

Annual Report of the
American Indian/Alaska Native
Health Research Advisory Council
(HRAC)

Fiscal Year 2012





TABLE OF CONTENTS

Introduction.....	1
Background	1
Presidential Memorandums and Executive Orders	1
Formation of the HRAC.....	2
HRAC History	2
Fiscal Year 2012 Activities	4
Research Roundtable.....	4
Meetings (Teleconference and In-person).....	5
Outreach Activities	9
Annual Health Research Report.....	9
Federal Partner Activities.....	9
Recommendations to HHS	10
National Children's Study	10
General Research Recommendations.....	10
HHS Data Council	12
National Institutes of Health Tribal Consultation Policy	13
Attachment A:	14
Member and Partner List for FY 2012 - 2013.....	14
HRAC Co-Chairs	14
Members	14
Federal Partners	18



INTRODUCTION

The *Annual Report of the American Indian/Alaska Native Health Research Advisory Council (HRAC)* provides a summary of events accomplished by the American Indian/Alaska Native (AI/AN) Health Research Advisory Council for Fiscal Year 2012. 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 in 1986 following the release of the groundbreaking *1985 Report of the Secretary's Task Force on Black Minority Health*. The mission of OMH is to improve and protect the health of racial and ethnic minority populations through the development of health policies and programs that will eliminate health disparities. OMH advises the HHS Secretary and Assistant Secretary for Health and works with Federal agencies and organizations across the country on health related matters affecting American Indians and Alaska Natives, Asian Americans, Blacks/African Americans, Hispanic/Latinos, Native Hawaiians, and Pacific Islanders.

This level of expertise made OMH the logical advocate and Executive Secretariat for the HRAC. In its role as Executive Secretariat OMH is responsible for the administrative and fiscal operation of the HRAC, solicitation and selection of tribal delegates to the HRAC and ensuring that delegates and alternates to the HRAC meet Federal Advisory Committee Act (FACA) requirements.

PRESIDENTIAL MEMORANDUMS AND EXECUTIVE ORDERS

President Clinton issued the Government-to-Government Relationship with Native American Tribal Governments memorandum on April 29, 1994, to executive departments and agencies that reinforced the special relationship between Tribal Governments and the Federal Government in regards to Tribal consultation and sovereignty. 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 on August 7, 1997—developed to strengthen the government-to-government relationship and ensure that Tribes are consulted on matters that affect them.

A revised Executive Order (13175) was issued by President Clinton on November 6, 2000, 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.

A Presidential Memorandum on Tribal Consultation was issued by President Barack Obama in 2009 that reaffirmed his Administration's commitment to regular and meaningful consultation and collaboration with Tribal officials through implementation of Executive Order 13175. As a result, the HHS worked with Tribal leaders in the development of a revised Tribal Consultation Policy. In December 2010, the Department's Tribal Consultation Policy was signed providing more opportunities for Tribal input throughout the development of policies, regulations, and budgets.



FORMATION OF THE HRAC

In November 2005, HHS solicited from Tribal leaders' nominations for HRAC delegates to facilitate communication between the Department and Tribes regarding health research priorities and needs in AI/AN communities. Members of the council are elected or appointed Tribal officials, and include one delegate and an alternate from each of the 12 Indian Health Service areas, and four National At-Large Members. The council is also comprised of Federal partners representing HHS Operating and Staff Divisions.

The HRAC was established to fulfill three primary functions:

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

The HRAC held its first meeting in May of 2006 and elected two co-chairs, Cara Cowan Watts and Cecilia Fire Thunder, 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 held in Albuquerque, New Mexico during November 2006, the HRAC reached a collective agreement to focus on three objectives:

1. Establish the HRAC 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

To help guide their work, the HRAC developed a Discussion Guide to ascertain health research priorities in Indian Country. The HRAC constructed the survey questions to examine health care delivery systems and research Tribes were conducting. From 2007 to 2009, HRAC members disseminated the Discussion Guide to the Tribal leaders in their respective Areas. The top health concerns reported but not listed in priority order were behavioral health issues including substance abuse, tobacco use, suicide, and domestic violence; cancer; cardiovascular disease; diabetes; and obesity. The respondents cited access to care; coordination of care; health information technology and systems; lack of funding; and recruitment/retention of highly qualified health care professionals/providers as their top five health delivery system concerns. The Discussion Guide results 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 participated in outreach events to make Tribes aware of the Council, its work, and how Tribes and Tribal communities can provide feedback to the HRAC regarding AI/AN health research. The HRAC attended events such as the Annual Native Health Research Conference (2008, 2010, and

2011), National Indian Health Board (NIHB) Annual Consumer Conference (2008, 2011, and 2012), AI/AN Health Policy Conference (2009), IHS/Health Canada Maternal and Child Health Research Meeting (2009), Third National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health (2009), NIHB Public Health Summit (2010), and the HHS Regional Consultations (2011). These events provided an opportunity to collaborate and share knowledge of paramount importance to the advancement of health care research in Indian Country.

