



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

**June 4-5, 2015
Arlington, VA**

HRAC Tribal Delegates and Alternates

Denise Dillard, Alaska Area Delegate (Proxy for Ilene Sylvester)
Aaron Payment, Bemidji Area Delegate
Dan Calac, California Area Delegate (via teleconference)
Anita Frederick, Great Plains Area (Proxy for Patrick Marcellais)
Charlene Jones, Nashville Area Delegate
Ramona Antone Nez, Navajo Area (Proxy for Navajo Nation)
Cara Cowan Watts and Tom Anderson, Oklahoma Area Delegate and Alternate
Stephen Kutz, Portland Area Delegate
Stacy Bohlen, National At-Large Member Alternate
Rodney Haring, National At-Large Member Delegate
Michael Peercy, National At-Large Member Delegate
Dawnette Weaver and Malia Villegas, National At-Large (Proxy for Jefferson Keel) and
Alternate

HRAC Federal Partners

Kathy Etz, National Institutes of Health (NIH)
J. Nadine Gracia, Rick Haverkate, Rashida Dorsey, Lena Marceno, and Mia Keeyes, Office of
Minority Health (OMH)
Mose Herne, Indian Health Service (IHS)
Joyce Hunter, National Institutes of Health (NIH)
Aleta Meyer, Administration for Children and Families (ACF)
Delight Satter, Centers for Disease Control and Prevention (CDC)
Adelle Simmons, Office of the Assistant Secretary for Planning and Evaluation (ASPE)
Kishena C. Wadhvani, Agency for Healthcare Research and Quality (AHRQ)
Michael Weaver, Health Resources and Services Administration (HRSA)
Faye Williams and Roland Zebina, OMH Resource Center (OMHRC)

Other Attendees

Kim Zillyet, Shoalwater Bay Tribe
Kendra King Bowes, Native American Management Services, Inc. (NAMS)
David Brown, Erika Noves, and Deborah Thornton, Professional and Scientific Associates (PSA)

DAY ONE

Invocation

Aaron Payment, MPA, HRAC Co-Chair

Chairperson Payment opened the meeting with a traditional prayer.

Welcome and Introductions

Aaron Payment, MPA, HRAC Co-Chair

Stephen Kutz, RN, BSN, MPH, HRAC Co-Chair

Mr. Haverkate welcomed participants and conducted a roll call of tribal delegates and federal representatives.

Councilman Kutz invited Council members to introduce themselves. Following the introductions, Chairman Payment noted that the Council includes researchers, members of institutional review boards (IRBs), and individuals with multiple doctorates, which is a testament to the resilience of the American Indian spirit.

Councilman Kutz reviewed the rules and process for participation in the meeting, as set forth in the Federal Advisory Committee Act (FACA). He noted that, as a government-to-government body, the HRAC is exempt from many FACA provisions.

Opening Remarks

J. Nadine Gracia, MD, MSCE, Deputy Assistant Secretary for Minority Health and Director, Office of Minority Health (OMH)

Dr. Gracia began by noting that 2015 is the 30th anniversary of the Report of the Secretary's Task Force on Black and Minority Health (Heckler Report). The report documented the existence of health disparities among racial and ethnic minorities in the United States, including American Indians and Alaska Natives (AI/AN) and led to the creation of OMH the following year. The report called for improvements in key areas, including education and information, healthcare service delivery and financing, health professions development, cooperative relationships with the non-public sector, data development, and a research agenda. Those issues are relevant today.

Dr. Gracia presented significant milestones since the publication of the Heckler Report, including the creation of OMH (1986), the Strong Heart Study that examined cardiovascular disease and its risk factors among AI/AN men and women (1988), actions to address data collection and disaggregation of data, and the establishment of the Secretary's Tribal Advisory Committee (STAC) at HHS (2010). She noted that Secretary Burwell has encouraged other federal departments to institute tribal advisory committees at the cabinet level.

Dr. Gracia emphasized that OMH recognizes tribal sovereignty and understands the important government-to-government relationship between HHS and tribal communities.

Dr. Gracia reviewed the mission of OMH, which is to improve the health of racial and ethnic minority populations through the development of health policies and programs that will help

eliminate health disparities. OMH achieves that mission through five core functions: raising awareness of health disparities and health equity; promoting data collection disaggregated by race and ethnicity and other important demographic information; engaging in partnerships and networks; advancing policies to reduce disparities and advance equity; and fostering research to reduce disparities.

Dr. Gracia noted that OMH has an AI/AN Health Disparities program that funds research and data collection at Tribal Epidemiology Centers (TECs) and urban Indian health programs.

Dr. Gracia provided examples of OMH networks and partners, which include tribes and tribal organizations and tribal colleges and universities.

Dr. Gracia reviewed the strategic priorities of OMH: 1) support the development and implementation of the provisions of the Affordable Care Act that address disparities and equity; 2) lead the implementation, evaluation, and monitoring of the HHS Action Plan to Reduce Racial and Ethnic Health Disparities; and 3) coordinate the National Partnership for Action to End Health Disparities (NPA) and the National Stakeholder Strategy for Achieving Health Equity.

The HHS Disparities Action Plan is a department-wide commitment. It includes strategies to improve data collection and promote research methodologies to reduce disparities, including community-based participatory research. An important aspect is the implementation of the National Standards for Culturally and Linguistically Appropriate Services in Health and Healthcare (National CLAS Standards). OMH looks to the HRAC for advice on culturally appropriate research in AI/AN communities.

The NPA is a national community-driven movement that uses a social determinants of health approach to address health disparities. It includes an AI/AN Health Equity Caucus that serves as a forum for members of Regional Health Equity Councils across the country. The caucus is looking at strategies to enhance tribal, state, and federal efforts to advance equity in all policies. Mr. Haverkate can provide updates on the activities of the caucus.

Dr. Gracia noted that the OMH Resource Center (OMHRC) provides extensive resources and products to support research on health disparities. The OMH website is the largest repository of data on minority health disparities and minority health. OMHRC also participates in OMH programs such as the “Circle of Life” HIV/AIDS prevention and intervention curriculum designed for AI/AN youth and the new Higher Education Technical Assistance Program (HETAP) that will provide technical assistance to strengthen the capacity of tribal colleges and universities and other minority-serving institutions of higher education over the next five years.

