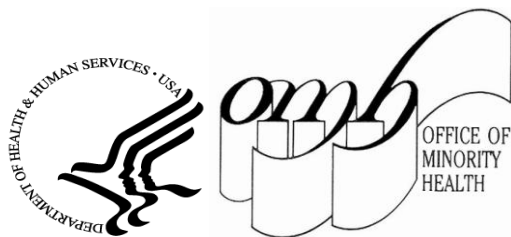


**The American Indian and Alaska Native  
Health Research Advisory Council (HRAC)**

*Third Annual Report*

*Fiscal Year 2011*



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## INTRODUCTION

The *Third Annual HRAC Report* represents a chronological summary of events accomplished by the American Indian/Alaska Native (AI/AN) Health Research Advisory Council (HRAC). The report also includes recommendations that were submitted to the U.S. Department of Health and Human Services (HHS) regarding pertinent AI/AN health and research topics, as well as a list of Council members and partners.

## BACKGROUND

The Office of Minority Health (OMH) was established by the HHS in 1986 to advise the Secretary on public health programs affecting ethnic and minority populations, including the AI/AN population. The OMH assists in the Federal delivery of health services and funding of programs to maintain and improve the health of racial and ethnic minorities. This includes ensuring that AI/ANs have access to critical health and human services as promised through numerous laws, treaties, and legislative acts dating as far back as 1787. The United States Government utilizes the special government-to-government relationship with Indian Tribes that recognizes and respects the sovereignty of Tribal Nations. Through numerous Presidential Memorandums and Executive Orders, HHS agencies consult with individual Tribal Governments via open, continuous, meaningful consultation on issues with significant impact on Tribal communities.

## PRESIDENTIAL MEMORANDUMS AND EXECUTIVE ORDERS

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.

On November 6, 2000, President Clinton issued a revised Executive Order (13175) that reinforced his Administration's commitment to Tribal sovereignty and the unique government-to-government relationship that exists between the United States Government and Tribal Governments. Executive Order 13175 directs agencies to establish regular and meaningful consultation and collaboration between Tribal Nations and the Federal Government. It directs all Federal agencies to coordinate and consult with Indian Tribal Governments whose interest might be directly and substantially affected by activities on federally administered lands.

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.

## **FORMATION OF THE HRAC**

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 established to fulfill three 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 on the health of AI/AN populations.

During 2006, the HRAC held its first meeting and elected two Co-Chairs to serve as its leaders and facilitators for outreach events and general activities of the Council. The Council held several conference calls to plan and organize its activities such as reviewing other HHS advisory models, discussing solicitation of research priorities, and planning for future meetings.

During a second meeting that was held in Albuquerque, New Mexico, 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.

## **HRAC HISTORY**

The HRAC has made great strides in developing the Council and making recommendations regarding health research to improve the lives of AI/ANs throughout Indian Country. The HRAC has attended numerous meetings and conferences; held bi-annual meetings to discuss the progress of the Council; collaborated with the 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), Intergovernmental and External Affairs (IEA), National Institutes of Health (NIH), Office of Minority Health, EpiCenter staff, and outside researchers and scientists to further its knowledge base regarding health research. The HRAC held quarterly conference calls, attended outreach events, and met with top Federal officials to offer recommendations and help them understand Native American culture and the problems plaguing Indian Country today.

The HRAC has attended and presented testimony at the HHS Annual National Tribal Budget and Policy Consultation Session. For the past few years, Councilwoman Cara Cowan Watts has presented testimony on behalf of the HRAC and the Native communities HRAC represents. During the testimony provided by Councilwoman Watts, she discussed the National Children's Study; and made general research recommendations such as quantification of chronic disease prevalence, chronic disease risk reduction, and methamphetamine prevalence and prevention.

The HRAC has participated in outreach events to make Tribes aware of the Council, its work, and how Tribes and Tribal communities can provide feedback to HRAC regarding AI/AN health research. The HRAC attended events such as the National Indian Health Board Public Health Summit and the Annual Consumer Conference, Annual Native Health Research Conference, Third National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health, IHS/Health Canada Maternal and Child Health Research Meeting, and the AI/AN Health Policy Conference. These conferences provided an opportunity to collaborate and share knowledge that is of paramount importance to the advancement of health care research in Indian Country.

The HRAC developed a survey, The Discussion Guide, 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 respective areas. 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 to the HRAC from the Tribes' perspective regarding health concerns, priorities, and the way in which research should be conducted. The HRAC uses the Discussion Guide results to assist in developing key research areas and priorities.