In addition, the HRAC collaborated with the Administration for Children and Families (ACF), Agency for Healthcare Research and Quality (AHRQ), Assistant Secretary for Planning and Evaluation (ASPE), Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Indian Health Service (IHS), Intergovernmental and External Affairs (IEA), National Institutes of Health (NIH), Substance Abuse and Mental Health Services Administration (SAMHSA), Tribal Epidemiology Center (EpiCenter) staff, OMH and outside researchers and scientists to further its knowledge base regarding health research.

The HRAC held quarterly conference calls and annual meetings from 2006 – 2011 with topics of continued interest and concern which included the National Children’s Study, NIH Tribal Consultation Policy, data sharing, as well as scholarships for Native researchers, and Native health research database. From these discussions, the HRAC developed and presented recommendations to HHS through letters to the Secretary and testimony at the annual HHS National Tribal Budget and Policy Consultation Sessions (2008-2012). 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.



HRAC Members at April 2009 Meeting



FISCAL YEAR 2012 ACTIVITIES

RESEARCH ROUNDTABLE

On November 10, 2011 the second annual HRAC Research Roundtable was held on the campus of the National Institutes of Health. HRAC members, Native researchers, EpiCenter representatives, and Federal Partners came together to discuss health research priorities for AI/AN communities. Chester Antone, HRAC Tucson Area Delegate, provided the opening invocation for the Roundtable. Opening remarks and introductions were provided by Wilbur Woodis, OMH Special Assistant on Native American Affairs, and Joyce Hunter, Deputy Director, National Institute on Minority Health and Health Disparities (NIMHD).

The HRAC presented on what had been identified as priorities from discussion guide results, testimony to HHS, and recommendations to HHS as well as requested feedback from the Native researchers and EpiCenter representatives on what specific areas need to be researched within broad categories like cancer and diabetes. The Roundtable participants discussed health disparities not previously identified by the HRAC that should be considered and recommended to HHS. Additional research priorities that were suggested but not listed in priority order included:

- Asthma
- Cancer (types and early diagnosis and access to treatment)
- Childhood obesity
- Chronic diseases
- Elder care
- High blood pressure
- Men's health
- Mental health
- Nutrition and fitness
- Oral health
- Prenatal/postpartum care
- Sexually transmitted diseases
- Teen pregnancy
- Vaccines for children

In addition, other concerns and recommendations mentioned during the Roundtable for the HRAC's consideration included:

- Research is needed to showcase the strengths of Native communities.
- The majority of American Indians and Alaska Natives are now in urban areas and not all belong to federally recognized Tribes due to termination, the fact they are descendants of multiple Tribes and do not qualify as members, or don't have the capacity to enroll. Research should be on Indians and not just Tribes.
- Agencies need to actively recruit Native reviewers for grant reviews and place them on standing study committees. More Native and minority involvement is needed in these committees.

- More analysis is needed when looking at data and making comparisons. For example, the trends and patterns of skin cancer incidence show that rates are lower in the American Indian population than in other races but the mortality rates are higher.
- There is a need for qualitative data to really understand what is going on in Native communities. The numbers are very important, but they do not tell the story.
- On broader based community research, if identifying any Tribal affiliations in research, there must be authorization from the Tribe. A Tribal member cannot name themselves as a Tribal member and publish research about the Tribe, without the approval of the Tribe.
- Communities need to review results before universities consider publication. Guidelines for publication rights are needed to ensure both sides are protected.

MEETINGS (TELECONFERENCE AND IN-PERSON)

October 13, 2011

The HRAC held its first teleconference for Fiscal Year 2012 on October 13, 2011. It was announced that Dr. J. Nadine Garcia would be serving as the Acting Director of the Office of Minority Health. Wilbur Woodis shared that the HRAC Federal Partners had been meeting via conference calls and in-person to assist the HRAC with follow-up on action items from HRAC meetings, conference calls, and recommendations provided to HHS. The Administration for Children and Families (ACF), Health Resources and Services Administration (HRSA), and Substance Abuse and Mental Health Services Administration (SAMHSA) were participating as new HRAC partners.

