

# American Indian/Alaska Native Health Research Advisory Council (HRAC)

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## **Annual Report**

**Fiscal Year 2009**



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## Introduction

The *First Annual HRAC Report* represents a concise summary of activities accomplished by the American Indian/Alaska Native Health Research Advisory Council. The report comprises a chronological account of events that led to the Council's creation and continues through Fiscal Year 2009 activities. The report also includes recommendations the Council has made regarding relevant American Indian and Alaska Native health and research topics, as well as a list of Council members and partners.

## Background

The U.S. Department of Health and Human Services (HHS) established the Office of Minority Health (OMH) in 1986 to advise the Secretary and the Office of Public Health and Science (OPHS) on public health program activities affecting minority populations, including American Indians and Alaska Natives (AI/ANs). The OMH aims to eliminate health disparities through the development of health policies and programs to improve and protect the health of racial and ethnic minorities. This provision includes ensuring that AI/ANs have access to critical health and human services. To this end, the Federal Government utilizes the special government-to-government relationship with Indian Tribes (where the United States recognizes the sovereignty of Tribal Nations) that was established in 1787, based on Article I, Section 8 of the Constitution, and subsequently reinforced by numerous laws, treaties, and legislative acts. Namely, HHS agencies consult with individual Tribal Governments via open, continuous, meaningful consultation on issues with significant impact on Tribes.

On April 29, 1994, President Clinton issued a memorandum, *Government-to-Government Relationship with Native American Tribal Governments*, to executive departments and agencies that reinforced the special relationship between Tribal Governments and the Federal Government in regards to Tribal consultation and sovereignty. In response to the memorandum, The Domestic Policy Council (DPC) Working Group on Indian Affairs requested that each Department develop its own operational definition of "consultation" with Indian Tribes. This request, along with other DPC recommendations, ultimately led to the creation of HHS' formal Tribal Consultation Policy (TCP) on August 7, 1997—developed to strengthen the government-to-government relationship and ensure that Tribes are consulted on matters that affect them. Since the TCP initiative, Tribal consultation has continued and is considered an important vehicle to advance the future of AI/ANs. However, Tribal leaders and HHS officials realized that consultation sessions typically focused on immediate needs and funding issues and therefore were not ideal forums to discuss health research topics and other priorities of AI/ANs. In recognition of this problem, and to allow for a more formal process to discuss research topics, the American Indian/Alaska Native Health Research Advisory Council (HRAC) was formed.



**Figure 1: The Health Research Advisory Council**

## **Activity Timeline**

### **2005 Activities**

#### HRAC Formation

In November 2005, HHS solicited nominations from Tribal leaders for HRAC delegates to facilitate the Department's consultations with Tribes concerning collaborative approaches to addressing health research priorities and needs in AI/AN communities. The HRAC was charged with the following primary functions:

1. Obtaining input from Tribal leaders on health research priorities and needs for their communities.
2. Providing a forum through which HHS Operating and Staff Divisions can better communicate and coordinate AI/AN health research activities.
3. Providing a conduit for disseminating information to Tribes about research findings from studies focusing on the health of AI/AN populations.

### **2006 Activities**

#### May 2006 HRAC Meeting

The first HRAC meeting was held May 16-18, 2006. The HRAC elected Cara Cowan Watts (Oklahoma Area) and Cecelia Fire Thunder (Aberdeen Area) as Co-Chairs of the Council. During the fall of 2006, the HRAC held several conference calls to plan and organize its activities. Agenda topics included reviewing other HHS advisory models, discussing solicitation of research priorities, and planning future meetings.

#### November 2006 HRAC Meeting

The second HRAC meeting was held November 28-30, 2006, in Albuquerque, New Mexico. Tribal representatives attended from the following areas and organizations: Alaska, Albuquerque, Bemidji, Nashville, Navajo, Oklahoma, Portland, National Congress of American Indians (NCAI), and the National Indian Health Board (NIHB). They were accompanied by Federal partners representing the following agencies: Agency for Healthcare Research and Quality (AHRQ), Assistant Secretary for Planning and Evaluation (ASPE), Centers for Disease

Control and Prevention (CDC), Indian Health Service (IHS), National Institutes of Health (NIH), Office of Intergovernmental Affairs (IGA), and the Office of Minority Health (OMH).

