices can and will be disseminated to our constituents and partners. More information on the Prevention Initiative, which serves as an example of this commitment, is available at the IHS Web site at [www.ihs.gov/HPDP](http://www.ihs.gov/HPDP).*

*The IHS-proposed Research Agenda will assist the Department in identifying and determining where partnerships can be used for the most impact on addressing health disparities among AI/ANs. The proposed agenda should be viewed as a continuous work in progress and subject to change as events or priorities change. It proposes possible research activities that could be conducted in collaboration with other Federal agencies to advance research that will be used to help eliminate health disparities between AI/ANs and other Americans.*

*The staff at the IHS are very knowledgeable in working with Tribal governments and can provide whatever assistance will be needed to accomplish this very important agenda.*

*If you have any questions, please contact Dr. Phillip L. Smith, M.D., Director, Office of Program Support, at 301-443-6528, or Ms. Deborah Melton, Senior Management Analyst, Office of Planning and Evaluation, at 301-443-2417 or [dmelton@hqe.ihs.gov](mailto:dmelton@hqe.ihs.gov).*

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## Indian Health Service Proposed Research Agenda Using Research Coordination Council Priorities

### INTRODUCTION

The Research Coordinating Council (RCC) proposed four major recommendations to the Secretary of Health and Human Services (HHS). One of these recommendations encouraged all HHS agencies to continue and expand research collaborations with the Indian Health Service (IHS), to propose studies that can yield important health-related information about the American Indian/Alaska Native (AI/AN) population, and to enhance these activities where appropriate. The IHS-proposed Research Agenda is provided in the context of the 10 RCC themes.

### AGENCY BACKGROUND

#### Mission:

The mission of the IHS is to raise the physical, mental, social, and spiritual health of AI/ANs to the highest possible level. The goal is to ensure that comprehensive, culturally acceptable personal and public health services are available and accessible to AI/AN people. Our foundation is to uphold the Federal Government's obligation to promote healthy AI/AN people, communities, and cultures and to honor and protect the inherent sovereign rights of Tribes. Funding from Congress for Indian health was provided through the 1921 Snyder Act, "... and expend such moneys as Congress may from time to time appropriate ... for ... Indians ... for relief of distress and conservation of health."

#### Federal Trust Responsibility:

The provision of Federal health care delivery services and the funding of Tribal and Urban Indian programs to meet the Agency's goals are consistent with the Federal Government's historical and unique legal relationship with AI/AN people. This relationship is reflected in the Constitution, treaties, Federal laws, and the course of dealings of the United States with Indian Tribes in a

special government-to-government relationship through which trust responsibilities and obligations to the AI/AN people are carried out.

#### Advocacy & AI/AN Tribal Consultation:

The IHS uses a proactive Tribal consultation process under the provision of the government-to-government working relationship. The Department has established the Intradepartmental Council on Native American Affairs to serve as the internal focal point within the Department for coordination and consultation on health and human services issues affecting the AI/AN population.

### CURRENT RESEARCH ACTIVITIES AND PARTNERSHIPS

#### Support for Research Training and Career Development:

The IHS and the National Institutes of Health (NIH), both agencies of HHS, continue their partnership initiative to include AI/ANs as participants in and beneficiaries of the research and training supported by NIH.

The partnership began in 2001 when the IHS and the National Institute of General Medical Sciences (NIGMS) jointly issued announcements seeking applications for Native American Research Centers for Health (NARCH). NIGMS provided \$1.5 million each year for 4 years to fund the NARCH. Other Institutes and Centers of NIH provided additional resources, and NIGMS provided an additional \$500,000 in the first year. The IHS is administering the grants.

The IHS and NIGMS believe that the NARCH applications received from the first solicitation showed the high quality of several proposed NARCHs. As a result, NIGMS approved a second solicitation for NARCH applications. NIGMS provided to the IHS an additional \$1.5 million per year for 4 more years starting in 2002 for new and supplemental grant proposals. Other NIH Institutes and Centers are likely to add to that total.

The IHS and five Institutes of NIH have made grants available to eight NARCH programs. The programs are designed to build a cadre of AI/AN researchers, who will work with Tribes to design research projects relevant to Indian communities. The grants illustrate how the various HHS agencies can work together as one department to make a difference in the lives of all Americans. This is an important grant program for the IHS and the AI/AN people. The IHS is very interested in collaborating with other Federal agencies to extend the work of the NARCH program.

