



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

Annual Meeting

Monday, June 23, 2014, 9:20 a.m.–4:45 p.m., EDT

Indian Health Service (IHS)

Rockville, MD

HRAC Tribal Delegates and Alternates

Ileen Sylvester, Alaska Area Delegate

Aaron Payment, Bemidji Area Delegate

Patrick Marcellais, Great Plains Area Delegate

Sandra Yarmal, Nashville Area Delegate and Ellen Omohundro (proxy for Sandra Yarmal)

Ramona Antone Nez, Navajo Area (proxy for Rex Lee Jim)

Cara Cowan Watts and Tom Anderson, Oklahoma Area Delegate and Alternate

Violet Mitchell-Enos, Phoenix Area Alternate

Stephen Kutz, Portland Area Delegate

Charles Headdress, National At-Large Member (proxy for H. Sally Smith)

Dawnette Weaver, National At-Large Member (proxy for Jefferson Keel)

HRAC Federal Partners

Gabrielle Quiggle and Kishena C. Wadhvani, PhD, AHRQ

Delight Satter, CDC

David Cummings and Christine Merenda, FDA

Chrisp Perry and Gwenivere Rose, HRSA

Michael Bartholomew, MD and Yvette Roubideaux, MD, (by video), IHS

Tracy Branch, J. Nadine Gracia, MD, Rick Haverkate, Aracely Macias, Lydia Sermons, OMH

Joyce Hunter, PhD, NIH

Sheila Cooper, SAMHSA

Other Attendees

Paulette Baukol, Indigo Solutions

Kendra King Bowes, Native American Management Services, Inc. (NAMS)

Felicia Schanche Hodge, DrPH, Native Research Network Co-Chair and UCLA Schools of
Public Health and Nursing

Erika Noyes and Deborah Thornton, Professional and Scientific Associates (PSA)

Action Items

- Dementia and Alzheimer's research:
 - This issue will be added to the list of HRAC priorities.
- Secretary's Tribal Advisory Committee (STAC):
 - An email of the list of STAC priorities will be sent to HRAC members.
 - Councilman Kutz and Chairman Payment will identify items from the STAC priorities to present to the HRAC for consideration at a future meeting.
 - HRAC members will review the list of STAC priorities and will send their comments to Chairman Payment and Councilman Kutz, with "STAC" in the subject line.
- Status of HRAC priorities:
 - Mr. Haverkate and Ms. King Bowes will create a table listing: (1) the HRAC priorities; (2) what has been done to request action on each priority, and when; (3) what response was received; and (4) contact information at the relevant Health and Human Services (HHS) agency.
- Uranium mining in the Navajo Nation:
 - Ms. Antone Nez will send information to the Office of Minority Health (OMH).
- HRAC Charter revision:
 - The charter revision work group will meet on Monday, July 28 at 4 p.m., EDT.
 - Proxies who attended this meeting will ask their leadership if they are interested in serving on this work group.
- Health Resources and Services Administration (HRSA) Briefing document:
 - Mr. Perry will obtain clarification regarding requirements for IHS tribal facilities to qualify as National Health Service Corps (NHSC) sites.
 - Mr. Perry will inquire whether the July 1 deadline for the Bureau of Primary Health Care (BPHC) Expanded Services supplemental funding opportunity may be extended.
- IHS information on best practices to capture information on suicide and attempted suicide:
 - Dr. Bartholomew will look into this issue and report back to the HRAC.
- NIH-funded researcher claiming to be Cherokee:
 - Councilwoman Cowan Watts will report back to the HRAC regarding how the Cherokee Nation handles this issue.
 - The process for pursuing complaints will be on the agenda for a future meeting.
- NIH Tribal Advisory Council (TAC):
 - Dr. Hunter will provide an update to the HRAC on the formation of the TAC.
- Communications between OMH and HRAC:
 - HRAC members will submit written suggestions to strengthen communications with OMH, including what kind of information, and what level of detail, would be most useful, and how to ensure that Council members and those they represent have access to that information.