At the New Mexico meeting, the HRAC reached a collective agreement to focus on three objectives:

1. Establish the HRAC Council Charter (outlining the purpose, background and structure of the council; and processes for voting, membership, and leadership).
2. Develop a Discussion Guide (a survey to inquire about health research priorities in Indian Country).
3. Set future meeting dates.

## **2007 Activities**

### September 2007 Federal Partners Meeting

In September 2007, the Federal partners met and discussed the HRAC Charter, Council membership, compliance with the Federal Advisory Committee Act (FACA), and the Annual HRAC Meeting.

### December 2007 HRAC Meeting

The *Annual HRAC Meeting* was held December 3, 2007, in Washington D.C. A quorum was not met but the following areas and organizations were represented: Albuquerque, Bemidji, Nashville, Oklahoma, Phoenix, Tucson, NIHB, and Tribal Self-Governance Advisory Committee. The following Federal agencies were also represented: AHRQ, ASPE, CDC, IGA, IHS, NIH, and OMH. Meeting participants discussed the HRAC Charter and the Discussion Guide at length. Following the meeting, the revised Charter, Discussion Guide and updated membership list were disseminated to the HRAC and Federal partners.

## **2008 Activities**

### February 2008 Co-Chair Vote

In February 2008, via an email vote, Cara Cowan Watts (Oklahoma Area) retained her seat as an HRAC Co-Chair. H. Sally Smith (NIHB) was newly elected to serve with Ms. Cowan Watts.

### HRAC Charter Ratification (June 2008)

The HRAC ratified its Charter in June 2008. The Charter outlines the infrastructure and purpose of the Council, noting that the HRAC is comprised of elected Tribal officials; one delegate and one alternate from each of the 12 IHS areas; and four Washington-based Tribal organization participants: Direct Service Tribes Advisory Committee, NCAI, NIHB, and Tribal Self-Governance Advisory Committee. Federal partners are also involved in Council activities and provide input, support, and linkages with HHS' Operating and Staff Divisions. The Federal partners included: AHRQ, ASPE, CDC, IGA, IHS, NIH, and OMH.

### 2008 HHS National Tribal Budget and Policy Consultation Session

The HRAC developed testimony and Co-Chair Cara Cowan Watts presented at the *2008 HHS National Tribal Budget and Policy Consultation Session* in March 2008. Ms. Cowan Watts cited various health concerns identified by the HRAC, including diabetes, cancer, obesity,

heart disease and behavioral health. As part of its testimony, the HRAC also recommended research activities to address the lack of access to care for AI/ANs; the lack of incorporation of traditional care and traditional diets; and the effectiveness of health promotion/disease prevention activities.

The HRAC stressed that all research activities should be evidence-based and, to the extent possible, community-based (participatory). Additionally, the Council felt that Tribal Governments were the rightful owners of their respective data and therefore should be consulted with prior to the data being shared with any entity.

The following recommendations were offered by the HRAC to assist in closing the gap in health research across Indian Country:

- HHS should become a leader on advancing the research agenda of AI/AN health and support innovative research that will serve to improve the health of AI/AN people in the United States.
- In collaboration with AI/AN Tribes, HHS should foster integration and leadership for health research; develop partnerships; create knowledge through scientifically sound and community/tribally supported health research; and exchange and transfer knowledge to those best positioned to apply the results of research.
- HHS should increase its knowledge and understanding of AI/AN health research issues including strengths, gaps, and opportunities so that more effective health services and products and a more strengthened AI/AN health care system can be realized.
- HHS should develop a specific line item for AI/AN health promotion/disease prevention programming and evaluation at the CDC.