Discussion

- Councilman Kutz noted that collecting all AI/AN research in one place, including historical records, was a longstanding priority of the Council. He asked if the OMHRC would serve that purpose. Dr. Gracia replied that Mr. Haverkate and Dr. Rashida Dorsey in the Division of Policy and Data had been exploring that issue.
- Dr. Haring stated that the OMHRC literature review service had been extremely helpful in his research. Other useful databases for research on Indian Country include the Native

Circle at Mayo Clinic and an online collection of historical documents in social sciences and health behavior at the University of New Mexico that is searchable by tribe.

- Ms. Frederick stated that tribal data centers are important because very few studies have been published. Information from those centers should be fed into the OMHRC.
 - Ms. Antone Nez noted that the TECs work with local tribes and the Indian Health Service (IHS) to develop local databases.
- Dr. Villegas noted that federal agencies are changing how they report data on race and ethnicity. An individual who is both AI/AN and Hispanic is only reported as Hispanic. It is increasingly difficult to look at regional trends if AI/AN data are not disaggregated. It is also challenging to get data on youth and children. The National Congress of American Indians (NCAI) is hosting a gathering in South Dakota for TECs and wants to work with OMH on meaningful approaches to expand research on children. She emphasized the need to build the infrastructure for tribal-level data collection.
 - Dr. Gracia said she would be having an in-depth discussion with the OMH data policy team to look at the quality of data sets that are used to inform policies and programs. OMH has grant funds this year for tribal and state public health agencies. The Affordable Care Act established offices of minority health across agencies such as HRSA and the National Institute for Minority Health and Health Disparities (NIMHD) at NIH. OMH works closely with those offices, and they present opportunities for collaboration.
- Chairperson Payment suggested that the HRAC should inform those who are doing research on AI/ANs to separate members of federally recognized tribes from those who self-report their tribal status, because self-reported data are not reliable. He noted that he prepared a comprehensive document on data collection in AI/AN populations to inform his dissertation committee.
 - Dr. Gracia reported that OMH chairs the HHS Health Disparities Council, which includes the Census Bureau and the Office of Management and Budget. They are looking at data collection, especially with regard to individuals who check more than one race, and it would be important for the HRAC to provide input for that discussion.
- Councilman Kutz expressed concern that Native researchers do not conduct research at the federal level. AI/AN communities and researchers have different perspectives on what is important. This presents challenges for funding, oversight, research, and publishing. It is difficult to get Native research published.
 - Dr. Meyer stated that ACF's Tribal Home Visiting Program helps to build the capacity of tribal researchers. All grantees are required to conduct a rigorous evaluation, which they design based on their own priorities. The Tribal Early Childhood Research Center in Denver is working with grantees to develop papers for a special issue of the Infant Mental Health Journal.
- Dr. Haring noted that several research mechanisms are emerging at the NIH, such as an R01 study for health promotion, but many Native researchers are not at that level. It is important to fund junior researchers and create a mentoring award.
 - Councilman Kutz noted that Chairperson Payment serves on the NIH Tribal Advisory Committee (TAC) and could bring those issues to their attention. He also stressed the need for more tribal researchers on review panels.

- Dr. Wadhvani noted that AHRQ receives grant applications from tribal researchers, but most are not funded. Since they began including tribal members on their review panels, proposals for tribal studies have been recommended for funding and the panels have provided feedback to improve the studies. Dr. Wadhvani encouraged HRAC members to participate on review panels. AHRQ learns from tribal researchers, and researchers learn what constitutes a competitive application.
- Ms. Antone Nez stated that the Navajo Nation would like to identify one or two individuals to participate in AHRQ review panels.
- Dr. Dillard supported the idea of more R21 options. Smaller awards are not sufficient to complete a study, because it costs more to conduct a study in Indian Country. She noted that the circle of Native researchers is very small, so there is often a conflict of interest. Some funders include community members who can speak to priorities, rather than researchers.
- Ms. Satter noted that HHS has an option to include reviewers from other agencies, but it is not widely used- this could be a possible solution.

HRAC History, Purpose, and Member Roles/Responsibilities

Cara Cowan Watts, MS, Oklahoma Area Delegate and Former HRAC Chair

Councilwoman Cowan Watts began by reviewing the history of the HRAC:

- 2005: A formal process was launched to discuss health research issues and priorities and to solicit nominations for members. Tribal leaders and HHS drove the process, with leadership from IHS.
- 2006: The first meeting was held in May, with Councilwoman Cowan Watts and Cecilia Fire Thunder (Aberdeen Area) as co-chairs. The FACA exemption was instituted at that time.
- 2007: A contractor was secured to support the HRAC. The federal working group met in September and October, and the HRAC met in December. The HRAC developed a discussion guide to ascertain health research priorities in Indian Country, and HRAC members sent the guide to tribal leaders in their Areas. Top concerns were cancer, diabetes, obesity, cardiovascular disease, and behavioral health. The study guide increased awareness about the HRAC. Councilwoman Cowan Watts recommended repeating the process with additional questions related to research ethics and policy.
- 2008: Councilwoman Cowan Watts and Sally Smith (National At-Large Member) were elected co-chairs. The charter was ratified in June, and town hall meetings were held at the annual Native Health Research conference and the National Indian Health Board (NIHB) conference.
- 2009: The HRAC held a face-to-face meeting in Washington, DC.
- 2010: The HRAC submitted recommendations to HHS Secretary Kathleen Sebelius in July and November, introduced the HRAC Research Roundtable to obtain perspectives that cannot be included in the HRAC due to FACA rules, and conducted outreach at the NIHB and Native Health Research conferences and the HHS Tribal Budget Consultation.
- 2011: The HRAC held a face-to-face meeting in June and approved the revised charter. The HRAC Research Roundtable was held in November.

- 2012: The HRAC held a face-to-face meeting in Denver, where Councilwoman Cowan Watts and Councilman Kutz were elected as co-chairs. The HRAC Research Roundtable was held in November.
- 2013: The HRAC submitted recommendations by testimony and submitted a letter of request to the HHS Data Council in July regarding sharing of tribal health data and requesting a tribal consultation.
- 2014: The HRAC held a face-to-face meeting in June and elected Councilman Kutz and Chairman Payment as co-chairs. The Research Roundtable was held the following day.

Councilwoman Cowan Watts reviewed the purpose of the HRAC:

- Obtain input from tribal leaders;
- Provide a forum to communicate and coordinate AI/AN health research activities; and
- Provide a conduit for dissemination of research information to tribes.