Dr. Jay Butler, HRAC Alaska Area Alternate, reported on his participation in a research breakout session at the National Indian Health Board's (NIHB) 28th Annual Consumer Conference held in Anchorage, Alaska during September 2011. At the session there was open discussion about the HRAC's function and activities. There was interest from attendees in the National Children's Study as well as the HRAC's recommendations to include Indian Country and an Adverse Childhood Events Study that was conducted in Northern California by Kaiser Permanente. He noted that there were some strong advocates for conducting a similar study in Alaska and throughout Indian Country.

Chester Antone provided updates on the March and September 2011 Secretary's Tribal Advisory Committee (STAC) meetings. The HHS budget was a focus of the discussions and specifically the STAC advocating for the Indian Health Service level of funding to be maintained. There was also an update on the Affordable Care Act (ACA) Tribal Consultations along with the work the Intradepartmental Council on Native American Affairs had been doing to improve accessibility of grants for Tribes. Councilman Antone also noted that Isabel Garcia from the National Institutes of Health discussed the NIH Tribal Consultation Policy and Implementation Guidance.

Dr. Alan Trachtenberg, Indian Health Service, reported that the Annual Native Health Research Conference was scheduled for July 16-19, 2012 in Seattle, Washington. The Native Research Network asked the HRAC to designate an individual to serve on the conference planning committee and Stephen Kutz, Portland Area Delegate, volunteered.

August 6, 2012

The HRAC teleconference call on August 6, 2012 began with Co-Chair Cara Cowan Watts asking each individual to briefly introduce themselves since there were new members participating on the call. Dr. J. Nadine Gracia, Deputy Assistant Secretary for Minority Health (Acting) and Acting OMH Director,



welcomed the HRAC members to the call and noted that she supported the work and guidance that the HRAC members provide to OMH. She mentioned the possibility of participating in the planned in-person meeting during September to meet the HRAC members and to learn more about the work of the Council. Dr. Gracia announced that Commander Jacqueline Rodrigue would be serving as the new Deputy Director of OMH. Dr. Gracia shared the three strategic priorities she set forth for OMH:

1. Affordable Care Act
2. HHS Action Plan to Reduce Racial and Ethnic Health Disparities
3. National Partnership for Action (NPA) to End Health Disparities

OMH reported that as part of the NPA there were 10 Regional Health Equity Councils (RHECs) and the purpose of these entities is to bring together the regions, Federal staff, local individuals, insurance companies, small businesses, foundations, and other stakeholders interested in reducing health disparities. These are independent bodies some of which may consider pursuing 501(c)(3) status so they can seek funding to support their local/regional disparity reduction activities.

Chester Antone reported on the STAC's key priorities. He also shared that HHS is working to finalize a matrix of HHS grants with all possible funding opportunities that identify eligibility for Tribes. If Tribes are not eligible, the matrix will note why, such as program authorizations, appropriation and/or budget restrictions, or other legislative issues (e.g., State waivers).

Wilbur Woodis shared that a Federal Register notice to Improve Rules Protecting Human Research Subjects was published with a notice of proposed rulemaking that requested comments. The last update was in 1991 and is needed due to advances in technology and multiple sites outside of universities that are now doing research. Dr. Jay Butler noted that this is of interest to the Alaska Tribal Health System because their Institutional Review Board (IRB) estimates about 50% of the proposals coming through would be exempted under the proposed rule. Mr. Woodis said that he spoke with the HHS Office of Health Research Protections and that they received over 1,000 comments and the staff is working to review and revise the rules.

A brief update was provided on behalf of Dr. Hunter on the National Institutes of Health Implementation Guidance of the HHS Tribal Consultation Policy. No comments were received on the draft guidance by the May 30, 2012 deadline, so NIH extended the deadline to June. Co-Chair Cowan Watts shared that she had submitted comments and NIH said they didn't receive them, so she resubmitted. Councilman Antone said that he had informed NIH that time should be allowed for Tribal comments rather than trying to fast track the process.

September 24, 2012

The HRAC held its in-person meeting for Fiscal Year 2012 on September 24, 2012, in Denver, Colorado as a pre-meeting to the NIHB Annual Consumer Conference. The HRAC received updates and presentations by the STAC, Tribal Epidemiology Centers, National Library of Medicine, the Effective Health Care (EHC) Program of the AHRQ, National Institute of Child Health and Human Development's National Children's Study (NCS), and the National Congress of American Indians (NCAI) Policy Research Center. The HRAC also discussed previous recommendations to HHS and key priority areas for the next year. Cara Cowan Watts was reelected as Chair and Stephen Kutz was elected as Co-Chair.