### 2008 Annual Meeting

The *2008 Annual HRAC Meeting* was held August 25, 2008 in Portland, Oregon in conjunction with the *National Native Health Research Conference*. The areas and organizations that participated were: Alaska, Albuquerque, Bemidji, California, Oklahoma, Phoenix, Portland, Tucson, Direct Services Tribes Advisory Committee, NCAI, and NIHB. The Federal partners in attendance included: CDC, NIH and OMH. Other attendees included the Alaska Native Health Consortium, Inter Tribal Council of Arizona, National Cancer Institute, and the Northwest Portland Area Indian Health Board.

Among the agenda topics included discussions on data sharing agreements; transition plans; resolutions with the NCAI and NIHB in support of the HRAC; and the Discussion Guide. There was agreement that the Discussion Guide needed format and content revisions. Additionally, an OMB-compliant dissemination strategy for the Guide was also discussed. A list of action items was developed as a post-meeting deliverable to ensure that the HRAC followed-up on its intended activities.

### 2008 Outreach Activities

#### *August 2008 Town Hall Meeting*

The HRAC held a Town Hall meeting on August 26, 2008, as part of *the National Native Health Research Conference* in Portland, Oregon. The Town Hall afforded conference participants an opportunity to learn about the HRAC, present questions and/or concerns, and to provide and receive feedback on issues associated with health disparities impacting Indian Country.

Participants at the Town Hall expressed an overwhelming concern about various issues related to Federal research grants. Specifically, they indicated a need for more planning grants; a lack of Native grant reviewers (and the repeated use of reviewers with no experience with/understanding of Native communities); a need for a longer response time to apply for funds (to receive community input and to consult with Tribal elders); and the need for coordinated efforts to fund overall health issues and a broader range of research grants. Feedback from participants prompted several Federal representatives to collect business cards from individuals that could potentially serve as grant reviewers. Participants also suggested that diversity training was needed among agencies, academic institutions, and researchers.

### *September 2008 Town Hall Meeting*

The HRAC held a second Town Hall meeting at the *National Indian Health Board Consumer Conference* on September 23, 2008. This Town Hall provided another opportunity for the HRAC to share information about its purpose, goals, and activities. The Discussion Guide was a main tenet of dialogue and provoked considerable interest among the conference participants. HRAC representatives used the Town Hall forum to inform attendees about the purpose and importance of the Discussion Guide in hopes of soliciting their participation once the Guide was distributed. The Town Hall attendees presented realistic challenges to health research, including the coordination, collection and dissemination of data; lack of trust; and data ownership. In order to build trust and credibility, they suggested that more AI/AN researchers were needed to address the fears Native communities feel from previous research experiences. They also recommended that research guidelines and processes be established to protect the intellectual property rights and indigenous knowledge of AI/AN communities.

Other topics broached during the Town Hall included mental health; hepatitis C; vocational rehabilitation; elder care (Alzheimer's, dementia, depression, abuse and neglect); health care in remote villages; breast cancer and mammography; healthy foods; injuries; emergency transportation; and health issues related to youth including obesity, diabetes, drug abuse, poverty, domestic violence, and suicide.

## **2009 Activities**

### Teleconference on the National Children's Study (January 2009)

On January 26, 2009, the HRAC held its quarterly teleconference meeting with Tribal delegates and discussed the National Children's Study<sup>1</sup> (NCS) coordinated by a consortium of Federal partners: HHS (including the *Eunice Kennedy Shriver* Institute of Child Health and Human Development, National Institute of Environmental Health Sciences of the National Institutes of Health, and CDC); and the Environmental Protection Agency (EPA). The study will consist of more than 100,000 children across the United States—following them from before birth until age 21; and it will examine important health issues with the goal of improving the health and well-being of children for generations to come. The HRAC expressed questions and concerns regarding the \$22 million dollar study, among which included the following items:

- The NCS does not appear to over sample for the AI/AN population.
- Since a cohort was not done, Indian Country knows very little about the study, which is expected to be of national importance.