### **Tribal Colleges and Universities:**

Tribal Colleges and Universities (TCUs) can be a great resource for providing health education within the AI/AN communities, as well as for providing the necessary preparatory academic and training needs to increase the number of AI/AN health care professionals. The IHS is very interested in collaborating with other Federal agencies in administering their TCU grants to ensure that the health needs of the AI/AN population are being addressed. Executive Order 13021 established a mandate to facilitate the access of TCUs to Federal resources. The Executive Order laid the groundwork for a White House initiative to raise awareness of Tribal institutes of higher education throughout the Federal Government and to promote their participation in Federal programs. For the most part, TCUs are young developing institutions. The Executive Order ensures that TCUs have the same opportunities afforded other institutions.

## **DATA COLLECTION AND MONITORING**

Based on recommendations of the Institute of Medicine “Unequal Treatment” report, data collection and monitoring would be an important piece for the IHS Research Agenda. We have incorporated the following steps into our Research Agenda: Evaluate data on health care access and use by race/ethnicity (and, where appropriate, Tribal affiliation), socioeconomic status, and primary language; include measures of race/ethnicity disparities in performance measurement; monitor progress toward the elimination of health disparities; evaluate the effectiveness of the current clinical data system; and develop strategies and prototypes to improve the use and clinical effectiveness of the research.

## **The IHS Research Agenda**

### **I. Working Toward Independence**

#### **A. Encouraging Work and Self-Sufficiency**

- Evaluate the impact of current economic development programs on Indian reservations.
- Determine the extent of unemployment on each Indian reservation. Develop a plan to address the unemployment rate, to determine the types of industries that can be established within the reservations, and to establish training for AI/ANs to become gainfully employed.

#### **B. Promoting Healthy Marriage and Strong Families**

- Assess the prevalence of domestic violence, and implement and evaluate prevention strategies and programs.
- Evaluate the impact of batterer prevention programs on family cohesiveness.
- Evaluate the current trend of marriage and divorce rates among AI/ANs, and establish a demographic data base.

#### **C. Improving Child Well-Being**

- Assess the impact of well-baby clinics on child health status and health outcomes.
- Evaluate the incidence and impact of child abuse in Indian communities.

#### **D. Promoting State Flexibility and Accountability**

- Evaluate the impact of partnerships among Federal, State, and Tribal Governments.
- Assess and evaluate the partnerships of AI/ANs in participation of State block grant programs.

#### **E. Collaboration and Partnership**

- Develop and evaluate mechanisms of collaboration and partnership for economic development related to health within Indian communities.

## II. Rallying the Armies of Compassion

- A. Expanding the Use of Faith-Based and Community-Based Organizations  
Priority Research Area**
- B. Addressing the Needs of Special Populations**
  - Evaluate the impact of using faith-based and community-based organizations to address AI/AN needs.
  - Evaluate the impact of the HHS policies on funding opportunities for educational institutions serving minority populations and particularly for the Tribal Colleges and Universities.

## III. No Child Left Behind

- A. Improving Reading and School Readiness**
  - Establish and evaluate early detection and intervention programs that promote normal behavioral or language progress in AI/AN children.
  - Assess the quality of education systems currently in place for AI/AN children on Indian reservations, and compare the quality and successes in large urban school systems. Determine what is needed to provide higher quality education for AI/AN youth living on Indian reservations.
  - Compare the reading and school readiness of children in American Indian Head Start (HS) programs with those non-Indian HS and day care programs.
- B. Preventing Teen Risk Behaviors**
  - Evaluate the impact of early education on high-risk behavior in the school system for AI/AN youth.
  - Study the determinants of risky behaviors among teens, particularly alcohol, substance abuse, tobacco use, violence, and sexual behavior. Evaluate the effectiveness of such interventions as school-based counseling, youth clubs and centers, counter-advertising, and sex education.
  - Assess the risk and prevalence of gambling addiction.

## C. Protecting Children and Youth

- Assess and evaluate the need for safe houses. Evaluate the impact of safe houses on homelessness, violence, and sexual abuse, as well as on clinical and functional status.
- Evaluate the impact of the U.S. Department of Agriculture Food Distribution Program on Indian Reservations. Assess the nutritional value and content to meet the developmental requirements of children and youth and the nutritional needs of pregnant women.
- Evaluate social and behavioral factors among incarcerated AI/AN youth.