Chester Antone noted that Secretary Sebelius informed the STAC that a review of the HHS Tribal Consultation Policy was underway and that HHS would be seeking feedback from Tribes. HHS will hold periodic reviews to ensure the policy is working and/or if there are changes to be considered. Councilman Antone also shared that the STAC identified its five major budget priorities as: Head Start, Native language programs, SAMHSA's Circles of Care program, cancer research, and the ACA.

Co-Chair Cara Cowan Watts ceded her seat to Alternate Tom Anderson from the Southern Plains Tribal Epidemiology Center to provide an update on the Tribal EpiCenters. Mr. Anderson reported that a cooperative agreement announcement from Indian Health Service resulted in awards to all 12 existing EpiCenters. In addition, the IHS provided base funding for certain activities that the EpiCenters could undertake for the Behavioral Risk Factor Surveillance System (BRFSS) as AI/ANs are underrepresented. In March 2012, EpiCenters received a Data Sharing Agreement from IHS for EpiCenters to interact with IHS and their database to extract certain data for the Area and for Tribes. Mr. Anderson was not aware of any agreement that was fully executed on both sides. The EpiCenters established a National Health Profile Workgroup as they are developing area profiles that will be compiled for a national profile. They have another workgroup to educate Tribes and government as to the purpose and function of Tribal EpiCenters, including the fact that the Indian Health Care Improvement Act (IHCIA) gave EpiCenters the authority to serve as public health authorities. Jim Crouch, California Area Alternate, asked that the HRAC consider a recommendation asking the Secretary to send a letter to all state governors regarding the federal statute change treating EpiCenters as public health authorities.

Dr. Shilpa Amin of AHRQ's Center for Outcome and Evidence provided a presentation on the EHC Program and how the HRAC can use this process for prioritizing topics. Dr. Amin discussed how research topics are defined and the steps to take for topic identification. The first step is for stakeholders, who are involved in making health care decisions, to help identify a topic. Then a vetting process follows with prioritization criteria looking at importance, appropriateness, duplication, feasibility and potential impact. She noted that various questions are asked when vetting the topic to help inform the program if it is a topic that should be invested in. Dr. Amin explained the next step is to see if the topic is appropriate for an evidence synthesis report, an evidence generation study and/or evidence dissemination and translation product. HRAC members can inform the EHC program as key informants, technical experts and peer reviewers in the process of formulating an evidence report or translational product. The HRAC was very interested in this process and requested technical assistance to help the HRAC move from broad research topics to a detailed and prioritized list of topics.

For the Indian Health Service, Carolyn Aoyama reported that she was the new lead for the Native American Research Centers for Health (NARCH) and managed the grant awards during this fiscal year. Over 9 million dollars in NARCH funding was awarded to 15 grantees through 20 programs. Dr. Alan Trachtenberg also shared that the IHS Division of Program Statistics has a new director, Kirk Greenway. They expect to release one to two new editions of *Regional Differences in Indian Health* in the current calendar year. They are also compiling reports on women and perinatal care, vision care and oral health. *New Trends in Indian Health* will also be released by the next calendar year.

Wendy Perry of AHRQ reported the agency has implemented a policy statement for project officers so they are aware when they receive grant applications from Tribes and Tribal organizations to look for a Tribal resolution from the Tribal government. Ms. Perry also mentioned that AHRQ assisted with two projects in Indian Country with Office of the Secretary American Recovery and Reinvestment Act (ARRA) funds that focused on comparative effectiveness research. The Indian Health Service detailed CAPT Sherry Yoder to AHRQ to lead these efforts.



Delight Satter of CDC noted they convened a meeting of all project officers working with Tribes and urban communities to better support grantees and applicants. She reported that the CDC's Tribal Advisory Committee requested a compendium of Tribal success stories and as a result several strong, evidence-based programs were identified that may not be included in research issues. CDC recently made two awards for a "Capacity Building Assistance to Improve Health in Tribal Communities Populations" announcement to the National Native American AIDS Prevention Center and the Southcentral Foundation in Alaska. CDC now has an FY2011 and FY2012 Resource Allocation Report that highlights, by state, the Tribes and organizations who received contracts and grants.

A representative of NIMHD did not attend the meeting, but provided updates via email on the NIH Plan for the Implementation of the HHS Tribal Consultation Policy. Various listening sessions were held and letters were sent to Tribal leaders to request Tribal input on the draft plan. NIH incorporated the comments received and finalized the draft. The NIH Implementation Package was submitted for clearance on September 13, 2012. After review and approval by the NIH director, the plan will be posted in the Federal Register and implementation will then follow with leadership from the NIMHD.