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<sup>1</sup> <https://nationalchildrensstudy.gov>

- HRAC is concerned about the self-identification method for the 2,000 American Indian children and the small number of participants.
- The study does not appear to sample across diverse groups of Tribal communities.
- There was no sampling in Alaska, where over 250 Tribes reside and the greatest environmental variables exist.
- HRAC is concerned about how the data will be used that is taken in Indian Country.

As a result of its concerns, the HRAC requested a briefing on the NCS (See the April 2009 meeting highlights).

### Discussion Guide

The Discussion Guide was developed and implemented to ascertain health research priorities in Indian Country. The survey questions were constructed to thoroughly examine the current health care delivery systems and current research Tribes may be conducting themselves. HRAC members disseminated the Discussion Guide to the Tribal leaders in their areas.

Responses to the Discussion Guide were obtained from the following areas: Alaska (61); Albuquerque (2); Bemidji (1); California (1); Oklahoma (7); and Portland (14), totaling 86 survey responses. Of the 86 respondents, 74 (86%) were engaged in health research. Respondents reported that their top health concerns were cancer; diabetes; obesity; cardiovascular disease; and behavioral health issues including substance abuse, tobacco use, suicide, and domestic violence. The respondents cited lack of funding; recruitment/retention of highly qualified health care professionals/providers; access to care; health information technology and systems; and coordination of care as their top five health delivery system concerns.

Results from the Discussion Guide provided valuable information from the Tribes' perspective regarding health concerns, priorities, and the way in which research should be conducted in Native communities. Complete survey results are posted on the HRAC website.

### 2009 Meetings

The first *2009 HRAC Meeting* was held on April 28, 2009, in conjunction with the *11<sup>th</sup> Annual HHS Tribal Budget Consultation* meeting at the Hubert Humphrey Building in Washington, D.C. The second meeting was held on November 12, 2009 in Tulsa, Oklahoma.

HRAC notes on the presentations are posted on the HRAC website under *HRAC Face-to-Face Meeting Notes* dated April 28, 2009 and November 12, 2009.

Highlights from the April *2009 HRAC Meeting* included:

- The HRAC received a briefing from Dr. Peter C. Scheidt, Director of the National Children's Study, and Dr. Jennifer Park, Senior Scientist and Study Center Project Officer for the National Children's Study, *Eunice Kennedy Shriver* Institute of Child Health and Human Development. Dr. Scheidt and Dr. Park provided background information on the study and discussed its overall purpose. They also addressed questions/concerns raised by the HRAC, noting that the NCS would not oversample for any subgroup and that the use of stratified sampling was the reason that Alaska was not sampled.

- A presentation by Dr. Robert William Blum, Johns Hopkins University, Bloomberg School of Public Health, entitled “An American Indian-Alaska Native Youth Health Survey: Preliminary Considerations.” The survey will establish baseline data and the initial collection of data will serve as a basis for comparisons with subsequent data collection efforts. Dr. Blum indicated that a national advisory board would be established in the summer of 2009 for the unfunded study.
- A presentation by Dr. Sarah Hicks, NCAI, on the role of NCAI’s Policy Research Center (PRC) as well as its research agenda and current research projects. Puneet Sahota, Research Fellow at NCAI PRC, provided an overview of community research regulation tools and presented questions for consideration when embarking upon Tribal research regulations.
- An overview by Alison Barlow and Olivia Sloan, Johns Hopkins Center for American Indian Health (CAIH), on CAIH and its program offerings.
- An overview by Dr. Jamila Rashid and Suzanne Heurtin-Roberts on the Federal Collaboration on Health Disparities Research (FCHDR).
- A briefing regarding the Federal Coordinating Council (FCC) for Comparative Effectiveness Research (CER), created to coordinate CER and related health services research conducted or supported by Federal Departments and agencies, from Dr. Garth Graham.
- Cara Cowan Watts (Oklahoma Area) retained her seat as an HRAC Co-Chair. Kathy Hughes (Bemidji Area) was newly elected to serve with Ms. Cowan Watts.