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.

On conference calls and during meetings held by the HRAC, The National Children's Study<sup>1</sup> (NCS) was a topic of continued interest and concern. The NCS is a study coordinated by a consortium of Federal agencies consisting of more than 100,000 children across the United States—tracking them from before birth until age 21. It will examine important health issues with the overall goal of improving the health and well-being of children for generations to come. When the HRAC learned about this study, many questions and concerns surfaced. The HRAC held one quarterly teleconference meeting with Tribal members and Federal Partners with discussions centering on the NCS. The HRAC expressed questions and concerns regarding the \$22 million dollar study, particularly the sampling of only 2000 American Indian (AI) children and the State of Alaska not being sampled in the study. While 2000 AI children is a reasonable representation of the total sampling frame and the selected counties do offer valuable information regarding the AI/AN population, it does not sufficiently depict the true health picture of AI/AN communities. The HRAC also identified the need to include Alaska Native communities in the study as there are over 250 Tribes residing and the greatest environmental variables exist. The HRAC continues to examine this study and the benefits of oversampling for the AI/AN population as well as the feasibility of a proposed Great Plains and Alaska Native Children's Study.

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

# **FY2011 ACTIVITIES**

## **RESEARCH ROUNDTABLE**

The first HRAC Research Roundtable was held October 21, 2010 on the National Institutes of Health campus. The purpose of this meeting was to bring together four HRAC members, four Native researchers, four EpiCenter representatives, and Federal Partners to discuss health research priorities for AI/AN communities. The HRAC presented on what has been identified as priorities from discussion guide results, testimony to HHS, and recommendations to HHS and requested feedback from the Native researchers and EpiCenter representatives on what specific areas need to be researched within the broad categories like cancer, diabetes, etc. The HRAC plans on taking this information back to the full Council for consideration and prioritization.

The meeting started off with an invocation by Steve Kutz. The Co-Chair, Cara Cowan Watts, and OMH Special Assistant on Native American Affairs, Wilbur Woodis, began the meeting with opening remarks and introductions. The first item on the agenda that was discussed was health disparities not identified by HRAC that should be considered and recommended to HHS.

Below is a list of additional research priorities that were suggested:

- Pain management for advanced stage cancer patients
- Breast cancer
- Chronic health issues
- Traditional pain management methods
- Depression (including post-partum depression and anger/rage accompanying depression in women)
- Psychiatric manifestations of historical trauma syndrome
- Nutrition and traditional foods
- Environmental impacts (i.e. how does a person's environment affect drug and alcohol abuse)
- Preventative care (what is effective)
- Spirituality as it relates to health and well-being
- Disabilities
- Suicide and substance abuse prevention (understand underlying causes; look at parenting patterns and skills, culture as a protective factor)
- Human trafficking

In addition, there was much discussion around the accuracy of research data and finding a good mechanism to collect data. Another area of discussion was on Clinical and Translational Science Awards (CTSAs) and the need for quality and accurate data.

## **MEETINGS (TELECONFERENCE AND FACE-TO-FACE)**

### **October 7, 2010**

The HRAC held its first face-to-face meeting for fiscal year 2011 on October 7, 2010, in Albuquerque, New Mexico. The HRAC covered topics such as the Native Health History Database (NHHD), the Government Performance and Results Act, EpiCenters, National Plan for Action and the HHS AI/AN

Blueprint for Tribal Consultation, HHS Tribal Federal Work Group, and the HRAC Charter. In addition, there were updates from the National Institutes of Health, Centers for Disease Control and Prevention, Intergovernmental Affairs Office, Indian Health Service, and the Office of Minority Health.

The HRAC discussed the University of New Mexico's two Native Health Databases. There is the Native Health History Database consisting of approximately 3300 records and the Native Health Research Database (NHRD) consisting of approximately 5700 records. The purpose of the databases is to create a high quality, single source of information regarding services and resources focused on historical American Indian and Alaska Native health/medical issues. The databases are a "one stop shop for Native American health information." Federal agencies, EpiCenters, States and other associations are encouraged to add their research to the database. The Native Health Database can be found at <https://hscssl.unm.edu/nhd>.