## IV. Promoting Active Aging and Improving Long-Term Care

### A. Improving Access to Long-Term Care Services

- Access the current status of long-term care (LTC) services for AI/AN elders, as well as the financing and service delivery models used. Evaluate the models in terms of utilization prediction models, cost, quality, and cultural values.
- Assess the need for services at the community, Tribal, and regional levels. These assessments should be linked to potential interventions; the unit area of assessment (community, Tribal, and regional) should be relevant to possible interventions.
- Assess the need for and the utilization of LTC services for the national AI/AN elder population and the cost of such services.
- Analyze the impact of different models of LTC services and systems on the culture of a community.
- Assess access to Medicaid LTC benefits by AI/AN elders. Evaluate barriers and potential remedies.
- Assess access to Veterans Affairs LTC benefits by AI/AN elders. Evaluate barriers and potential remedies.
- Evaluate and analyze LTC service delivery models not currently used in Indian country for their application in Indian country.
- Establish and evaluate LTC demonstration projects in AI/AN communities (such as the Program of All-Inclusive Care for the Elderly or home- and community-based waiver programs).

- Assess the role of faith-based initiatives as a resource for Tribal LTC services.

## **B. Improving Long-Term Care Delivery and Finance**

- Assess the AI/AN population that needs LTC. Determine and evaluate their options. Develop pilot projects to provide LTC to those AI/ANs in need and assess their efficacy.
- Establish and evaluate the cost of LTC services currently being provided through IHS, Tribal, Urban, and State programs for AI/AN elders.
- Investigate the potential mechanisms for the State and the Federal Government, including the IHS, to assist Tribes in developing on-reservation long-term nursing facilities.
- Evaluate the State policies for all licensing issues for LTC facilities. Determine the impact of these policies on Tribally operated LTC facilities.
- Develop a pilot demonstration project with the Centers for Medicare and Medicaid Services (CMS) and States to waive the Certificate-of-Need requirement, which is the major barrier for Tribes to provide LTC on reservations.
- Consider expanding the Medicare Home Health/Home Care reimbursement policy to promote participation by Tribal families and members.

## **C. Long-Term Care Data Infrastructure**

- Evaluate the current AI/AN LTC interactive data bases, and determine their most effective use. Establish a plan to incorporate this analysis into a national AI/AN LTC interactive data base.

## **D. Improving Nursing Home Quality**

- Assess the current trends of AI/AN use of nursing homes, and evaluate the quality of life for those participants.
- Evaluate the impact of nursing homes on reservations versus off reservations.

## **E. Promoting Home and Community-Based Services**

- Establish a plan that will address the health care needs of AI/AN elders within their home communities. Determine the best plan for each community, and design and evaluate implementation models.
- Assess using faith-based and Tribal organizations to provide these services. Determine and establish how these organizations can work to best serve the AI/AN communities and how to implement the plan.

## **F. Active Aging**

- Evaluate the impact of specific chronic diseases and conditions (e.g., arthritis, osteoporosis, dementia, depression, renal disease, and diabetes mellitus) on the health and functional status of AI/AN elders as well as the impact of disease management approaches.
- Evaluate the prevalence of disease prevention activities (e.g., immunizations, cancer screening, and exercise) among AI/AN elders.
- Evaluate the prevalence of disease prevention interventions at IHS, Tribal, and Urban health facilities for elders.
- Evaluate intervention models designed to increase disease prevention activities among AI/AN elders.
- Evaluate intervention models designed to decrease the functional and health status impact of chronic disease among AI/AN elders.
- Design optimal management methods for depression, and evaluate their effectiveness.
- Evaluate current medical safety issues within the IHS that are specific to elderly patients; design appropriate interventions to decrease the incidence of medical errors in the elderly, and evaluate their effectiveness.
- Evaluate the prevalence of elder abuse, neglect, and exploitation in AI/AN communities. Evaluate potential intervention models.
- Assess the current research being conducted for the elderly; determine whether the AI/AN population is participating in the research. Determine what the differences are in need, access, utilities, facilities, and current activities in place and what could be established to assist elders with active aging. Implement and evaluate those services or activities within the communities.