HRAC’s second meeting of 2009 was held on November 12, 2009 in Tulsa, Oklahoma.

Highlights from the November 2009 HRAC Meeting included:

- An overview of the Cherokee Nation's current health research activities and partnerships presented by: Melissa Gower, Group Leader of Health Services and Government Relations for the Cherokee Nation; Dr. Gloria Grim, Medical Director, Cherokee Nation Health Services; and Sohail Khan, Director of Health Research and Co-Chair Cherokee Nation Institutional Review Board (IRB).
- Representatives from Tribal Epidemiology Centers reported on EpiCenter activities and data issues.
- An update by Dr. Donald Warne (Aberdeen Area) on the National Children’s Study and the status of the proposed Great Plains/Alaska Native adjunct study.
- An overview from Dr. Sarah Hicks regarding NCAI’s Introduction to Research Training for Tribal leaders and their Human Resources Research Agenda.
- An overview of the National Institute on Drug Abuse’s (NIDA) American Indian/Alaska Native Coordinating Committee presented by Dr. Kathy Etz.
- A presentation from Dr. Ralph Bryan, Senior CDC Tribal Liaison for Science and Public Health, about current projects, health concerns, and new CDC structure.
- An overview of AHRQ's current research activities and funding by Wendy Perry, Senior Program Analyst.
- An update by Dr. Garth Graham, Deputy Assistant Secretary for Health at HHS’ Office of Minority Health, on FCC CER.

## 2009 HHS National Tribal Budget and Policy Consultation Session

The HRAC developed testimony and Co-Chairs Cara Cowan Watts and H. Sally Smith presented at the *2009 HHS National Tribal Budget and Policy Consultation Session* in April 2009. The Co-Chairs offered recommendations regarding research priorities and the health disparities plaguing Indian Country. They informed HHS officials about the high and disproportionate rates of morbidity and mortality experienced among AI/ANs. The Co-Chairs placed special emphasis on the particularly high rate of suicide, recommending immediate steps to address the suicide epidemic in AI/AN communities. On behalf of the HRAC, the Co-Chairs requested that HHS Operating and Staff Divisions make the following areas of research a top priority: 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; stroke prevalence/prevention; methamphetamine prevalence/prevention; suicide prevention; autoimmune disorders; evaluation of the use of emerging technology; and health services research (such as utilization of prenatal care, preventable hospitalizations, and emergency room utilization).

To address the concerns, they recommended that research focus on data quality and accuracy to address under-representation of American Indians 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. Additionally, they suggested, efforts should be made to support research aims that attempt to understand exposure to risk and vulnerability over the lifespan to American Indian health due to social determinants such as social exclusion, marginalization and inequality. And research should address the complex interactions between health determinants and long term exposure to risks unique to American Indians as an indigenous population, they argued.

The Co-Chairs echoed the HRAC's sentiment from the previous year's meeting, that all research conducted should be evidence-based and to the extent possible, community-based (participatory); and that Tribal Governments were the rightful owners of their respective data and therefore all efforts should be undertaken to ensure Tribal Governments are consulted before such data is shared with any entity.

The Co-Chairs closed their testimony by citing current barriers to undertaking research activities in Indian Country and possible remedies:

- The elimination of impediments for collaboration, including information sharing, between Tribal EpiCenters and HHS.
- Increasing cultural sensitivity among researchers.
- Increasing the number of AI/AN researchers, possibly through additional funding for the IHS Health Professionals Scholarship Program and Loan Repayment Program (specifically for research positions).
- Improving the accuracy of data related to AI/ANs and the interoperability of data among HHS Operating and Staff Divisions.
- Increasing the amount of comparative data—when research includes a comparison of racial and ethnic data that does not include American Indians and Alaska Natives, the

HRAC recommended that HHS make oversampling a priority to provide this data for comparison.