Francis Frazier and Diane Louis Leach, with the Indian Health Service, provided a presentation on the Government Performance and Results Act (GPRA) of 1993 and provided an overview of how IHS approaches GPRA. They also provided information on the Program Assessment Rating Tool (PART) which is another measurement tool. The Tribal PART reports on a specific set of clinical measures and these measures are included in the IHS budget submission. Mr. Frazier concluded that it is a group effort to really improve performance not just for GPRA measures but for performance in general. This would also include providers, administrative staff, data entry, and Information Technology staff as well. HRAC members had questions and were concerned about the number of visits required before evaluated as well as how performance was tied to the IHS budget. There was also discussion as to how GPRA targets are set, including Tribal input, and how else GPRA data is used in terms of health data for Indian Country.

Ileana Herrell, with the National Institutes of Health, reported that The National Center on Minority Health and Health Disparities has been elevated to a full fledged Institute. The NIH Director, Dr. Francis Collins, has designated Dr. John Ruffin as the NIH Representative to the Intradepartmental Council on Native American Affairs (ICNAA). Dr. Herrell advised the HRAC to view HRAC's Second Annual Health Research Report for additional activities and programs of the NIH.

Stacey Ecoffey, with the Intergovernmental Affairs (IGA) Office, provided updates from IGA Headquarters. IGA was in the process of sending out a notification to Tribal leaders announcing the Secretary's Tribal Advisory Committee. In addition, they were seeking nominations for 17 representatives, one from each area of IHS and five at-large members. They also have been in the process of revising the Tribal Consultation Policy. The Tribal Federal Work Group met several times over the summer and provided recommendations to the Secretary.

Leo Nolan, with Indian Health Service, noted that the Indian Health Service does not have a research line item. Mr. Nolan also commented on the number of HHS advisory committees that are in existence that do not have Tribal representation on the committees. Mr. Nolan said IHS sends out "requests to serve" but does not get a lot of responses back from Tribal leaders. He encouraged the HRAC to disseminate to Tribes these opportunities to serve on the committees. He also asked that the HRAC encourage AI/ANs to apply for positions within HHS. Mr. Nolan also briefly discussed the Friends of Indian Health program that advocates for IHS Tribal and Urban Health Programs.

Patricia Parker reported that an initiative coming out of OMH is the National Plan for Action (NPA). The NPA is one of three components to end health disparities. The two other components include: (1)

ten Regional Blueprints for Action which are aligned with the NPA and include strategies and actions most pertinent to communities in each region; and (2) targeted initiatives that will be undertaken by partners across the public and private sectors in support of the NPA.

### **January 18, 2011**

On January 18, 2011, the HRAC held its quarterly teleconference call with Tribal delegates, alternates and Federal Partners. The HRAC discussed the HRAC Research Roundtable held in October of 2010; the meeting held with the NIH Director on November 8, 2010 concerning the National Children's Study, Tribal Consultation and the University of New Mexico's Native Health Database need for funding; the 2011 HRAC budget; the HRAC invitations to the Health Resources and Services Administration (HRSA) and the Substance Abuse and Mental Health Services Administration (SAMHSA); coordination for HRAC's next face-to-face meeting; the Secretary's Tribal Advisory Committee; the HHS Tribal Consultation Policy; and the National Plan for Action to End Health Disparities.

Wilbur Woodis discussed the status of the HRAC Charter. The charter was revised in December and sent back to the Office of General Counsel (OGC) for review. Some of the language from the Secretary's Tribal Advisory Committee (STAC) was used for the national organizations as OGC suggested. The national organizations are now referred to as National At-Large Members (NALMs).

Bud Nicola reported that the CDC now has a Tribal website, under the Office of State, Tribal, Local and Territorial Support (OSTLTS) section of the website with CDC's consultation policy, biannual session information, new cooperative agreements, funding for grantees, etc.

Dr. Steven Hirschfield, from NICHD, reported on the current approach to the National Children's Study. The study, which follows a model that is data-driven, evidence-based, and community and participant informed, started off with seven locations that were selected based on infrastructure. The study started moving into 30 new areas in November 2010 and by the end of 2011, the NCS will have data to help inform NIH. Steve Kutz was concerned about the Tribes not being notified in the planning phases of the NCS and suggested that NCS reach out to Native populations. Dr. Hirschfield reported that there are Community Advisory Boards located in the targeted areas and information can be found on the NCS website, along with the Outreach Coordinator who can provide information.