Dr. Steven Hirschfeld, Director of the NCS, reported they have multiple components and they are currently in the Vanguard/pilot phase which will run 21 years as its own study. The main NCS has yet to begin and enrollment is expected to start in 2014. Councilman Kutz noted that he had mentioned this previously, but the University of Washington has yet to reach out to Tribal governments regarding recruitment efforts. Dr. Hirschfeld replied that recruitment closed in Grant County, Washington about a year ago. He added that recruitment was limited to relatively small areas and not even entire counties. They do want to build in consultation to have engagement, which is why they established new regional boards as the local boards might not have all the requisite knowledge. They also instituted a formative research program where the University of Arizona engaged a site in Apache County, Arizona with a toolkit developed to specifically engage various Tribal Nations in observational research and to understand communications and dynamics of those interactions. Co-Chair Cowan Watts asked about the topics that have been brought up previously by the HRAC including that the Aberdeen Area and Alaska were completely left out of the study. Dr. Hirschfeld said they have listened and are addressing these issues by proposing a multilayer approach to the main study. One proposal is that supplemental recruitment could be utilized if there are justifiable reasons to examine a particular population. They are continuing to get feedback and input on this feature as it is a change from the earlier proposal.

Emily White Hat, National At-Large Proxy for Lieutenant Governor Jefferson Keel, reported that NCAI just completed a Genetics Research Guide which can be found at: <http://genetics.ncai.org>. They also have partnered with the Washington University Center for Diabetes Translation Research on a project through the National Institute of Diabetes and Digestive and Kidney Diseases. NCAI is working with The Robert Wood Johnson Foundation (RWJF) to identify public health laws in Indian Country that are presently developed and putting them in a public database.

The HRAC reviewed the testimony that was submitted to HHS for the 2012 HHS Tribal Budget and Policy Consultation and developed the following next steps and/or new recommendations:

- Invite Secretary Sebelius to communicate directly with state departments of health and governors on the status of EpiCenters as public health authorities.
- Continue to follow up on the NIH Consultation Policy to make this a priority and have it become a policy across NIH.
- Draft a letter from HRAC to the NCS regarding concerns on oversampling, sampling in Indian Country, Tribal IRBs in general, and reports from contractors on evidence of consultation and

approval from IRBs in Indian Country. Also, HRAC would like follow-up in detail on the \$1 million dollar grant to the University of Arizona before the NCS proceeds with creating a model. The HRAC would like to request a meeting with NCS after receiving the report.

- Revise recommendation to the HHS Data Council regarding an HHS-wide Research Policy for Indian Country and address minimum standards, data sharing and data ownership.
- Provide scholarship opportunities for AI/ANs in the health research field and develop protocols that ensure scholarship providers check proof of enrollment from a Federally-recognized Tribe or meet the BIA definition of AI/AN as provided by a Certificate Degree of Indian Blood.
- Draft a letter to HHS regarding data ownership and issues such as oversampling and data sharing with IHS.
- Recommend development of a Native research database/clearinghouse.



HRAC Members at September 2012 Meeting

OUTREACH ACTIVITIES

Chester Antone, presented at the Interdepartmental Tribal Justice, Safety, and Wellness Session on December 14, 2011 in Albuquerque, New Mexico.

Co-Chair Cara Cowan Watts attended the 14th Annual National Tribal Budget Consultation Session on March 7-9, 2012 in Washington, DC and presented testimony on behalf of the HRAC.

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 OMH and HRAC extended invitations, which were accepted, to new Federal Partners including ACF, HRSA, and SAMHSA.



RECOMMENDATIONS TO HHS

The HRAC submitted recommendations to HHS via testimony in March 2012 on issues of concern from the Tribal communities that HRAC represents. The recommendations that were submitted are provided below:

NATIONAL CHILDREN'S STUDY

While the HRAC fully supports the intent and purpose of the NCS, 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 in a manner consistent with longstanding Federal policy. However, HRAC believes there is still an opportunity at this stage in the NCS 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 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 should demonstrate outreach efforts to Native Communities to enroll native children into the study.

GENERAL RESEARCH RECOMMENDATIONS

The HRAC is acutely aware of the high and disproportionate rates of morbidity and mortality experienced by AI/ANs, therefore many of the recommendations focus on addressing the health disparities that continue to plague Indian Country. Additionally, the HRAC would like to recommend that HHS increase its activities to address the suicide epidemic in AI/AN communities, including the research of the root causes of the epidemic.

In order to address the health concerns identified by the HRAC, research should focus on: data quality and accuracy to address under-representation of AI/ANs 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 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
 - Suicide Prevention
 - The readiness of Tribal governments for public health accreditation
 - Health care reform impact and effectiveness

In addition, 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. Research should address the complex interactions between health determinants and long term exposure to risks unique to AI/ANs as an indigenous population and resulting from misguided Federal Indian policy.