- Improving infrastructure among AI/AN Tribal Governments to increase Tribal capacity to carry out research and/or implement recommendations identified through research.
- Increasing the amount of community-driven research.

## 2009 Outreach Activities

### *2009 Outreach Meetings*

Co-Chair, Cara Cowan Watts and Leo Nolan (IHS) presented at the *Third National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health* on February 27, 2009. Their workshop, *Addressing American Indian and Alaska Native Health Disparities into the 21<sup>st</sup> Century*, focused on health and social concerns that are prevalent throughout Indian Country. Wilbur Woodis, OMH, served as moderator.

Governor Norman Cooyate (Albuquerque Area) represented HRAC at the *IHS/Health Canada Maternal and Child Health Research Meeting* in Albuquerque, New Mexico in conjunction with the *International Conference on Indigenous Women's Health and International Meeting on Indigenous Child Health*. He also presented at the *Indian Health Summit* in Denver, Colorado.

Co-Chair, Cara Cowan Watts attended the *American Indian/Alaska Native Health Policy Conference* in Albuquerque, NM on October 22-23, 2009. Ms. Cowan Watts presented at the breakout session for Tribal Health Codes and Research Policies.

### *HRAC Website*

The HRAC website, <http://www.minorityhealth.hhs.gov/hrac>, was launched in April 2009. The HRAC Charter, membership list, meeting agendas and minutes, as well as other documents relevant to the HRAC and its activities are posted on the site. The website serves as a central repository of research priorities, activities, and resources for the HRAC and members of Native communities.

## **Recommendations**

### **Comparative Effectiveness Research Recommendations**

In response to the Federal Coordinating Council for Comparative Effectiveness Research's request for input regarding defining CER, the HRAC submitted the following recommendations on June 15, 2009:

- Allow time for the Tribal consultation process in order for Tribes to provide their input into the FCC CER plan and implementation.
- Establish separate guidelines and measures for CAM and AI/AN traditional healing practices.
- CER should concentrate in areas of health promotion, disease prevention, and community-based interventions.
- Clinical effectiveness should be the focus of research and not cost effectiveness.
- CER studies should be adequately powered and not sacrifice statistical significance. (It has been noted that in CER minority and disability groups have not been given a broad enough population sample. *Ref: Debate Heats Up Over CER*, Cancer Policy Monitor, 4/2009).

- The Government is planning on making major investments in CER in order to try to improve health care and reduce costs. Any research opportunities that are open to either state or local health departments or to research universities should also be open to Tribal organizations. Tribal organizations hold a special place in the health research field and the health care delivery system for AI/AN people. In many cases, Tribal organizations—alone or in partnership with other research institutions—will be best suited to conduct CER among AI/AN people. Without their participation, it is likely that the results of CER will not accurately reflect the AI/AN population.
- The American Recovery and Reinvestment Act (ARRA) of 2009 sets aside money for research that compares the clinical outcomes, effectiveness, and appropriateness of items, services, and procedures that are used to prevent, diagnose, and treat diseases, disorders, and other health conditions. It is important for the AI/AN community that the phrase "items, services, and procedures" be broadly interpreted to include traditional healing and other culturally appropriate complementary and alternative treatments.
- Additional services aimed at primary prevention such as programs to improve access to healthy food or otherwise promote healthy lifestyles.
- The ARRA sets aside money to encourage the development and use of clinical registries, clinical data networks, and other forms of electronic health data that can be used to generate or obtain outcomes. This is an area where the IHS and Tribal health facilities are well suited to participate. It is important that any research opportunities open to State Governments or universities also be open to Tribal organizations. Beyond that, it is important for the FCC CER to remember that there is a wealth of current and historical data available on both treatments and outcomes for IHS beneficiaries. The Tribal Epidemiology Centers as well as Tribal researchers are well suited to use this data for CER.
- Inclusion of Native cultural practices/traditional healing in CER monies and health outcomes.
- CER monies/studies should include oversampling on AI/AN populations.
- The IHS should be provided stimulus monies to provide research grants.
- The IHS should be at the table as a member of the FCC CER.
- Tribal consultation should be required as part of the HHS Tribal Consultation Policy and the government-to-government relationship that exists.
- AI/AN's identities should be defined by enrolled Federally-recognized Tribal citizens and not by self-identification; otherwise the data will likely be skewed.
- The IHS operates a mixed delivery system serving 1.3 million AI/ANs that reflects Tribal sovereign choices as to the extent of Tribal participation in the management of these resources under the authorities of the Indian Self-Determination Act (PL 93-638 seq. et. al.). The IHS delivery system is additionally distinguished by a diversity of levels of system vertical integration independent of levels of Tribal participation. It is therefore recommended that CER include analysis of the comparative effectiveness of the various permutations of IHS system integration and levels of Tribal participation in system governance