Welcome and Introductions

Cara Cowan Watts, HRAC Co-Chair

Stephen Kutz, HRAC Co-Chair

Councilwoman Cowan Watts confirmed a quorum and called the meeting to order at 9:19 a.m.

Chairman Payment opened the meeting with a blessing.

Councilwoman Cowan Watts and Councilman Stephen Kutz introduced themselves and welcomed participants to the meeting.

Councilwoman Cowan Watts reviewed the provisions of the Federal Advisory Committee Act (FACA) that govern the procedures of the HRAC, including special provisions for government-to-government meetings. She noted that CDR Branch would provide guidance during the course of the meeting to ensure that all procedures were in accordance with the guidance.

Councilwoman Cowan Watts invited Council members, federal partners, and guests to introduce themselves. Following the round of introductions she reviewed the agenda for the meeting.

Opening Remarks

J. Nadine Gracia, MD, MSCE, Deputy Assistant Secretary for Minority Health and Director, OMH, U.S. Department of Health and Human Services (HHS)

Dr. Gracia thanked HRAC members for their commitment and service and welcomed new members. She noted that there were two vacancies on the Council, for which OMH was actively pursuing nominations.

Dr. Gracia announced that Rick Haverkate recently joined OMH as a Public Health Advisor. He will serve as Executive Secretary of the HRAC and as staff liaison to the White House Initiative on American Indian and Alaska Native (AI/AN) Education. He will also support Dr. Gracia on intradepartmental tribal committees and councils and other initiatives. Dr. Gracia thanked CDR Branch for her service to the Council.

Dr. Gracia assured Council members that HRAC would remain a priority for OMH under the new Secretary, Sylvia Burwell. The Council plays an important role in identifying key health research priorities for AI/AN communities. That research is essential to address health disparities that affect tribes and to achieve the HHS Disparities Action Plan.

Dr. Gracia requested the Council's input on how to strengthen communications to ensure that Council members have access to information disseminated by OMH and can inform OMH of opportunities for collaboration. She would like to know what kind of information and what level of detail would be most useful; how and when to distribute information; and how to ensure that Council members and those they represent have access to that information. OMH is looking at various models to determine the most effective mechanism.

Dr. Gracia closed by stating that she looked forward to dialogue and discussion about the priorities the Council puts forward.

Councilwoman Cowan Watts said she would add the topic of communications to the discussion period at the end of the day.

Questions and Answers

- Councilwoman Cowan Watts asked how OMH would work with the new Secretary to ensure the HRAC's agenda is addressed. Dr. Gracia replied that Secretary Burwell was holding briefings and meetings to learn about various HHS programs and activities. OMH will conduct an orientation to ensure that the Secretary has an overview of the Department's work with tribes, including the HRAC. OMH will work closely with the HRAC to ensure that the Secretary has a solid understanding of the HRAC's history and its priorities going forward. Dr. Gracia noted that the Secretary is dedicated to ensuring that the Department's programs have an impact on the people that they serve. As the HRAC identifies new priorities, it should emphasize their impact and how they benefit tribal communities.
- Ms. Antone Nez (for Rex Lee Jim) noted that the Navajo Nation had requested funding for long-term, comprehensive research on the impact of uranium mining on the Navajo Nation. They continue to bring this issue to the attention of the federal government. The Agency for Toxic Substances and Disease Registry (ATSDR) funded a short-term study. The Navajo Nation is requesting a long-term study.
- Councilwoman Cowan Watts responded that environmental justice was on the list of potential HRAC priorities. She hoped that Ms. Antone Nez could help elevate that issue.
- Chairman Payment shared that a number of HRAC members also serve on the Secretary's Tribal Advisory Committee (STAC). The STAC was preparing a list of priorities to deliver to the new Secretary in the next month. Chairman Payment said he would review the STAC's priorities to identify any areas of overlap with the HRAC and areas where the STAC could support or strengthen the HRAC's priorities. He invited other HRAC members to identify issues where the STAC could provide advocacy.
- Councilman Kutz thanked Ms. Antone Nez for raising the important issue of uranium mining, which was also raised at the STAC's last meeting. The Navajo Nation is not the only tribal community that is affected. Cancer risk is one of the HRAC's priorities, and uranium exposure could be linked to that area.