## V. Protecting and Empowering Specific Populations

### A. New Freedom Initiative—Enable People with Disparities to Live Self-Sufficiently with Dignity

- Assess the quality of life of AI/ANs with disabilities.
- Evaluate current Disability Association Life Year values for AI/AN people.
- Evaluate access to services for AI/AN people with disabilities; assess the impact of these services.

### B. Medicare Modernization

- Explore the possibility of increased enrollment of AI/ANs in Medicare through third-party payment of Medicare premiums.
- Evaluate the Medicare modernization legislation for prescription drug payments for AI/ANs.
- Assess the need for expanding IHS' Medicare Part B authority to include Durable Medical Equipment, prosthetic devices, and covered vaccines, as well as other necessary medical devices.
- Assess the use of supplemental insurance by elderly AI/ANs. Assess CMS education and outreach strategies targeting the AI/AN population for enrollment in Medicare and Medicaid and in the State Children's Health Insurance Program (SCHIP).

### C. Mental Health and Drug Treatment

- Assess and evaluate the incidence and predictors of dual diagnosis in AI/AN populations; assess the efficacy of treatment options.
- Identify the incidence of co-morbidity in behavioral health disorders.
- Evaluate the incidence of intimate partner violence as a predictor of mental health.
- Evaluate the cost-effectiveness of alcohol and substance abuse prevention treatment, healing, and recovery for Indian communities.
- Assess age-appropriate treatment approaches for AI/AN children and youth with behavioral health disorders.
- Evaluate the effectiveness of current suicide tracking and interventions; develop and evaluate pilot projects for community-based suicide intervention and prevention.

- Assess the impact of personal cultural perception on mental health disorders.
- Determine and assess the impact of personal spiritual identification on treatment outcomes.
- Propose and evaluate inhalant abuse prevention and treatment programs.

## VI. Helping the Uninsured and Increasing Access to Health Insurance

### A. Increasing Access to Health Insurance Coverage and Services

- Conduct a national assessment of health care insurance coverage; determine the level of coverage for Urban Indians.
- Develop and evaluate alternate ways to ensure adequate access for Urban AI/ANs.

### B. Medicaid and SCHIP

- Assess the participation and barriers to participation of AI/ANs in the Medicaid and SCHIP programs; develop and evaluate ways to increase participation in these programs, such as through education and outreach.
- Address exempting AI/ANs from various forms of enrollment fees (e.g., State of Utah) or premiums that many States are now implementing for Medicaid programs, under 1115 waiver approval from CMS, as States' budgetary priorities continue to increase. In most cases, even a modest enrollment fee could pose a significant barrier to eligible AI/ANs for participation.
- Assess and evaluate the enrollment process for AI/AN communities to determine best practices.

### C. Promoting Effective State Innovations and Accountability

- Conduct a State-by-State assessment of all HHS State block grants. Determine how much of those funds are used to care for AI/ANs.
- Evaluate the impact of changing HHS policies and legislative language to include AI/AN Tribes as competitors and participants in the State block grant programs.
- Establish a plan that will ensure the successful application and delivery of health care block grants to Tribes to improve the health care of AI/ANs.

- Research medical home health care service delivery for Indian children and their families who live in geographically remote, isolated communities.

## **VII. Realizing the Possibilities of the 21<sup>st</sup> Century Health Care**

### **A. Organ Donation and Transplantation**

- Evaluate the need for separate AI/AN donor and transplantation data bases.
- Evaluate the increasing incidence of End-Stage Renal Disease among AI/AN women with diabetes.
- Evaluate survival on dialysis for AI/AN populations compared to non-AI/AN populations despite low initial albumin.
- Evaluate the most cost-effective way to deliver care to AI/AN people with Chronic Kidney Disease (CKD) in high-risk populations.
- Evaluate the most cost-effective way to deliver care to AI/AN people with CKD in rural areas.

## **VIII. Ensuring Our Homeland Is Prepared to Respond to Health Emergencies**

### **A. Research on Bioterrorism and Chemical Terrorism**

- Develop and evaluate bioterrorism and chemical terrorism protocols for rural and isolated communities.
- Evaluate the need for Indian Health Service, Tribal, and Urban (I/T/U) clinical facilities to purchase decontamination devices and equipment needed in the event of a bioterrorism or chemical attack.
- Develop and assess best practices for local communities as well as I/T/U facilities to initiate protection against water or food contamination or against radiation attacks.
- Assess the integration of I/T/U programs, facilities, and Tribal communities in state-wide coordinated emergency preparedness and response activities related to bioterrorism and other public health emergencies.
- Assess the current public health infrastructure serving Tribal communities; evaluate their ability to perform surveillance capacity, epidemiological investigations, public

education, surgical capacity in clinical facilities, and laboratory diagnosis of biological and chemical agents.