### **Joint Commission Recommendations**

The HRAC responded to a request for feedback from the Joint Commission on cultural competence requirements for hospital accreditation. Specifically, the Joint Commission sought input on a set of proposed accreditation requirements designed to help hospitals improve patient safety and quality of care. The proposal targeted effective communication, cultural

competence, and patient-centered care, acknowledging that poor communication due to language or cultural barriers leads to “poorer health outcomes.”

As stated on the Joint Commissions website, the mission of this independent, non-profit organization is “to continuously improve health care for the public, in collaboration with other stakeholders, by evaluating health care organizations and inspiring them to excel in providing safe and effective care of the highest quality and value.”

The HRAC sent recommendations asking for representation from AI/AN communities; and it recommended that additional members be added to the Expert Advisory Panel to include a Tribal representative, as well as a representative from IHS. Other recommendations included: training and education money should be spent or set aside for hiring local Native community members as they understand cultural issues and have a commitment to the community; race/ethnicity for AI/ANs should be identified based on enrollment in a Federally-recognized Tribe as published by the U.S. Department of Interior’s Bureau of Indian Affairs; and links to the IHS and NIHB might provide additional resources for those working with AI/ANs.

### **HHS Recommendations to the Secretary**

HRAC sent a letter to HHS Secretary Kathleen Sebelius on July 13, 2009 to offer recommendations on issues of concern on behalf of the Tribal communities that HRAC represents. The recommendations that were submitted are provided below:

- **National Institutes of Health**

AI/AN leadership must be put in place throughout NIH 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, 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 NIH 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.”
- Oversampling of AI/AN 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 AIs 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 AI/ANs 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 AI/AN 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 (FCHDR) work to recruit and involve members from the Department of Interior (DOI), Department of Justice (DOJ), and the U.S. Department of Agriculture (USDA). These Departments all play a crucial role in the health and well-being of AI/ANs and should be part of the discussions on health disparities research.

## **Attachment A: Member and Partner List**

### **HRAC CO-CHAIRS**

Cara Cowan Watts  
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### **MEMBERS**

#### **Tribal Officials**

##### ***Aberdeen Area***

**Delegate:** Adrian Pushetonequa  
Chairman, Sac and Fox Tribe of the Mississippi in Iowa, Meskwaki Nation  
**Alternate:** Donald Warne  
Executive Director, Aberdeen Area Tribal Chairmen's Health Board

##### ***Alaska Area***

**Delegate:** Emily Hughes  
Chairperson, Norton Sound Health Corporation  
**Alternate:** Tim Gilbert  
Senior Director, Division of Community Health Services, Alaska Native Tribal Health Consortium

##### ***Albuquerque Area***

**Delegate:** Norman Coeeyate  
Governor, Pueblo of Zuni  
**Alternate:** Francine Gachupin  
EpiCenter Director, Albuquerque Area Indian Health Board

##### ***Bemidji Area***

**Delegate:** Kathy Hughes  
Vice Chairwoman, Oneida Nation of Wisconsin  
**Alternate:** Terrie Terrio  
Tribal Treasurer, Stockbridge-Munsee Band of Mohican Indians

