

## **HHS American Indian and Alaska Native Health Research Advisory Council 2009 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**

American Indian and Alaska Native leadership must be put in place 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.

In addition, HRAC recommends that NIH develop and adopt a meaningful tribal consultation policy in compliance with the HHS Tribal Consultation Policy, adopted in January 2005 which requires that “each HHS Operating and Staff Division shall have an accountable process to ensure meaningful and timely input by Tribal officials in the development of policies that have Tribal implications.” 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.

### **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 Tribal Nations 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.'

## **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.

### **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.

### **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.

### **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.

### **Federal Collaboration on Health Disparities Research**

The HRAC recommends that the Federal Collaboration on Health Disparities Research work to recruit and involve members from the Department of Interior, Department of Justice and the U.S. Department of Agriculture. These Departments all play a crucial role in the health and well-being of American Indians and Alaska Natives and should be part of the discussions on health disparities research.