Councilwoman Cowan Watts thanked Dr. Gracia for her presentation and her support of the HRAC.

Councilwoman Cowan Watts thanked CDR Branch for her service to the HRAC. Council members acknowledged CDR Branch with a round of applause.

Comments from OMH AI/AN Health Policy Advisor

Rick Haverkate, Public Health Advisor/American Indian & Alaska Native Health Policy Lead, OMH

Mr. Haverkate thanked CDR Branch for her assistance in bringing him up to date on the HRAC and his duties as Executive Secretary. He noted that he began his career as a health educator with his tribe and had worked with nearly all of the tribal areas in his previous positions at HHS. He hoped that his prior experience and what he would learn from HRAC members would help the Council have a significant impact.

Councilman Kutz thanked CDR Branch for her support and service to the Council. He welcomed Mr. Haverkate to the HRAC and emphasized the importance of his new role.

Welcome from Indian Health Service

Yvette Roubideaux, MD, Director, IHS

Dr. Roubideaux addressed the Council by video and expressed her gratitude for the HRAC's work in identifying health research priorities and community research needs. IHS believes that tribal consultation and partnerships are an integral part of research efforts in Indian Country. The priorities of all research efforts that affect American Indian and Alaska Natives should include honoring tribal sovereignty and ensuring tribal ownership of data.

IHS is not authorized or funded to do research, and its primary focus is on healthcare services. However, research and evaluation help IHS deliver high-quality, evidence-based care and help IHS see the impact of their programs. This is crucial, because Congress increasingly requests information on the effectiveness of programs to ensure that resources are used wisely. IHS has an active Institutional Review Board (IRB), and Tribal Epidemiology Centers (TECs) help IHS with data collection, public health surveillance, and evaluation.

IHS also operates the Native American Research Centers for Health (NARCH) program. Since 2000, IHS and the National Institutes of Health (NIH) have supported the NARCH initiative, which is a partnership between tribes and tribal organizations and academic institutions. NARCH has helped increase the capacity of tribes and academic institutions to conduct culturally appropriate academic research in partnership with tribal communities. These efforts will help reduce long-standing health disparities among AI/AN people. Dr. Roubideaux noted that she previously worked with the NARCH program.

IHS is continuing to look for opportunities to work with academic and research institutions in formal, research-related arrangements. IHS recently renewed their memoranda of understanding (MOUs) with the Mayo Clinic and The Johns Hopkins University and has developed new MOUs with Goddard College and the University of Buffalo to support student programs and collaborate on research in tribal communities. IHS provides opportunities for groups such as the Native Research Network to engage in culturally appropriate work in AI/AN communities.

Dr. Roubideaux assured the Council that IHS appreciates and values the work of the HRAC and will support it in any way possible. She thanked Council members for their commitment and support and wished them a productive meeting.

Business Items

Facilitator: Cara Cowan Watts

Approval of Minutes of Previous Meeting

Councilwoman Cowan Watts provided time for Council members to review the minutes of the March 31, 2014, quarterly conference call and called for a motion to approve the minutes. The motion was made by Chairman Payment and seconded by Councilman Kutz. No comments, corrections, or omissions to the minutes were noted. The motion carried by unanimous voice vote.

Nominations for Co-Chair Positions

Councilwoman Cowan Watts opened the floor for nominations for the Council Co-Chair positions. She noted that she and Councilman Kutz would assist the new Co-Chairs with logistics for this meeting and for the Research Roundtable on June 24.