Councilwoman Cowan Watts reviewed the structure of the HRAC:

- Federally recognized tribal delegates;
- Elected and/or appointed tribal officials representing the 12 IHS Areas, plus four National At-Large members; and
- Participating HHS components: ACF, AHRQ, ASPE, CDC, HRSA, IHS, NIH, OMH, Intergovernmental and External Affairs (IEA), and the Substance Abuse and Mental Health Services Administration (SAMHSA).

Councilwoman Cowan Watts noted that the HRAC meets via quarterly conference calls and one in-person meeting per fiscal year (FY). If a delegate or alternate does not participate in three successive meetings, they may be removed per the charter. Voting is by consensus.

Councilwoman Cowan Watts outlined HRAC member responsibilities:

- Participate in calls, meetings, and other communications;
- Provide feedback and recommendations on health research issues to their community and Area tribes; and
- Share information and resources with tribes in their Areas..

Councilwoman Cowan Watts highlighted key challenges for the HRAC:

- Difference between HHS and IHS geographic regions;
- Loss of key staff partners at federal agencies; and
- Difficulty of disseminating information.

Councilwoman Cowan noted that the HRAC raised awareness within Indian Country about the National Children's Study (NCS). These discussions were important even though the NCS is no longer funded. The HRAC provides a forum to communicate concerns about health research issues with HHS agencies that impact the lives of AI/ANs.

Councilwoman Cowan Watts suggested a number of priorities for the HRAC going forward:

- HHS-wide policy on research in Indian Country;

- Oversampling for all research that will impact Indian Country, including existing research such as the CDC Behavioral Risk Factor Surveillance System;
- Explicit request for ownership of data;
- Single healthcare research database (qualified by tribes; include articles and church records; list of disqualified researchers; ownership of data);
- Data sharing agreements with IHS National Data Warehouse (NDW), HHS, NIH, and universities;
- IRB Point of Contact list published annually in the Federal Register;
- Promote IRB best practices throughout Indian Country;
- HHS IRB recognition process (all agencies);
- Recognition of tribes as lead or co-lead research entity by HHS and universities;
- Scholarships/training/pipeline;
- Definition of AI/AN;
- Direct reporting relationships with the STAC and Native Research Network (NRN); and
- Cultural and linguistic competence requirements for review panels.

Discussion

- Councilman Kutz emphasized the importance of establishing IRBs. Those who fund research in Indian Country should recognize that research is not valid unless it is authorized and should require documentation that tribal approval has been obtained.

HRAC Research Roundtable Discussion on Historical Trauma Research

Maria Yellow Horse Brave Heart, PhD, Associate Professor Psychiatry and Behavioral Sciences, University of New Mexico Health Sciences Center

Dr. Brave Heart provided context for her presentation with a quote from the Hunkpapa Lakota Elders Council about traditional mourning and a quote from a Lakota parent in recovery. Key points of her presentation were as follows:

- Native communities suffer from multiple losses, trauma exposure, and psychosocial risk factors. Many community members state that they feel they are always in a state of mourning.
- Cumulative massive group trauma originated in genocide and negative boarding school experiences; generational adversity compounded that trauma. Trauma is transferred across generations through impairment of traditional parenting skills, identification, and other complex processes.
- Historical trauma (HT) is defined as cumulative emotional and psychological wounding from massive group trauma across generations, including the current lifespan.
- Historical trauma response (HTR) is a constellation of features in reaction to massive group trauma; it includes historical unresolved grief.
- Development of HT theory and interventions:
 - 1985-1988: Developed HT concept to reduce the suffering of Native people.
 - 1992: Conducted first Native HT intervention. Founded the Takini Network/Institute to address healing from HT among the Lakota and other Native people. Takini is a Lakota word that means survive or return to life.

- 1996-2004: Designed the first Lakota parenting curriculum incorporating HT and was awarded a number of SAMHSA grants.
 - 2001-2004: Models for Healing Indigenous Survivors of HT conferences, with support from SAMHSA.
- 2009: Historical Trauma and Unresolved Grief (HTUG) intervention was named a Tribal Best Practice by First Nations Behavioral Health and SAMHSA.
- The HTUG intervention “Return to the Sacred Path” was developed in recognition of the need to define normal and healthy grief within a Native cultural framework, while being mindful of regional and tribal differences. It incorporates the Lakota Seven Laws and has been tailored for tribal groups across the U.S. and Canada. The model has four components:
 - Understanding the trauma
 - Releasing our pain
 - Transcending the trauma
 - Confronting historical trauma and embracing our history
- HTR factors vary widely, which makes research difficult. Responses that have been studied include suicidal behaviors, depression, post-traumatic stress disorder, and prolonged grief. Historical unresolved grief also includes yearning, pining, preoccupation with thoughts of ancestors lost in massacres, and loyalty to ancestors with a focus on one’s own suffering as a way to honor them.
- Evaluation of the HTUG intervention found:
 - Reduction in sense of feeling responsible for undoing painful historical past
 - Less shame, stigma, anger, sadness
 - Decrease in guilt
 - Increase in joy
 - Improved valuation of true self and of tribe
 - Increased sense of personal power
- A qualitative evaluation of the parenting program found:
 - Increased sense of parental competence
 - Increase in use of traditional language
 - Increased communication with own parents and grandparents about historical trauma
 - Improved relationships with children, parents, grandparents, and extended kinship network
 - Increased pride in being Lakota and valuing one’s own culture
- Dr. Brave Heart currently serves as principal investigator for a pilot clinical trial funded by the National Institute of Mental Health (R34-Iwankapia-Healing Study) that builds on prior development and evaluation of HTUG. Emerging themes include:
 - Limited resources, travel distances, multiple IRBs/RRBs
 - Differences between and within tribes regarding degree of acculturation and assimilation and need to respect tribal cultural diversity
 - Participants and research team members must deal with historical trauma and ongoing family and community trauma
 - Traditional tribal culture as protective factors
 - Participants’ testimonies of perceived positive response to interventions

Dr. Brave Heart offered the following concluding remarks:

- Empirically supported treatment (EST) and evidence-based practice (EBP) are imposed on tribal communities when there is no evidence that they work with AI/ANs, since no Natives are included in studies of these interventions.
- Cultural adaptations of EST/EBP are often superficial and do not emerge from tribal culture and wisdom.
- Tribal communities have traditional and innovative practices, with some impressions or qualitative data illustrating positive responses. These should be supported with funding to develop the evidence base and determine whether they are helpful.
- Studies on inherited vulnerability to depression and addiction are meaningful, and it is important to increase knowledge about brain chemistry in addictions and depression.
- There is some evidence that alternative-healing strategies can increase brain activity and that traditional and alternative healing can alter brain chemistry.
- There is a need to define healthy grief resolution within Native attachment styles, traditional grieving practices, and other cultural aspects.