### **May 12, 2011**

On May 12, 2011, the HRAC held its quarterly teleconference call. Updates were provided on HRAC's testimony at the HHS Tribal Budget and Policy Consultation in March, 2011 as well as HRAC's presentation to the Secretary's Tribal Advisory Committee Meeting in March, 2011. HRAC discussed charter revisions to be made in line with suggestions from the HHS Office of General Counsel to be Federal Advisory Committee Act (FACA) exempt. Also, discussed was the University of New Mexico Health Database which HRAC has been advocating for funding from NIH to support this effort. The purpose of this database is to create a high quality, single source of information regarding services and resources focused on historical AI/AN health/medical issues.

HRAC discussed its next meeting and agreed to hold in June in conjunction with the Annual Native Health Research Conference. The Indian Health Service also reported during that week it would be holding a roundtable discussion with the IHS Director, Dr. Yvette Roubideaux, to hear Tribal priorities.



Other updates were provided by the Centers for Disease Control and Prevention and Office of Minority Health.

### **June 27, 2011**

The second HRAC face-to-face meeting was held on June 27, 2011 in Niagara Falls, New York in conjunction with the Annual Native Health Research Conference. Mr. Dean Seneca, Centers for Disease Control and Prevention and Native Research Network Member, provided the opening blessing. Kathy Hughes, HRAC Co-Chair, called the meeting to order. Ms. Hughes provided an update on the May meeting of the Secretary's Tribal Advisory Committee and reported that the STAC would be asking all Tribal Advisory Committees, including HRAC, for regular reports to determine key issues that should be elevated to the STAC.

Christina Daulton, HRAC National At-Large Member Alternate and National Congress of American Indians Policy Research Center Program Manager, updated the HRAC on its activities at the recent NCAI MidYear Session held in Milwaukee, Wisconsin. She also shared that NCAI is developing a web-based guide for the National Human Genome Research Institute which will provide tools and resources to Tribes to make informed decisions on genetics research. She also mentioned that NCAI and NIHB sent a letter to Dr. Collins at NIH in April informing him that Tribal leaders were not given an opportunity to discuss NIH's Tribal Consultation Policy, but they have not received a response yet.

Annie Huntington-Kriska and Ric Bothwell provided an update on the National Partnership for Action and AI/AN Health Disparities Report. HRAC is very interested in reviewing and utilizing to help in their work. Other Federal agency updates were provided by OMH, AHRQ, CDC, and IHS.

Ms. Hughes designated Kristin Hill to speak on her behalf regarding the *Data Sharing Agreement: Standards and Practices* and *Data Use Agreement* from the Great Lakes Inter-Tribal Epidemiology Center. She knew HRAC was very interested in addressing these and she was trying to update for the Great Lakes EpiCenter and wanted to get feedback from HRAC. She admitted that they were not perfect, but it's a start at getting something in place to be more standardized.

Other HRAC business included approval of the revised charter, discussion on 2011 Recommendations to HHS, and thoughts on potential priorities to submit to the STAC once requested. The group also discussed that HRAC should take two to four of the big topics like diabetes, mental health, substance abuse and heart disease to identify specific research in those areas. Wendy Perry suggested that evidence reports (what has already been done) be developed, which will identify what is still not known. It was further suggested that the HRAC recommend starting with one topic like diabetes and ask that funds be put towards identifying gaps.

### **OUTREACH ACTIVITIES**

Co-Chair Cara Cowan Watts attended the *13th Annual National Tribal Budget Consultation Session* on March 2-4, 2011 in Washington, DC and presented testimony on behalf of the HRAC.

Steve Kutz and Jay Butler represented the HRAC and provided brief reports to attendees of the Region 10 Tribal Consultations.

Jay Butler, Alaska Area Alternate, served on a panel as the HRAC representative at the *National Indian Health Board's (NIHB) Annual Consumer Conference* on September 26-29, 2011 in Anchorage, Alaska.

## **ANNUAL HEALTH RESEARCH REPORT**

The HRAC produced its Annual Health Research Report, a compilation of findings related to important health research topics in AI/AN communities. This report is utilized as a resource to share research findings, topics and available federal programs with Tribes.

## **FEDERAL PARTNER ACTIVITIES**

The Office of Minority Health and HRAC extended invitations, which were accepted, to new Federal Partners including the Administration for Children and Families, Health Resources and Services Administration, and the Substance Abuse and Mental Health Services Administration.

The HRAC Federal Partners held meetings on July 14, August 11, and September 22, 2011. The meetings were chaired by Wilbur Woodis and each meeting began with a short introduction on the HRAC background and functions.