Responding to a question from Councilwoman Cowan Watts, Councilman Kutz stated that he would be willing to continue to serve as Co-Chair. Councilwoman Cowan Watts noted that, as Co-Chair, she could not make a nomination. Chairman Payment nominated Councilman Kutz to continue to serve as Co-Chair. Ms. Mitchell-Enos seconded the nomination.

Ms. Sylvester nominated Councilwoman Cowan Watts to continue to serve as Co-Chair. Councilwoman Cowan Watts respectfully declined the nomination.

Councilman Marcellais nominated Chairman Payment to serve as Co-Chair. Ms. Mitchell-Enos seconded the nomination.

Councilwoman Cowan Watts announced that both nominated members were elected officials of their tribes, as required by the HRAC Charter. Councilwoman Cowan Watts called for additional nominations. There were no additional nominations, so she closed the floor and noted that voting would take place later in the day.

Administration for Children and Families (ACF)

Facilitator: Kimberly Romine, Deputy Commissioner, Administration for Native Americans (ANA)

This presentation was tabled, because Ms. Romine was unable to attend the meeting.

Substance Abuse and Mental Health Services Administration (SAMHSA) and AI/AN Activities

Facilitator: Sheila Cooper, Senior Advisor for Tribal Affairs, SAMHSA

Ms. Cooper noted that the meeting materials included a briefing document from SAMHSA. Although SAMHSA does not conduct research, the agency generates a variety of data through national surveys. AI/AN sample sizes often present a challenge, but SAMHSA staff are getting better at aggregating data.

SAMHSA encountered a challenge this year in obtaining data for a tribal behavioral health program to promote positive mental health and mitigate suicide. The legislation required SAMHSA to ensure that the money went to tribes with the highest per capita rate of suicides. SAMHSA consulted the TECs, Centers for Disease Control and Prevention (CDC), and other sources, but they were unable to find national percentage rates. They used CDC annual state data and developed formulas to obtain approximate percentages for a tribe or consortium of tribes. The intention of the legislation was good, but the implementation was challenging for Indian Country.

SAMHSA's Center for Behavioral Health Statistics and Quality (CBHSQ) maintains four national surveys that contain AI/AN data:

- National Survey on Drug Use and Health (NSDUH)
- Drug Abuse Warning Network (DAWN)
- National Survey of Substance Abuse Treatment Facilities (N-SSATS)
- Treatment Episode Data Sets (TEDS).

CBHSQ's list of substance abuse treatment facilities now includes tribal facilities. The list is available online at <http://www.samhsa.gov/data/DASIS.aspx#N-SSATS>.

SAMHSA's Tribal Discretionary Grant Portfolio has been fairly consistent over the past three years, both in terms of the number of grants and overall funds. SAMHSA's programs for tribal communities include Circle of Care grants to increase the capacity and effectiveness of mental health systems that serve tribal communities.

SAMHSA funds a number of technical assistance (TA) providers that work with tribal communities, including the National AI/AN Addiction Technology Transfer Center (ATTC) System and the Tribal Training and Technical Assistance Center.

Much of SAMHSA's work is collaborative. The agency is currently looking for ways to work more closely with the TECs to meet the challenges of data collection.

SAMHSA has a Regional Administrator (RA) in the HHS regional office who serves as the agency's point of contact for tribes in the region. Ms. Cooper recently accompanied the Region X RA on a trip to Alaska, which included a listening session with tribal council members and a boat trip to a remote village.

SAMHSA's Office of Indian Alcohol and Substance Abuse (OIASA) coordinates interagency collaboration between HHS, the Department of the Interior, and the Department of Justice to combat alcohol and substance abuse, as mandated by the 2010 Tribal Law and Order Act.

SAMHSA's AI/AN team is a cross-cutting, internal group that works on various priorities. The team created a document to help guide tribal organizations through the grant application process, which can be challenging.