Following her remarks, Dr. Brave Heart presented a video, *Celebration of Survival: The Takini Network*.

Discussion

- Chairman Payment stated that it would be important to continue the momentum of the STAC into the next administration. He suggested that the STAC and HRAC could convene a colloquium, with the proceedings edited by Dr. Brave Heart.
- Ms. Bohlen noted that the NIHB national conference this year would focus on healing from the boarding school trauma. She invited Dr. Brave Heart to engage with them.
- Councilman Kutz stated that many of the interventions developed to heal from historical trauma are not seen as valid. SAMHSA funding can be a linchpin.

HRAC Website Updates and AI/AN Health Research Portal/Clearinghouse

Roland Zebina, IT Manager, Office of Minority Health Resource Center (OMHRC)

Faye Williams, Knowledge Center Manager, OMHRC

Mr. Zebina introduced the revised HRAC website, which had a soft launch on June 3 (<http://minorityhealth.hhs.gov/hrac>). The site is more functional and is easier to update. It includes a new feedback section with a dropdown feature that allows comments to be sent to a specific region, which will help to manage the volume of email that members receive.

Ms. Williams provided an overview of the OMHRC Knowledge Center and highlighted resources related to AI/AN populations:

- Information services, including funding searches;
- Program services, including document retrieval, literature searches, organization searches, statistics and data, legislative tracking, and current awareness;
- Library collection of 52,000 records (books and documents, indexed journal articles, organizations, journal subscriptions), with 57 percent available online;
- Catalog search <http://minorityhealth.hhs.gov/omh/opac>;
- Digital archives on minority health (<http://archive.org/details/minorityhealth>);

- Statistical profiles on the five major racial and ethnic groups, including AI/AN.

Ms. Williams noted that HRAC members can stay connected with OMHRC through email updates, the website, and social media.

Discussion

- Ms. Antone Nez asked if OMHRC would track traffic to the website.
 - Mr. Zebina said they would do that and could provide data to the HRAC.
- Chairperson Payment asked if the website could include a function where individuals in Indian Country could provide input on the HRAC's priorities.
 - Mr. Zebina said they could create another form based on fields that the HRAC provides.
- Dr. Haring suggested that a press release about the new site could help the HRAC disseminate information.
- Mr. Zebina noted that the HRAC could share videos and documents through the website and could track how many times they are viewed or downloaded. OMHRC can create widgets that members can cut and paste onto their own websites.
- Mr. Haverkate encouraged members to use the website to communicate with their communities and obtain feedback on HRAC activities and priorities.
- Councilwoman Cowan Watts suggested linking the priorities page to the existing comment form.
- Chairperson Payment asked if the Knowledge Center could provide personal help for online searches.
 - Ms. Williams replied that OMHRC staff is happy to answer questions.

Business Item

Chairperson Payment called for a motion to approve the minutes of the March 26, 2015 quarterly conference call.

MOTION: Councilman Kutz moved to approve the minutes of the March 26, 2015 quarterly conference call. The motion was seconded by Mr. Peercy and carried by unanimous voice vote.

HRAC Charter

Rick Haverkate

Mr. Haverkate reviewed the revisions to the HRAC charter. He noted that many of the revisions entailed minor changes in formatting or punctuation. Other changes made the HRAC compliant with the STAC charter.

Major changes include the following:

- The nomination process and term limits were clarified;
- At-Large seats can no longer be reserved for a specific organization; and
- The statement that the Tribal Consultation Policy of 2010 authorizes the HRAC was removed, because the Council was created prior to that date.

Mr. Haverkate stated that the Office of the General Counsel (OGC) at HHS approved the revised version. However, Council members could propose additional revisions.

Chairperson Payment called for a motion to review the redlined version, with key changes highlighted.

MOTION: Councilwoman Cowan Watts moved to review the redlined version of the HRAC charter. Ms. Bohlen seconded the motion.

MOTION: Councilwoman Cowan Watts moved to table approval of the charter to the first order of business on Day Two. Ms. Bohlen seconded the motion, and the motion carried by unanimous voice vote.

Tribal Advisory Committees (STAC, CDC, CMS, SAMHSA, NIH)

STAC

Stephen Kutz, Aaron Payment, Ramona Antone Nez

Chairperson Payment reported that the Secretary brought a question related to suicide and its links to historical trauma to the STAC, and the committee spent the entire session with the Secretary discussing that issue.

Ms. Antone Nez outlined the issues the STAC had prepared to present to the Secretary:

- Arizona Medicaid: Reject a 1092 waiver that would be detrimental to AI/ANs;
- Contract support costs: Impact on self-governance and ACA implementation;
- IHS “Dear Tribal Leader” letter dated May 22, 2015 regarding the settlement with employee unions. The Navajo Nation expressed concern about the lack of tribal consultation regarding re-allocation of funds;
- Suicide is a leading cause of death among AI/AN communities. There is a need to better understand the impact of historical trauma, alcohol and substance abuse, mental health issues, and unemployment. The STAC recommends establishing a workgroup to review existing approaches and develop a comprehensive approach, which is flexible, based on taboo/culture/language/community/traditional practitioner;
- 477 program expansion and Head Start;
- Dental health and special diabetes project initiatives;
- Definition of Indian;
- Tracking and follow-up of STAC priorities;
- Medical marijuana/recreational marijuana (state and federal laws); and
- Indian Child Welfare Act issues.

Chairperson Payment noted that he submitted a proposal to grant an exception for Head Start programs that might have a challenge in meeting annual yearly progress standards due to limited funding and to work with those programs to meet the standards.

Councilman Kutz reported that the STAC asked HHS to coordinate research across agencies on critical issues such as HT, substance abuse, and suicide. He also noted that concerns about

medical marijuana extend to recreational use. Research is needed to understand how to deal with marijuana in the behavioral health system.