Other topics of discussion were:

- An overview of the Indian Health Service Research Roundtable that occurred at the Annual Native Health Research Conference (Niagara Falls, NY – June 27, 2011).
- Evidence based reports.
- The role of the new STAC and its relationship with current HHS Tribal Advisory Councils.
- Plans for a second HRAC Research Roundtable to be held on the NIH campus in the fall of 2011.
- The possibility of scheduling a meeting with the HHS Data Council and HRAC.

## **HHS RECOMMENDATIONS TO THE SECRETARY**

HRAC sent recommendations to HHS Secretary Kathleen Sebelius in November 2010 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**

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 consulted 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 should be encouraged to 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 conducting research or pursuing State or Federal grants 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 owners of 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

- Access to high quality healthcare

**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.

# ATTACHMENT A: MEMBER AND PARTNER LIST

## HRAC CO-CHAIR

### **Cara Cowan Watts**

Deputy Speaker and Tribal Council Representative, Cherokee Nation

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## MEMBERS

### AREA REPRESENTATIVES

#### *Aberdeen Area*

**Delegate:** Adrian Pushetonequa

Chairman, Sac and Fox Tribe of the Mississippi in Iowa, Meskwaki Nation

**Alternate:** Donald Warne

Senior Policy Advisor for Great Plains Tribal Chairmen's Health Board

#### *Alaska Area*

**Delegate:** Emily Hughes

Chairperson, Norton Sound Health Corporation

**Alternate:** Jay Clarence Butler

Senior Director, Division of Community Health Services, Alaska Native Tribal Health Consortium

#### *Albuquerque Area*

**Delegate:** Vacant

Alternate: Francine Gachupin

EpiCenter Director, Albuquerque Area Indian Health Board

#### *Bemidji Area*

**Delegate:** Vacant

**Alternate:** Phyllis Davis

Tribal Council Member, Gun Lake Tribe of Michigan

#### *Billings Area*

**Delegate:** Vacant

**Alternate:** Vacant

***California Area***

**Delegate:** Michelle Howard  
Tribal Secretary, Redding Rancheria  
**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:** Tom Anderson  
Tribal EpiCenter Manager, Oklahoma City Area Inter-Tribal Health Board

***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

**NATIONAL AT-LARGE MEMBERS**

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

**Delegate:** Jefferson Keel

Lt. Governor of Chickasaw Nation and President of National Congress of American Indians

**Alternate:** Christina Daulton

National Congress of American Indians Policy Research Center

**Delegate:** H. Sally Smith

Chair of the Board of Directors, Bristol Bay Area Health Corporation and Alaska Representative of National Indian Health Board

**Alternate:** Stacey Bohlen

Executive Director, National Indian Health Board

**Delegate:** Michael Percy

Epidemiologist, Choctaw Nation Health Services Authority

**Alternate:** Mickey Percy

Executive Director of Health Services, Choctaw Nation of Oklahoma

## **FEDERAL PARTNERS**

### *Administration for Children and Families*

**Delegate:** Molly Irwin

Office of Planning, Research and Evaluation

**Alternate:** Hilary Forster

Office of Planning, Research and Evaluation

### *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:** Ansalan Stewart

Program Analyst

### *Centers for Disease Control and Prevention*

**Delegate:** Melanie Duckworth

Senior Tribal Liaison for Science and Public Health

**Alternate:** Bud Nicola

CDC Field Assignee

### *Health Resources and Services Administration*

**Delegate:** Michelle Allender-Smith

Director, Office of Health Equity

**Alternate:** Elijah Martin

Special Assistant, Office of Health Equity

**Alternate:** Darci Eswein

Special Assistant to the Office of the Administrator, Office of Health Equity



***Indian Health Service***

**Delegate:** Vacant

**Alternate:** Alan Trachtenberg  
Research Director

***Intergovernmental and External Affairs***

**Delegate:** Stacey Ecoffey

Principal Advisor for Tribal Affairs

**Alternate:** Elizabeth Carr  
Tribal Affairs Specialist

***National Institutes of Health***

**Delegate:** John Ruffin

Director, National Institute on Minority Health and Health Disparities

**Alternate:** Joyce A. Hunter

Deputy Director, National Institute on Minority Health and Health Disparities

***Office of Minority Health***

**Delegate:** Nadine Gracia

Acting Director

**Alternate:** Wilbur Woodis

Special Assistant on Native American Affairs

***Substance Abuse and Mental Health Services Administration***

**Delegate:** Sheila Cooper

Senior Advisor for Tribal Affairs

**For Additional Information on the HRAC:**

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