It is important to stress that all research conducted should be evidence-based and to the extent possible, community-based participatory. Tribal governments are 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. In addition to health concerns and research priorities, many barriers exist regarding research activities in Indian Country. These barriers could be addressed by:

- Increasing cultural sensitivity among researchers.
- Increasing the number of AI/AN researchers. A possible avenue is through additional funding through the IHS Health Professions 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 available comparative data: When research includes a comparison of racial or ethnic data that does not include AI/ANs, we recommend 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.
- Providing the IHS with a research funding line item to support research by and for AI/ANs.
- HRAC recommends that HHS adopt HHS-wide minimum standards and requirements 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 citizens 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.

- Additionally, one of the most beneficial improvements would be the establishment of single data sources. As an example, the Federal government maintains several AI/AN data sources through IHS, BIA, Centers for Medicare & Medicaid Services, CDC, NIH, SAMHSA, U.S. Census Bureau, and several others. A single, integrated internet accessible website with data available to calculate simple statistics, such as incidence and prevalence rates, etc. would assist in identifying areas of focus within AI/AN communities. Additionally, the resource could provide access to published data as well.

While the HRAC would like to see more grants awarded directly to Tribal governments, we realize that academic institutions and research organizations are often the most suitable awardees for certain highly technical and advanced research grants. Unfortunately, when academic institutions and research organizations are awarded grants for research affecting AI/AN communities, no uniformity or requirements exist for collaboration and cooperation with Tribal governments. The HRAC recommends that grant requirements include demonstrated cooperation and collaboration with Tribal governments. While some grant awardees may consider such a requirement too burdensome, numerous resources exist to reduce any burdens on grant awardees. Resources that are readily available to assist include the HRAC, other AI/AN Federal advisory bodies, Inter-Tribal organizations, area Indian health boards, Tribal Epidemiology Centers, and numerous others. We offer this recommendation not only because it is the right thing to do, but we have seen too many times where a research project has been rendered useless by the AI/AN community because it was conducted without adequate collaboration, or relied on illegitimate AI/AN expertise.

In addition to requiring Tribal collaboration and cooperation as part of grant funding requirements, it is important to have grant reviewers that have demonstrated experience with Tribal governments and are culturally sensitive. Such reviewers can ensure that grant applications adequately include collaboration and cooperation components, as well as evaluate grant applications from the AI/AN community which may have extensive subject matter experience but less academic credentials and degrees.

HHS DATA COUNCIL

The HRAC requests 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.' Self-identification is not adequate.

- 
- 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.' Self-identification is not adequate.

NATIONAL INSTITUTES OF HEALTH TRIBAL CONSULTATION POLICY

The HRAC is encouraged that NIH has finally started to address Tribal consultation with its Draft Guidance on the Implementation of the HHS Tribal Consultation Policy. However, we are concerned about the delays in consulting with Tribal leaders regarding this draft guidance. We recommend all Tribal leaders be informed of NIH's efforts and receive a copy of the draft guidance for their review and comment, as well as additional consultation opportunities.

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. The HRAC urges NIH to move forward in this effort.

In addition, HRAC would like more focus placed on putting AI/AN leadership 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 closing, it is important to stress that Tribal governments are 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 HRAC looks forward to continued collaboration with the various HHS operating and staff divisions to improve research activities affecting Indian Country.

ATTACHMENT A:

MEMBER AND PARTNER LIST FOR FY 2012 - 2013

HRAC CO-CHAIRS

Cara Cowan Watts

Tribal Council Representative, Cherokee Nation
PO Box 2922
Claremore, OK 74018
Phone: (918) 752-4342
Fax: (918) 341-3753
Email: cara@caracowan.com

Stephen Kutz

Councilman, Cowlitz Indian Tribe
1055 9th Ave, Ste. A
Longview, WA 98632
Phone: (360) 508-6347
Fax: (360) 575-1948
Email: skutz.health@cowlitz.org

MEMBERS

2012 Area Representatives	2013 Area Representatives
<p><i>Aberdeen Area</i> Delegate: Adrian Pushetonequa Chairman, Sac and Fox Tribe of the Mississippi Alternate: Donald Warne Senior Policy Advisor, Great Plains Tribal Chairmen's Health Board</p>	<p><i>Aberdeen Area</i> Delegate: Vacant Alternate: Vacant</p>
<p><i>Alaska Area</i> Delegate: Emily Hughes Chairperson, Norton Sound Health Corporation Alternate: Jay Clarence Butler Senior Director, Division of Community Health Services, Alaska Native Tribal Health Consortium</p>	<p><i>Alaska Area</i> Delegate: Ileen Sylvester Vice President of Executive & Tribal Services, Southcentral Foundation Alternate: Jay Clarence Butler Senior Director, Division of Community Health Services, Alaska Native Tribal Health Consortium</p>
<p><i>Albuquerque Area</i> Delegate: Vacant Alternate: Vacant</p>	<p><i>Albuquerque Area</i> Delegate: June Shaw Tribal Council Member, Mescalero Apache Tribe Alternate: Joycelyn Dutchie Tribal Council Member, Southern Ute Indian Tribe</p>