SAMHSA's Tribal Technical Advisory Committee (TTAC) was formed in 2008 and meets at least twice a year. The TTAC currently has vacancies for a position from the Phoenix Area and an at-large position. The TTAC establishes its own priorities; it also reviews the priorities of the STAC, the HRAC, and the HHS Office of Intergovernmental and External Affairs (IEA). The TTAC is currently revising its charter and SAMHSA's tribal consultation policy.

Questions and Answers

- Chairman Payment noted that when he returned to office in 2012, his tribe was experiencing as many as two suicides or overdoses every other week for nearly a year. He formed a task force that brought together community members and youth to develop a tribal action plan. They wanted to apply for a SAMHSA grant, but they were unable to meet the deadline because they had to gather the data in a piecemeal fashion. The need in the tribal community is great, but tribes cannot get funding without data.
- Chairman Payment stated that suicide was a common experience in tribal communities, and the desire to invest in an understanding of why this is happening is not tribal-specific. The leading cause of death for young people is accidents, and many accidents are related to alcohol or drugs. A broad-based study is needed to examine the causes of alcohol and drug-related deaths.
- Councilman Kutz suggested that IHS should have a system that would capture data on any patient who has suicidal issues, regardless of their tribal affiliation. Suicide is not a tribal problem; it is a community problem.
- Councilman Kutz also noted that his clinic had requested funds for research to legitimize the work that is needed to overcome historical trauma. There are some emerging best practices to help youth develop resiliency and help adults recover by bringing people back to their cultural roots and language.
- Ms. Cooper acknowledged that there are compounding conditions in tribal communities. Tribes need to work on these issues together, and communication is essential.
- Councilman Kutz reported that school districts in the Northwest were developing recovery schools that provide wrap-around services when youth come out of recovery programs. His clinic became involved because many tribal youth go to urban centers and lose touch with tribal services. In larger communities, this might be a model for tribes to consider. He asked if SAMHSA was familiar with wrap-around services that might be effective for those programs.
- Ms. Cooper said she was not familiar with recovery schools but hoped the programs were designed to meet the learning styles and cultural needs of tribal youth affected by substance abuse. She noted that a Circle of Care project in Oakland, California had an initiative working with public schools.

- Ms. Sylvester responded that suicide was also an issue in Alaska. Her organization's healthcare system emphasizes core values of the tribe, such as responsibility. They designed a half-day program to address historical trauma that emphasizes the importance of being true to those core values. A CDC study of adverse childhood experiences and aging found a strong connection between childhood experiences and chronic diseases and identified 10 factors that impact health, including alcohol, divorce, and abuse. Reducing even one or two factors has a significant impact on improving health. Her organization redesigned their behavioral health program and embedded psychiatry into primary care services. This reduced duplication of paperwork and streamlined the system. The program includes talking circles with a facilitator. Patients can address any issue and can bring family members. A pilot study with 957 people found that the first two sessions encouraged patients to take ownership of their health and connected them with people who had successful experiences. The combination of learning circles, a focus on the whole person, and a core values approach has resulted in Native people owning health care. Ms. Sylvester urged Ms. Cooper to continue to ask for funding, because it is critical for the work people are doing in their communities.
- Ms. Antone Nez reported that the Navajo Nation was working with the CDC tribal epidemiologist, the Department of Behavioral Health Services, IHS, and the Navajo Department of Public Safety to build a tribal surveillance system, with an emphasis on suicide prevention. When a suicide does occur, they get involved with the criminal investigation component, and they are looking at ways to address cross-jurisdiction issues. They developed a suicide prevention tool that looks at the multiple variables contributing to a suicide. Ms. Antone Nez reported that IHS built a model to allow TECs to establish a Data Sharing Contract with IHS and federal agencies. About five TECs currently have an agreement in place, and they are working to expand the model nationwide. Tribes need data access and data sharing agreements so they can access vital statistics. Ms. Antone Nez noted that some data sources are fragmented. Data quality is another issue. A patient might be diagnosed with one condition, but it is coded as something else.
- Councilman Kutz reported that the STAC found that tribes were still having trouble getting data from states. The HRAC had asked the Secretary to send letters to states requesting that Tribal EpiCenters be treated as public health authorities so they can receive needed data. It would be helpful if the Navajo TEC's project with the CDC could identify states where this is still a problem.
- Councilman Marcellais said that his tribe experienced similar problems. Federal grants fund drug courts and other programs, but young people have nowhere to turn to when the money runs out. Tribes have become dependent on federal grants and can't function without them. The Department of Justice is always willing to fund correctional facilities, but it won't fund preventive measures. The Great Plains Area is working on a project to build a rehabilitation center for youth and wants IHS to provide mental health and rehabilitation services. Suicide prevention is important, but families also need support after a suicide takes place. Councilman Marcellais read a moving testimony that underscored the need for a proactive approach to help people overcome their problems. He would like to see SAMHSA do more research and involve people who have experienced these issues first-hand.