Discussion

- Councilman Kutz noted that the Tribal Advisory Committee for the CDC would include a behavioral health consultation on traditional healing on August 4, 2015. It would be important to have tribal representatives in attendance.
 - Ms. Satter said she could provide information to help HRAC members publicize the meeting.
- Dr. Etz stated that a number of NIH centers are beginning to fund marijuana research, including the impact of policy changes regarding marijuana.
- Ms. Satter noted that the Public Health Law program at CDC has conducted research on issues related to marijuana, such as legal limits for driving, and could provide advice to tribal communities. There is currently not enough information to develop a legal memo.
- Chairman Payment expressed concerns about miscommunication that marijuana is legal in Indian Country. Decriminalization is sending mixed messages. Tribes have to sign assurances that housing on the reservation will be drug free, and IHS clinics will lose their license if they prescribe medical marijuana.

HRAC Priorities Breakout Discussions

The Council broke into three groups to identify their top priorities for the remainder of the current fiscal year and for FY2016. The groups identified the following issues:

GROUP 1

1. Social determinants cluster:
 - Historical trauma; and
 - Adverse childhood experiences.
2. Culture as prevention/intervention:
 - Spirituality;
 - Family/social connections;
 - Traditional values promotion; and
 - Language(s).
3. What works the Indian way? (culture-specific modes of intervention)
4. Special study sections:
 - Culturally competent

GROUP 2

1. HHS-wide research policy on AI/AN:
 - Oversampling;
 - Funding; and
 - Data sharing, access, ownership.
2. IRBs:
 - List of point of contacts in Federal Register (include tribal colleges); and
 - Technical assistance.

3. Library/database housed at the Institute of Medicine
4. Formalize reporting relationship with the Native Research Network (NRN) and STAC
5. Scholarships/pipeline

GROUP 3

1. Resources/access to information:
 - Native research database/clearinghouse;
 - Research to include evaluation, public health activity, surveillance; and
 - “Grandma test”.
2. Accountability:
 - Annual data call;
 - Intradepartmental Council on Native American Affairs (ICNAA)/Westat;
 - Efficacy and impact of the data;
 - Application of the results (“So what?”); and
 - Federal grant announcements reflecting more culturally based research questions.
3. Training:
 - Local level capacity building to inform practice; and
 - Working with researchers to develop more applied research.

Next Steps and Closing Blessing

Mr. Haverkate distributed the redlined version of the charter for Council members to review.

Councilman Kutz closed the day with a traditional Potlatch song in honor of Councilwoman Cowan Watts and presented her with a hand-carved shaker.

DAY TWO

Invocation

Councilman Kutz began the meeting with a traditional prayer.

Welcome and Introductions

Chairperson Payment provided a recap of Day 1 and reviewed the agenda for Day 2.

Chairperson Payment called for a motion to approve the reports from FY2013 and FY2014 and the Health Research Report for FY2013.

MOTION: Councilwoman Cowan Watts moved to approve the reports from FY2013 and FY2014 and the Health Research Report for FY2013. The motion was seconded by Councilman Kutz and carried by voice vote, with one abstention.

Councilwoman Cowan Watts noted that the new website was not mobile phone ready, which meant that it would not appear in Google searches. Chairperson Payment noted that *Indian Country Today* would feature a story on the revised website once it is fully compliant.

Approval of Revised Charter

Council members discussed the proposed revisions to the HRAC charter, using the redlined version. Chairperson Payment reminded the Council that the revisions were made to make the HRAC charter compliant with FACA and to bring it into alignment with the STAC charter.

Mr. Haverkate reviewed the three main changes, which he presented on Day 1. He noted that many of the comments in the redlined version were internal comments within OMH. The revised version that was included in the meeting packet addressed all of those comments.

Ms. Antone Nez noted that the version in the meeting packet did not include the Background section. Mr. Haverkate stated that some of the history in the Background section was removed at the suggestion of the OGC. Information that was deemed relevant, such as the list of HHS components, was incorporated into the Purpose and Function sections of the revised document.

Council members reviewed the document section by section. Key points were as follows:

- Term limits
 - Mr. Haverkate pointed out that there is no term limit, but members must be re-nominated every two years by an elected or appointed tribal leader.
 - Councilman Kutz stated that the language about Period of Service did not clearly indicate whether the terms of current members are overlapping.
 - Mr. Haverkate replied that OMH was in the process of determining how to stagger the terms of current members so they would not expire at the same time. He would contact current members in the coming months to determine when their terms expire.
 - Dr. Haring requested clarification of the role of an alternate.
 - Mr. Haverkate stated that an alternate is tied directly to the member and represents that member when he or she is unable to attend a meeting.
 - Chairperson Payment noted that the alternate is a proxy, which is different from the STAC.
- Nominations
 - Councilwoman Cowan Watts noted that the term “tribal leader” was not defined.
 - Chairperson Payment suggested using the term “Elected or Appointed Governing Official.”
 - Mr. Haverkate pointed out the priority order listed in section VII.A (Selection Process, Area Representatives).
 - Chairperson Payment noted that this was consistent with the tribal consultation process. However, he felt that the nominating official should be up to the discretion of the tribe.
 - Mr. Haverkate stated that HRAC membership should be tied to someone who is an elected official. HRAC members themselves do not need to be elected officials of their tribes.
 - Ms. Satter stated that nomination by an elected official makes the HRAC a government-to-government body, which qualifies it for FACA exemption.
 - Councilwoman Cowan Watts asked how conflicts would be resolved.
 - Mr. Haverkate referred to the end of section VII.A, which outlines the process to be followed when there is more than one nomination for a given Area. He

noted that the Deputy Assistant Secretary would make the final decision, which is consistent with the STAC. That language would be added to the HRAC charter.

- Ms. Antone Nez noted that the Navajo Nation has three branches of government and it has 110 chapters, each with a president and vice president. They are working on how to address situations where there are multiple messages coming from the Navajo Nation. It will be important to define that issue for Council nominations.
 - Mr. Haverkate stated that if multiple nominations were received from the Navajo Nation, OMH would follow the priority order.
- Vacancy
 - Councilman Kutz referenced a statement on Page 4 of the redlined version regarding the process to be followed if a tribe removes a leader. He felt it would be important to honor the commitment and work of the alternate.
 - Mr. Haverkate stated that the proposed language in the redlined version was not approved. The process that would be followed when a vacancy occurs is described in the second paragraph of Page 6 of the revised document. The alternate would become the delegate, if there is one.
 - Councilman Kutz noted that the section on page 6 did not state that the alternate would become the delegate. He emphasized that the process should align with the STAC.
- Other issues
 - Ms. Antone Nez suggested that the charter should include a glossary of terms.
 - Ms. Satter noted that the CDC's Tribal Support Unit developed a glossary of terms that might be available on their website.
 - Ms. Satter suggested that it would be helpful to provide Council members with a copy of the FACA guidance.
 - Councilwoman Cowan Watts said it would be helpful to send the revised charter to all tribes and Area health representatives with a letter outlining the new process and expectations.