***Billings Area***

**Delegate:** Tracy (“Ching”) King

Councilman/At-Large Assiniboine Representative, Assiniboine and Gros Ventre Tribes Fort Belknap Indian Community Council

**Alternate:** Bill Whitehead

Council Member, Fort Peck Tribal Executive Board

***California Area***

**Delegate:** Reno Franklin

Chairman, California Rural Indian Health Board

**Alternate:** James Crouch

Executive Director, California Rural Indian Health Board

***Nashville Area***

**Delegate:** Elizabeth Neptune

Tribal Council Member, Passamaquoddy Indian Township

**Alternate:** Tihtiyas (“Dee”) Sabattus

Health Policy Analyst, United South and Eastern Tribes, Inc.

***Navajo Area***

**Delegate:** Madan Poudel

Health Services Administrator, Navajo Nation

**Alternate:** Roselyn Begay

Program Evaluation Manager, Navajo Nation

***Oklahoma Area***

**Delegate:** Cara Cowan Watts

Tribal Council Representative, Cherokee Nation

**Alternate:** Seeking New Alternate

***Phoenix Area***

**Delegate:** Diane Enos

President, Salt River Pima-Maricopa Indian Community

**Alternate:** Violet Mitchell-Enos

Health and Human Services Director, Salt River Pima-Maricopa Indian Community

***Portland Area***

**Delegate:** Stephen Kutz

Councilman, Cowlitz Indian Tribe

**Alternate:** Stella Washines

Council Member, Yakama Nation

***Tucson Area***

**Delegate:** Chester Antone

Councilman, Tohono O'odham Nation

**Alternate:** Michelle Ortega  
Councilwoman, Tohono O'odham Nation

## **Tribal Organizations**

### ***Direct Services Tribes Advisory Committee***

**Delegate:** Darrell Flyingman  
Governor, Cheyenne and Arapaho Tribes

**Alternate:** Andrew Joseph, Jr.  
Chairman, Human Services Committee, Confederated Tribes of the Colville Reservation

### ***National Congress of American Indians***

**Delegate:** Jefferson Keel  
President of NCAI and Lt. Governor of Chickasaw Nation

**Alternate:** Sarah Hicks  
Director, Policy Research Center, NCAI

### ***National Indian Health Board***

**Delegate:** H. Sally Smith  
Alaska Representative of NIHB and Chair of the Board of Directors Bristol Bay Area Health Corporation

**Alternate:** Stacey Bohlen  
Executive Director, NIHB

### ***Tribal Self-Governance Advisory Committee***

**Delegate:** Lloyd Hanks  
Council Member, Duck Valley Shoshone Paiute

**Alternate:** Mickey Percy  
Executive Director of Health Services, Choctaw Nation of Oklahoma

## **FEDERAL PARTNERS**

### ***Agency for Healthcare Research and Quality***

**Delegate:** Wendy Perry  
Senior Program Analyst

### ***Assistant Secretary for Planning and Evaluation***

**Delegate:** Sue Clain  
Indian Health Desk Officer

**Alternate:** Peggy Halpern  
Program Analyst

### ***Centers for Disease Control and Prevention***

**Delegate:** Ralph Bryan  
Senior Tribal Liaison for Science and Public Health

**Alternate:** Pelagie ("Mike") Snesrud  
Senior Tribal Liaison for Policy and Evaluation

***Indian Health Service***

**Delegate:** Leo Nolan  
Program Analyst for External Affairs  
**Alternate:** Alan Trachtenberg  
Research Director

***Intergovernmental Affairs***

**Delegate:** Stacey Ecoffey  
Principal Advisor for Tribal Affairs

***National Institutes of Health***

**Delegate:** Ileana C. Herrell  
Director, Division of Scientific Strategic Planning & Policy Analysis

***The Office of Minority Health***

**Delegate:** Garth Graham  
Deputy Assistant Secretary for Health  
**Alternate:** Wilbur Woodis  
Special Assistant on Native American Affairs