- Ms. Cooper thanked Councilman Marcellais. She noted that SAMHSA has a project in juvenile justice to identify lessons learned and best practices related to alternatives to incarceration. The study identified a need to establish wellness centers that would also provide wrap-around services— since this type of center would not carry a stigma for those needing help.
- Dr. Omohundro (representing Sandra Yarmal) raised the issue of racial misclassification on death certificates. A recent study found that roughly 15 percent of all deaths among AI/ANs were not classified correctly; moreover, this rate is probably an underestimate. Dr. Omohundro stated that improving data sharing within the IHS system will help, but many events happen outside of IHS clinics. Many tribes in the Nashville Area do not have clinics.

Councilwoman Cowan Watts summarized the key issues that emerged from the discussion:

- How to gather data in Indian Country when multiple agencies are involved and when a person is not a member of a tribe
- Tribes need to own and have access to data
- Tribes should be involved in decisions about classification of data
- AI/ANs are not just a race, they are citizens of a tribe
- Funding is needed to address addiction and severe health disparities and should not be limited to one-year cycles
- Some data are not captured in the IHS system.

HRAC Potential Priority: Dementia/Alzheimer’s Disease

Facilitator: Cara Cowan Watts

Councilwoman Cowan Watts noted that Ms. Mitchell-Enos and Councilman Kutz had proposed adding dementia and Alzheimer’s research to the list of HRAC priorities. She asked them to provide information on the type of research that is needed in this area.

Ms. Mitchell-Enos cited a number of factors to demonstrate the need for research in this area:

- The lack of a culturally appropriate research instrument makes it difficult to determine the incidence of these diseases among AI/ANs.
- Most health research conducted within tribes has focused on other types of disease, such as cancer, diabetes, and substance abuse.
- As tribal populations grow older, the incidence of dementia and Alzheimer’s is increasing. In the past, elders were cared for in communities, and caregivers may not have known that the people they were caring for were suffering from dementia or Alzheimer’s.
- A diagnosis of dementia or Alzheimer’s could lead to higher costs, because services are not available in tribal communities. Patients have to be removed from their families to receive appropriate care.
- Research is needed to determine whether dementia or Alzheimer’s are related to other diseases in tribal communities, such as diabetes and stroke.

Councilman Kutz added that AI/ANs are now living long enough to develop Alzheimer's. Early treatments are only effective if the condition is identified in time. IHS does not systematically collect that information, and development of early diagnosis is not a priority. As Indian Country ages, data on these conditions will be increasingly important.

Ms. Cooper shared that SAMHSA has looked at the issue of aging and depression, and one SAMHSA grantee is looking at the impact of diet and lifestyle on depression.

Dr. Omohundro noted that dementia and Alzheimer's can impact patients' ability to take medication. Effective screening tools for early detection would be valuable.