Chairperson Payment suggested that the Council could approve the revised charter and make further revisions during a future conference call, or table it for another meeting.

Dr. Gracia stated that nothing would preclude the Council from tabling the vote. However, it would be important to move forward to ensure that the charter is aligned with the STAC.

Councilman Kutz noted that it would be important to ensure a quorum on the conference call so the charter could be approved and would not need to be deferred to the next annual meeting.

Mr. Haverkate suggested that Council members could send their comments or questions to him, and he would copy all members on his reply.

MOTION: Councilwoman Cowan Watts moved to table discussion of the charter to a conference call on Thursday, June 18 at 4 p.m. ET, with electronic vote to be registered by 5 p.m. ET on Friday, June 19. The motion was seconded by Councilman Kutz and carried by unanimous voice vote.

Ms. Antone Nez requested clarification of the minimum number of votes that must be received to validate the decision. Chairperson Payment stated that the quorum for the HRAC is 50 percent, plus one. If the quorum is met, the majority of votes would carry. If the quorum is not met, the proposed action expires.

Mr. Haverkate noted that the Council has 16 seats, with one vacancy. The quorum is 9 members.

Ms. Antone Nez stated that it would be important to inform the seated members who were not in attendance at this meeting about the conference call and the voting process and provide contact information for two additional people that OMH could communicate with on their behalf.

ACTION: Mr. Haverkate will send an email to HRAC members who missed this meeting regarding the schedule for the conference call and vote. The email will include a copy of the previous version of the charter, the redlined version, and the revised version.

HRAC Communications

Mr. Haverkate asked the Council for their preferences regarding the most effective way to communicate with members so they can fulfill their responsibilities without overwhelming them with emails. He suggested that OMH could create a password protected section of the website where information could be posted for members to review.

Chairperson Payment said it would be helpful for all members to submit dates when they will not be available for conference calls. He noted that multiple levels of tribal councils make it challenging for delegates to obtain input.

Councilman Kutz said it might be useful to provide an alternate email address so HRAC messages would be easier to find. It would be helpful to receive documents in a way that does not overburden members' accounts, or post them where they can be downloaded. It would also be helpful to receive a brief synopsis of conference calls prior to receiving formal minutes.

Mr. Haverkate stated that OMH could send text messages, if requested. He offered to send a poll asking members to provide an alternate email address. He noted that he would like to have contact information for two additional people that OMH could communicate with on behalf of each delegate.

Dr. Haring stated that the NRN could disseminate information through its list serve.

Councilwoman Cowan Watts suggested that the HRAC website could include a place to sign up to receive communications. Mr. Haverkate said that OMH was working with the logistics contractor to make that mechanism as user-friendly as possible.

ACTION: Mr. Haverkate will request 1) an alternate email address for each delegate and alternate and 2) the names and contact information for two additional people that OMH could communicate with on their behalf.

Business Items

Nomination of Chair and Co-Chair

MOTION: Councilwoman Cowan Watts nominated Aaron Payment and Stephen Kutz to serve as chair and co-chair of the HRAC for the coming year. Ms. Bohlen seconded the motion.

Both candidates accepted the nominations. Council delegates agreed to vote on the motion after lunch.

Other Business

Ms. Satter announced that the Tribal Advisory Committee for CDC invited traditional healers to attend a meeting in August 2015. The Center is interested in funding programmatic activities on the use of traditional medicine to promote well-being. They would like to identify participants by June 17, 2015.

Councilman Kutz said this was mentioned at the STAC meeting, but no details were provided. It would be important to know if travel sponsorship was available, because spiritual leaders are located across the country.

ACTION: Ms. Satter will forward the flyer to Dr. Gracia for distribution to Council members.

Workgroup Planning

Council delegates reviewed the priorities that emerged during the breakout session on Day 1 and discussed how to consolidate them.

Councilwoman Cowan Watts noted that she reorganized her recommendations from the previous day into six major points, most of which were reflected in the issues that emerged from the breakout session. Many of her points were related to the development of an HHS-wide policy for research in Indian Country. Councilwoman Cowan Watts felt that most of the work could be done within two years, and many items could be addressed within the coming year.

Councilman Kutz noted that data ownership is a critical issue. When HHS funds research in Indian Country, the grants do not specify that the data belong to the tribes.

Ms. Frederick stated that developing a data agreement would be a major undertaking, especially since each agency has its own programs and each tribe has its own law. She suggested developing a five-year plan, with specific components for each year.

Council members agreed to use Councilwoman Cowan Watts' recommendations as a framework and incorporate the issues from the breakout sessions within that structure. The following list of priorities emerged from that process:

HHS-wide (umbrella) policy for research:

- Oversampling;
- Funding;
- Data sharing, access, ownership;

- Accountability;
 - Annual data call
 - ICNAA/Westat
 - Efficacy and impact of the data
 - Application of the results (“so what?”); and
- HHS Office of the General Counsel (OGC).

Native healthcare research database/clearinghouse:

- Housed at the National Library of Medicine;
- Include evaluation, public health activity, and surveillance research; and
- “Grandma test”.

IRB Point of Contact list published in the Federal Register annually:

- Include all federally recognized tribes and tribal colleges.

Build local capacity to inform practice:

- Scholarships/training/pipeline; and
- Promote IRB best practices throughout Indian Country.

Social determinants of health:

- Historical trauma, adverse childhood experiences;
- Culture as prevention/intervention; and
- Working with researchers to develop more applied research.

Culture-specific modes of intervention:

- Special study sections; and
- Federal RFAs reflecting more culturally based research questions.