2012 Area Representatives	2013 Area Representatives
<p><i>Bemidji Area</i> Delegate: Don Eubanks Commissioner of Health and Human Services, Mille Lacs Band of Ojibwe Alternate: Phyllis Davis Tribal Council Member, Gun Lake Tribe of Michigan</p>	<p><i>Bemidji Area</i> Delegate: Aaron Payment Tribal Chairman, Sault Ste. Marie Tribe of Chippewa Indians Alternate: Vacant</p>
<p><i>Billings Area</i> Delegate: Vacant Alternate: Vacant</p>	<p><i>Billings Area</i> Delegate: Patty Quisno Councilwoman, Fort Belknap Indian Community Alternate: Darrin Old Coyote Chairman, Crow Nation</p>
<p><i>California Area</i> Delegate: Michelle Hayward Secretary, Redding Rancheria Tribal Council Alternate: James Crouch Executive Director, California Rural Indian Health Board</p>	<p><i>California Area</i> Delegate: Daniel Calac Chief Medical Officer, Indian Health Council Alternate: James Crouch Executive Director, California Rural Indian Health Board</p>
<p><i>Nashville Area</i> Delegate: Elizabeth Neptune Tribal Council Member, Passamaquoddy Indian Township Alternate: Tihtiyas (“Dee”) Sabattus Health Policy Analyst, United South and Eastern Tribes, Inc.</p>	<p><i>Nashville Area</i> Delegate: Sandra Yarmal Health Director, Passamaquoddy Tribe Pleasant Point Alternate: Tihtiyas (“Dee”) Sabattus Health Policy Analyst, United South and Eastern Tribes, Inc.</p>
<p><i>Navajo Area</i> Delegate: Madan Poudel Health Services Administrator, Navajo Nation Alternate: Roselyn Begay Program Evaluation Manager, Navajo Nation</p>	<p><i>Navajo Area</i> Delegate: Madan Poudel Health Services Administrator, Navajo Nation Alternate: Roselyn Begay Program Evaluation Manager, Navajo Nation</p>
<p><i>Oklahoma Area</i> Delegate: Cara Cowan Watts Tribal Council Representative, Cherokee Nation Alternate: Tom Anderson Tribal EpiCenter Manager, Oklahoma City Area Inter-Tribal Health Board</p>	<p><i>Oklahoma Area</i> Delegate: Cara Cowan Watts Tribal Council Representative, Cherokee Nation Alternate: Tom Anderson Tribal EpiCenter Manager, Oklahoma City Area Inter-Tribal Health Board</p>



2012 Area Representatives	2013 Area Representatives
<p>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</p>	<p>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</p>
<p>Portland Area Delegate: Stephen Kutz Councilman, Cowlitz Indian Tribe Alternate: Stella Washines Council Member, Yakama Nation</p>	<p>Portland Area Delegate: Stephen Kutz Councilman, Cowlitz Indian Tribe Alternate: Stella Washines Council Member, Yakama Nation</p>
<p>Tucson Area Delegate: Chester Antone Councilman, Tohono O'odham Nation Alternate: Michelle Ortega Councilwoman, Tohono O'odham Nation</p>	<p>Tucson Area Delegate: Chester Antone Councilman, Tohono O'odham Nation Alternate: Vacant</p>
2012 National At-Large Members	2013 National At-Large Members
<p>Delegate: Andrew Joseph, Jr. Chairman, Human Services Committee, Confederated Tribes of the Colville Reservation Alternate: Vacant</p>	<p>Delegate: Andrew Joseph, Jr. Chairman, Human Services Committee, Confederated Tribes of the Colville Reservation Alternate: Vacant</p>
<p>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</p>	<p>Delegate: Jefferson Keel Lt. Governor of Chickasaw Nation and President of National Congress of American Indians Alternate: Malia Villegas National Congress of American Indians Policy Research Center</p>
<p>Delegate: H. Sally Smith Chair of the Board of Directors, Bristol Bay Area Health Corporation and Alaska Representative of National Indian Health Board Alternate: Stacy Bohlen Executive Director, National Indian Health Board</p>	<p>Delegate: H. Sally Smith Chair of the Board of Directors, Bristol Bay Area Health Corporation and Alaska Representative of National Indian Health Board Alternate: Stacy Bohlen Executive Director, National Indian Health Board</p>



