



## **HHS American Indian and Alaska Native Health Research Advisory Council 2010 Recommendations to HHS**

The American Indian and Alaska Native Health Research Advisory Council (HRAC) of the Department of Health and Human Services (HHS) would like to offer recommendations to HHS on issues of concern on behalf of the Tribal communities that we represent.

### **National Institutes of Health**

HRAC recommends that the National Institutes of Health develop a single Tribal consultation policy for all 27 Institutes and Centers within the NIH in compliance with: U.S. Health and Human Services (HHS) Tribal Consultation Policy; Executive Order 13175, “Consultation and Coordination with Indian Tribal Governments;” and the November 5, 2009 Presidential Memo “Tribal Consultation For The Heads Of Executive Departments And Agencies.” Tribal consultation policies have been effectively used by other HHS Operating and Staff Divisions to increase communication between Tribal Nations and the Federal government and a policy within the National Institutes of Health could have a profound positive impact on the development of research policy to address serious medical and behavioral health issues plaguing Indian Country. The HRAC urges NIH to move forward in this effort.

In addition, more focus should be placed on putting American Indian and Alaska Native leadership throughout the National Institutes of Health to provide advice on issues of importance to Native communities and to ensure Tribes are consulted on priorities, research design and community-based research.

### **National Children's Study**

While the HRAC fully supports the intent and purpose of the National Children’s Study, the study could have more meaningfully included the participation of Tribal Nations and the AI/AN community. Tribal consultation should have been required before the study was planned and funding committed. However, HRAC believes there is still an opportunity at this stage in the National Children’s Study to implement the following recommendations:

- Health research participants defined as American Indian or Alaskan Native must present proof of enrollment from a Federally-recognized Tribe as provided in the current 'Indian Entities Recognized and Eligible to Receive Services from the

United States Bureau of Indian Affairs' or meet the BIA definition of American Indian or Alaskan Native as provided by a 'Certificate of Degree of Indian Blood.' Self-identification is not adequate.

- Oversampling of AI/AN populations should be done. The target number of 2,000 AI is not adequate.
- The study lacks diversity within Indian Country. It is unacceptable to leave out entire communities such as Alaska Natives and Plains Indians. Funding for additional cohorts in Indian Country is required to meet oversampling and diverse community needs.
- Sampling protocols promised including preservation of DNA and tissue samples must be followed and Tribes educated before, during and after as an on-going partner.
- Commitment to Tribal sovereignty must be kept.
- De-identification of data must be reviewed with Tribes.
- A data sharing agreement with Tribes must be established in partnership with the Tribe before the local study commences.
- Study centers yet to be named could target Indian Country.
- The centers in charge of the studies be instructed in a stronger way to reach out to the Native Communities to enroll native children into the study.

### **HHS Data Council**

The HRAC asks that the HHS Data Council adopt an HHS wide Research Policy for Indian Country. Recommendations include:

- HHS wide minimum standards and requirements for a Tribal data sharing agreement.
- Recognition of diverse Tribal research/data approval and on-going oversight mechanisms such as an IRB, Tribal Council, etc.
- When possible, solicitations for research funding in Indian Country or targeting Indian Country should give preference to proposals from Federally-recognized Tribes and Tribal Organizations or proposals which include Federally-recognized Tribal Nations and entities serving those communities partnerships.
- Anyone claiming Tribal identity for the purpose of research or obtaining funds must present proof of enrollment from a Federally-recognized Tribe as provided in the current 'Indian Entities Recognized and Eligible to Receive Services from the United States Bureau of Indian Affairs' or meet the BIA definition of American Indian or Alaskan Native as provided by a 'Certificate of Degree of Indian Blood.'
- Over-sampling of American Indian and Alaskan Native populations should always be considered in planning health research projects.
- Health research in Indian Country requires the explicit approval of the Tribal Nation(s) involved and requires on-going oversight by the Tribal Nation(s).
- Tribal consultation should occur before the study begins including planning of the study.
- Health research participants defined as American Indian or Alaskan Native must present proof of enrollment from a Federally-recognized Tribe as provided in the

current 'Indian Entities Recognized and Eligible to Receive Services from the United States Bureau of Indian Affairs' or meet the BIA definition of American Indian or Alaskan Native as provided by a 'Certificate of Degree of Indian Blood.'

### **Data Sharing and Collaboration**

HRAC recommends that HHS adopt HHS wide minimum standards and requirement for a Tribal data sharing agreement. Federally-recognized Tribes, as sovereign nations, must be recognized as the exclusive owner of indigenous knowledge, biogenetic resources, and intellectual property. Data collected from tribal members within the community setting must be returned to the community from which it was obtained. The Tribe is the only entity that has the authority to decide how the data will be used in the future, and thus must retain ownership and control over the data upon the study's conclusion. Without complete access to the data collected, Tribes will not have the information needed to improve health outcomes for their people.

### **Indian Health Service Scholarships**

The HRAC recommends that IHS Scholarships be limited to American Indians and Alaskan Natives with proof of enrollment from a Federally-recognized Tribe as provided in the current 'Indian Entities Recognized and Eligible to Receive Services from the United States Bureau of Indian Affairs' or meet the BIA definition of American Indian or Alaskan Native as provided by a 'Certificate of Degree of Indian Blood.' In addition, IHS Scholarship recipients should be held accountable for their payback period to either IHS or a Tribal 638 qualified Health Department.

### **General Research Recommendations**

The HRAC is acutely aware of the high and disproportionate rates of morbidity and mortality experienced by American Indians/Alaska Natives. In order to address the health concerns identified by the HRAC, research should focus on: data quality and accuracy to address under-representation of American Indians and Alaska Natives in population health data, the lack of access to health care services for AI/ANs in both rural and urban settings, lack of incorporation of traditional health care practices and traditional diets, the efficacy of health promotion/disease prevention activities, and the lack of health insurance coverage for AI/ANs. The HRAC has identified and recommends several research priorities (list is not prioritized), including:

- Quantification of Chronic Disease prevalence (e.g., cancer, heart disease, diabetes) and associated risk factors (e.g., obesity, diet, physical activity) through sustained support of prospective studies among AI/AN populations
- Chronic disease risk factor reduction
- Intentional and unintentional injuries
- Hypertension – evaluating methods to improve awareness and treatment of hypertension
- Stroke Prevalence/Prevention
- Methamphetamine and Other Drugs Prevalence/Prevention
- Evaluation of the use of emerging technology (such as telemedicine, electronic health records, health information exchange, etc.) for the provision of care

- Health Services Research (such as utilization of prenatal care; preventable hospitalizations, emergency room utilization, etc.)
- Auto Immune Disorders
- Mental Health and Suicide Prevention

**HHS American Indian and Alaska Native Health Research Advisory Council**

HHS should continue to fund and support the American Indian and Alaska Native Health Research Advisory Council (HRAC) with additional funding for two physical meetings per fiscal year. HRAC meetings provide the opportunity for face-to-face interaction between tribal leaders, federal partners, researchers and other stakeholders with the goal of healthy Native communities through health research.