Discussion

- Mr. Haverkate noted that work on developing a Native research database or clearinghouse was already underway. The policy recommendations were also feasible.
- Councilwoman Cowan Watts suggested that an annual IRB POC list in the Federal Register could be an activity for Year 1, and developing best practices could be addressed in subsequent years.
- Chairperson Payment noted that IRB best practices would build capacity within tribes, and many things flow from that.
- Ms. Satter noted that the NRN was created with funding from OMH because there was no professional organization to bring together Native researchers and support the next generation. The organization has had leadership challenges and is not holding an annual conference this year. CDC would do whatever it can to support the Council’s relationship with the NRN.
- Dr. Haring noted that the NRN had begun planning for a conference in 2016. The network is a unique blend of science, federal support, and business. He encouraged Council members to support the organization and present at the conference.

- Ms. Bohlen raised four points: 1) Leveraging what the HRAC and the STAC do is a structural issue. There are tribal advisory committees (TACs) across HHS. NIHB has asked the Secretary for at least one joint meeting of the TAC chairs each year to leverage their knowledge and work. If they were to meet the day before the STAC meeting, they could inform the work of the STAC. 2) HRAC goals and objectives should include budget, analysis, and positioning in terms of tracking federal investment in tribal health research. 3) All federal advisory committees should recognize that tribal consultation occurs only once per year, and participation is not funded. The HRAC should take steps to ensure that chairs of all TACs attend that meeting to bring issues forward to the larger body. 4) The NRN is welcome to join the NIHB's annual conference this year.
- Councilman Kutz noted that the STAC addresses many issues in addition to research so STAC members have a broad focus. However, if there was a specific seat on the STAC for an HRAC delegate, he/she can bring a laser focus on the Council's priorities.
- Ms. Satter noted that the HRAC would have more access to the STAC once the charters are aligned.

Business Item

HRAC Chair and Co-Chair Election

MOTION: Councilwoman Cowan Watts made a motion to approve Chairperson Payment and Councilman Kutz as co-chairs. Ms. Frederick seconded the motion.

Mr. Haverkate called the motion. The motion carried by unanimous voice vote.

Federal Partner Updates

AHRQ

Kishena C. Wadhwani, PhD

- AHRQ's new mission is to produce evidence to make healthcare safer, higher quality, more accessible, equitable, and affordable, and to work within HHS and with other partners to make sure that the evidence is understood and used.
- AHRQ's new priorities are to: 1) improve healthcare quality by accelerating implementation of patient-centered outcomes research (PCORI); and 2) make healthcare safer; increase accessibility to healthcare; and improve healthcare affordability, efficiency, and cost transparency.
- AHRQ has issued many funding opportunity announcements (FOAs) related to implementation and dissemination of evidence-based research.
- HRAC members are encouraged to bring existing evidence-based research to tribal communities of participate on review committees.
- AHRQ continues to provide partial funding support to HRAC activities, including the annual meeting.
- A detailed list of AI/AN-related research was provided in the written report.

ACF

Aleta Meyer, PhD

- The Children's Bureau convened a workgroup that developed a road map to create a new narrative for research and evaluation in tribal communities that extends beyond child

welfare. The roadmap has a strong focus on data collection to benefit communities and is an excellent model for many kinds of health research.

- ACF began a process two years ago to redesign the Head Start national study of children and families, which did not previously include AI/AN Head Start centers. They launched a study of Head Start families in Region 11 two years ago. The process for recruiting study participants includes tribal IRB review and a qualifying statement. A workgroup comprised of Head Start directors and researchers is reviewing every measure to determine whether it is relevant, whether it should be modified for tribal communities, and whether additional measures are needed.

Discussion

- Chairman Payment noted that the advisory group includes Tribal Head Start directors, who are providing input regarding culturally appropriate approaches. Participation in this study helps to demonstrate the efficacy of Tribal Head Start.

ASPE

Adelle Simmons

- The office coordinates work across the department and conducts analysis of program evaluations. Findings are published on their website (www.aspe.hhs.gov).
- ASPE works with IHS to identify research questions that can be answered with available data. Many administrative data sets do not include refined categories of race and ethnicity. Council members are welcome to submit research questions or proposed methodology.

Discussion

- Ms. Antone Nez asked if it was possible to receive a copy of the report on Tribal Medical Collections. Ms. Simmons replied that the full report was in clearance and would be published on the ASPE website once it is approved. Summary findings are available on the NIHB website for the Data Symposium.

NIH

Joyce Hunter, PhD

- The FY2014 report on AI/AN activities at NIH was included in the meeting materials.
- The NIMHD focuses on biomedical and behavioral research to promote better health outcomes for all Americans. One of its goals is to make research more diverse and to eliminate research gaps.
- The NIH Tribal Consultation Advisory Committee has vacancies for a primary representative from the Albuquerque Area and alternate representatives from the Aberdeen, Billings, and Phoenix Areas. The first tribal consultation is scheduled for September 25, 2015, in conjunction with the NIHB conference. A conference call will be held on July 21.
- A new website will provide information on research projects conducted by AI/AN researchers and publications stemming from those projects. The website should be active by September 2015. The link will be posted on the main NIH website as well as the websites for the 27 institutes and centers within NIH. AI/AN organizations such as NIHB and NCAI can post the link on their websites.

- Following the STAC meeting on historical trauma in March 2015, NIH prepared a preliminary report on research in this area. The portfolio is small, but it is extremely diverse.
- NIH wants to ensure the diversity of its peer review committees. Dr. Hunter encouraged HRAC members to identify qualified researchers who could serve as reviewers or to apply to serve as reviewers themselves. Names or applications should be submitted to Dr. Lawrence Tabak (Lawrence.tabak@nih.gov).
- NIMHD held the first annual AI/AN Research Forum in November 2014.
- NIMHD is in transition and has had an acting director since April 2014. The new director, Dr. Eliseo Perez-Stable, will start in September 2015.

Discussion

- Chairperson Payment noted that tribal representation on peer review panels was a priority for the Council. He asked if a flyer was available to help recruit reviewers. Dr. Hunter said she would get the materials from the Center for Scientific Review and provide them to Mr. Haverkate.
- Councilman Kutz asked when the compendium of research on historical trauma would be available. Dr. Hunter said the information was currently being compiled. She would provide it to the Council as soon as it is available.

ACTION: Dr. Hunter will provide materials for recruitment of peer reviewers to Mr. Haverkate.