- Evaluate the feasibility and effectiveness of incorporating community public health data into individual patient health records.

## **IX. Understanding Health Differences and Disparities—Closing the Gaps**

### **A. Research on Health Disparities**

- Evaluate the role of racial misclassification in AI/AN health care statistics.
- Determine the most effective prevention interventions, for example, clinical and community based, for primordial, primary, secondary, and tertiary prevention and implementation strategies.
- Evaluate increased susceptibility to non-diabetes mellitus renal injury among AI/ANs.
- Assess participation of AI/AN populations as participants in current Federal Government-sponsored research.
- Perform an analysis of the disparities in health research participation. Establish a plan to incorporate AI/AN populations into appropriate research.
- Evaluate the participation of AI/AN people to provide direction and input into HHS-sponsored research.
- Assess the role of culture in the research process and in the health service delivery system. Determine which cultural values affect an individual's perception of research.
- Evaluate the effect of community participation on research outcomes, and determine the most successful models of community participation.
- Assess the current inclusion of AI/AN health statistics in the different national health data bases.
- Assess the effectiveness of Medicare and Medicaid, SCHIP, and Tribal self-insurance programs in meeting the needs of AI/ANs, including eligibility for CMS programs, by doing the following:
  - Enroll AI/ANs in these programs, and educate and provide outreach about these programs.
  - Access using health services under these programs.

- Evaluate the effectiveness of particular interventions.
- Evaluate the quality of care that AI/AN people receive, measured by health care outcomes and quality performance measurements.
- Assess State programs including Medicaid, SCHIP, Temporary Assistance for Needy Families, the Food Stamp Program, and housing assistance designed to provide care to AI/AN populations. Identify any gaps in services.
- Assess the health status of all Urban Indians compared to that of all U.S. races.
- Evaluate Urban AI/AN access to care; assess effectiveness of Medicare and Medicaid and of SCHIP in meeting the needs of this population.
- Evaluate current and alternate models of health care delivery, including direct care, managed care contracts, Title V, and Public Law 93-638, used by American Indian communities.
- Evaluate and quantify the impact of socioeconomic determinants on health status in AI/AN populations.

#### **B. Women's Health**

- Assess the overall health of American Indian women compared to that of American Indian men; determine where the gaps are, and establish an effective plan to address the disparities.
- Assess the overall health of American Indian women compared to that of all U.S. women; determine where the gaps are, and establish an effective plan to address these disparities.
- Assess incidence of domestic violence in the AI/AN population; devise research to develop and evaluate the impact of domestic violence programs on patterns of health care use and health outcomes.
- Evaluate the use and impact of family planning programs.
- Assess and analyze rates of sexual abstinence among AI/AN women over age 18.
- Assess and analyze rates of sexual abstinence among male and female adolescents.
- Evaluate intervention models to determine the best health care practices for AI/AN women.

#### **X. Preventing Disease and Illness and Injury. The IHS will strengthen and expand research on the risk factors related to a variety of diseases and conditions that disproportionately affect AI/ANs, including:**

##### **A. Prevention Research—Disease Specific**

New and improved approaches for preventing or delaying the onset or progression of diseases and disabilities in AI/ANs will be studied as they relate to:

- Cardiovascular Disease
- Alcohol and other substance abuse
- Tobacco abuse
- Type 2 Diabetes
- CKD (Chronic Kidney Disease)
- Asthma
- Cancer
- HIV/AIDS and other Sexually Transmitted Diseases
- Hepatitis C, Chronic Liver Disease
- Metabolic Syndrome
- Hypertension
- Dyslipidemias
- SIDS (Sudden Infant Syndrome)
- Congenital anomalies

##### **B. Prevention Research—General**

Although injuries are decreasing slightly, the incidences of obesity and lack of physical activity still remain high.

- Injuries (unintentional and intentional)
- Obesity
- Immunizations and vaccines
- Physical inactivity

##### **C. Biomedical and Scientific Research**

- Evaluate the incidence of inherited illnesses, including single gene disorders, in the AI/AN population.