2012 National At-Large Members	2013 National At-Large Members
<p>Delegate: Michael Percy Epidemiologist, Choctaw Nation Health Services Authority/Chickasaw Nation</p> <p>Alternate: Mickey Percy Executive Director of Health Services, Choctaw Nation of Oklahoma</p>	<p>Delegate: Michael Percy Epidemiologist, Choctaw Nation Health Services Authority/Chickasaw Nation</p> <p>Alternate: Mickey Percy Executive Director of Health Services, Choctaw Nation of Oklahoma</p>

FEDERAL PARTNERS

2012 Federal Partners	2013 Federal Partners
<p><i>Administration for Children and Families</i> Delegate: Anne Bergan Office of Planning, Research and Evaluation Alternate: Hilary Forster Office of Planning, Research and Evaluation Alternate: Molly Irwin Office of Planning, Research and Evaluation</p>	<p><i>Administration for Children and Families</i> Delegate: Anne Bergan Office of Planning, Research and Evaluation Alternate: Hilary Forster Office of Planning, Research and Evaluation Alternate: Molly Irwin Office of Planning, Research and Evaluation</p>
<p><i>Agency for Healthcare Research and Quality</i> Delegate: Wendy Perry Senior Program Analyst</p>	<p><i>Agency for Healthcare Research and Quality</i> Delegate: Wendy Perry Senior Program Analyst</p>
<p><i>Assistant Secretary for Planning and Evaluation</i> Delegate: Sue Clain Indian Health Desk Officer Alternate: Ansalan Stewart Program Analyst</p>	<p><i>Assistant Secretary for Planning and Evaluation</i> Delegate: Sue Clain Indian Health Desk Officer Alternate: Ansalan Stewart Program Analyst</p>
<p><i>Centers for Disease Control and Prevention</i> Delegate: Delight Satter Associate Director Tribal Support Alternate: Kimberly Cantrell Deputy Associate Director Tribal Support</p>	<p><i>Centers for Disease Control and Prevention</i> Delegate: Delight Satter Associate Director Tribal Support Alternate: Kimberly Cantrell Deputy Associate Director Tribal Support</p>
<p><i>Health Resources and Services Administration</i> 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</p>	<p><i>Health Resources and Services Administration</i> Delegate: Michelle Allender-Smith Director, Office of Health Equity Alternate: Chris Perry Public Health Analyst, Office of Health Equity</p>



2012 Federal Partners	2013 Federal Partners
<p><i>Indian Health Service</i> Delegate: Alan Trachtenberg Research Director, United States Public Health Service Alternate: Vacant</p>	<p><i>Indian Health Service</i> Delegate: Alan Trachtenberg Research Director, United States Public Health Service Alternate: Carolyn Aoyama Senior Consultant, Women’s Health and Advanced Practice Nursing</p>
<p><i>Intergovernmental and External Affairs</i> Delegate: Stacey Ecoffey Principal Advisor for Tribal Affairs Alternate: Elizabeth Carr Tribal Affairs Specialist</p>	<p><i>Intergovernmental and External Affairs</i> Delegate: Stacey Ecoffey Principal Advisor for Tribal Affairs Alternate: Elizabeth Carr Tribal Affairs Specialist</p>
<p><i>National Institutes of Health</i> 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</p>	<p><i>National Institutes of Health</i> 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</p>
<p><i>Office of Minority Health</i> Delegate: Nadine Gracia Acting Director Alternate: Wilbur Woodis Special Assistant on Native American Affairs Alternate: LCDR Tracy Branch Public Health Advisor</p>	<p><i>Office of Minority Health</i> Delegate: Nadine Gracia Acting Director Alternate: LCDR Tracy Branch Public Health Advisor</p>
<p><i>Substance Abuse and Mental Health Services Administration</i> Delegate: Sheila Cooper Senior Advisor for Tribal Affairs</p>	<p><i>Substance Abuse and Mental Health Services Administration</i> Delegate: Sheila Cooper Senior Advisor for Tribal Affairs</p>



For Additional Information on the HRAC:

Please Contact:

Tracy Branch, MPAS, PA-C

Lieutenant Commander, U.S. Public Health Service

Public Health Advisor

Office of Minority Health

1101 Wootton Parkway, Suite 600

Rockville, MD 20852

Phone: (240) 453-6157

Email: Tracy.Branch@hhs.gov