HRSA

Michael Weaver

- Mr. Weaver serves as tribal liaison to the acting HRSA Administrator and coordinates with all Bureaus and Offices within HRSA.
- The National Health Service Corps (NHSC) offers financial support to primary care providers who practice in underserved areas across the country through loan repayment and scholarships. They do not fund research, but they can assist with pipeline issues.
- Bureau of Primary Healthcare (BPHC) funds health centers across the country. They are actively trying to increase the number of tribal applicants for HRSA programs and to recruit AI/AN grant reviewers.
- The Maternal and Child Health Bureau (MCHB) works with tribal communities through the Healthy Start and Home Visiting programs.
- HRSA's tribal consultation will take place in the fall of 2015. Dates will be provided as soon as they are finalized. Outcomes of the 2014 tribal consultation can be accessed through the AI/AN Health link on the home page of HRSA's website (www.hrsa.gov).
- HRSA will look closely at how to implement the HRAC's recommendations.

Discussion

- Councilman Kutz noted that many tribal clinics do not qualify for the NHSC loan repayment programs because they are not located in underserved areas. A recent study in the State of Washington found that despite healthcare reform and Medicaid expansion, Indian people engage in the healthcare system at the lowest rate. AI/AN clinics need resources to ensure better access to care.

IHS

Mose Herne

- IHS depends on federal partners such as NIH and CDC, because it is not funded to do research. Collaboration with the CDC resulted in a series of papers on AI/AN mortality that were published as a supplement to the *American Journal of Public Health* in June 2014.
- IHS funds the TECs, with some resources from CDC. A list of TEC publications was included in the meeting packet.
- A list of upcoming TAC meetings and points of contact was included in the meeting packet.
- IHS collaborated with NIH to support several environmental health and justice research projects through the Native American Research Center for Health (NARCH).
- IHS collaborated with the Johns Hopkins School of Public Health to develop a research proposal that was submitted to the National Institutes of Environmental Health Sciences.
- IHS is conducting an evaluation of emerging technologies, including telehealth.
- The 2014 edition of *Trends in Indian Health* is available at www.ihs.gov/dhs.

Discussion

- Ms. Frederick asked if IHS provided data reports for individual tribes or specific locations.
 - Mr. Herne replied that the Division of Program Statistics handles those requests and provides information on a case-by-case basis.
- Councilman Kutz asked if IHS assists direct service tribes with their health research needs.
 - Mr. Herne replied that IHS has an advisory committee for direct service tribes. He was not aware of any research issues being raised during those meetings. However, the National IRB (NIRB), which he chairs, receives a fair number of proposals for large studies of national significance. The NIRB requires researchers to obtain approval from any tribal IRB or committee before they will consider it. They generally defer to the Area IRBs.
- Councilman Kutz stated that his health center wanted to conduct research to improve the integration of primary care and behavioral health services.
 - Mr. Herne said that behavioral health integration was a focus area for IHS. He would contact the Behavioral Health program to see what approach they would recommend.
- Councilman Kutz asked if IHS had found a mechanism to obtain Medicaid funding for behavioral health services provided via telehealth.
 - Mr. Herne replied that IHS funded a Telebehavioral Health Center of Excellence in Albuquerque. Medicaid funding varies, depending on the region. The director of the Center of Excellence could provide more information.
- Councilwoman Cowan Watts requested an update on the data sharing agreement with tribes.
 - Mr. Herne replied that the Business Office developed a template and IHS developed agreements for the TECs. He offered to provide copies of the template. He noted that IHS had asked Secretary Sebelius to send a letter informing states

that the TECs are public health authorities and that data could be shared with them.

- Councilman Kutz noted that Secretary Sebelius wanted to contact specific states that were not in compliance, rather than sending a letter to all states.
- Councilwoman Cowan Watts said it was time to revisit that issue. She suggested that Mr. Haverkate could follow up with IHS and the HRAC could contact the IHS Area offices to see if there were any issues with particular states.
- Ms. Satter noted that the CDC Public Health Law program prepared a memo on TECs as public health authorities. The memo is available on their webpage (www.cdc.gov/phlp).

ACTION: Mr. Herne will provide a copy of the template for a tribal data sharing agreement.

ACTION: Mr. Herne will contact the IHS Behavioral Health program regarding research approaches to improve behavioral health integration.

CDC

Delight Satter

- The Native Specimen Policy Development project at the Agency for Toxic Substances and Disease Registry (ATSDR) is a multi-pronged effort to develop a comprehensive policy for respectful treatment of AI/AN specimens. Other federal agencies are interested in this project, because it may have implications beyond CDC. ATSDR has conducted listening sessions with AI/AN stakeholders across the country regarding cultural values and ethics. Input from those will be provided to CDC's Internal Policy Board, who will develop the policy.
- The Rocky Mountain Spotted Fever (RMSF) demonstration project provided important information on patient behavior issues and community-based prevention of this disease.
- New initiatives include a number of scholarship opportunities and training programs for AI/ANs in health research fields. A complete list of training programs and career development opportunities for current students was included in the meeting packet.
- Ms. Satter asked Council members to help identify community-based approaches for a project that is developing a series of success stories in Indian Country. Potential topics could include historical trauma or suicide.

Discussion

- Chairperson Payment noted that he provided input for the Native specimen policy project. It would be important to respect traditional perspectives.
- Councilman Kutz reported that directors from the Food and Drug Administration (FDA) and CDC wanted to obtain input on ceremonial uses of tobacco so they could be protected from tobacco regulations. He informed them that many tribes are unwilling to talk about ceremonial uses and suggested that they contact NCAI. He asked if Ms. Satter had any updates on that situation.
 - Ms. Satter replied that this would be the purview of the FDA, because CDC does not regulate tobacco. She noted that she approves all native-specific scientific materials for ATSDR and recently worked on a fact sheet on sacred and ceremonial use of tobacco.

- Chairperson Payment noted that all social indicators in tribal communities stem from historical trauma. His tribe received a Department of Justice grant to develop a tribal action plan for suicide prevention. They are using a community-based approach and are aligning their services to create a wrap-around model. They want to promote their tribal action plan, because many tribes do not have one.

Wrap Up

Councilwoman Cowan Watts expressed appreciation for the honor and privilege of serving on the HRAC.

Councilman Kutz reminded members of the quarterly conference calls on August 21, 2015 and December 11, 2015 at 2:00 p.m. Eastern time. It would be important to have a quorum for those calls.

Chairperson Payment closed the meeting with a traditional prayer and reminded members that their work on the Council was on behalf of their people at home.