Councilwoman Cowan Watts noted the need for targeted research to capture data on the incidence of dementia and Alzheimer's in tribal communities. Research data could potentially lead to funding for facilities to care for tribal patients with dementia or Alzheimer's. Hearing no objections, Councilwoman Cowan Watts proposed adding this issue to the list of HRAC research priorities.

Secretary's Tribal Advisory Committee (STAC) Updates

Facilitator: Stephen Kutz

Councilwoman Cowan Watts noted that Councilman Kutz, Chairman Payment, and Councilman Chester Antone serve on both the HRAC and the STAC. She asked Councilman Kutz to provide an update on the STAC.

Councilman Kutz reported that the STAC recently met with five Native researchers who are currently conducting research at NIH. One researcher described the challenges she faced in conducting a study in Indian Country.

Councilman Kutz stated that Secretary Sebelius had a strong relationship with tribes, and significant progress was made under her leadership on issues that are important to tribal leaders. The new Secretary had not been appointed at the time of the STAC meeting, but the Committee hopes to continue this successful relationship.

The STAC is currently working on revising its by-laws and identifying priorities that it would like the incoming Secretary to address.

Councilman Kutz and Chairman Payment highlighted several STAC priorities:

- Indian Child Welfare Act (ICWA): Compliance is a problem across the country because states do not keep track of AI/AN children. A STAC subcommittee is developing a tracking list and has requested a meeting.
- SAMHSA: More funding is needed for behavioral health. The STAC is asking the federal government to fulfill its treaty obligation to provide health, education, and social services. Tribes should not have to compete with states for these funds.

- HRSA: Alternatives should be explored to support mid-level oral health providers in the Indian health system. This proposal will face steep opposition from the American Dental Association.
- Self-governance: The STAC is advocating expansion of self-governance, with funding for HHS programs flowing directly to tribes, rather than through the states.
- Affordable Care Act (ACA) definition of Indian: The ACA definition is based on federally recognized membership, which excludes some people from coverage. By comparison, the Medicaid definition includes several generations below the registered member. The STAC is asking for clarity through an administrative rule or a legislative change. This is a cross-cutting issue with the HRAC.
- Priority points for grants: The STAC recommended that HHS grant programs should provide priority points in the grant application process so AI/AN applicants can be more competitive.

Ms. Sylvester expressed concerns about changes to the tribal consultation policy. Councilman Kutz noted that the Vice Chair of the STAC is from the Alaska Area. He urged Ms. Sylvester to contact him about her concern.

Chairman Payment stated that the STAC circulated the list of priorities to tribal communities for review and held listening circles at the National Congress of American Indians (NCAI) session. He urged HRAC members to submit comments on the document.

Chairman Payment stated that some of the HRAC's priorities, such as greater cooperation and consultation with TECs, were not reflected in the STAC's priorities. HRAC members on the STAC will advocate for this to be included on the list, as well as the issue of a tribal advisory role in research.

Chairman Payment acknowledged that the new Secretary's priorities were unknown, and it was not clear whether she would choose to continue the STAC. He noted that Secretary Burwell came to HHS from the Office of Management and Budget (OMB). The STAC has been asking for someone at OMB to be assigned to monitor AI/AN issues, including full funding for contract support. This might be an opportunity for the Secretary to communicate with OMB regarding the President's commitment to trust and treaty obligations.

Councilman Kutz added that Secretary Burwell also worked for the Bill and Melinda Gates Foundation, which addresses health disparities issues in developing countries. He hoped that this experience would inform her approach to tribal communities.

Questions and Answers

- Councilwoman Cowan Watts requested that the list of STAC priorities be emailed to members.
- Councilwoman Cowan Watts asked for suggestions to improve communications between the STAC and the HRAC.

- Councilman Kutz stated that communication currently takes place informally, through members who serve on both groups. It would be helpful to have a more formal process.
- CDR Branch stated that the package that OMH prepares for STAC meetings includes a list of HRAC priorities.
- An HRAC member requested that STAC meeting summaries be provided to HRAC members.
- It was noted that STAC meeting summaries only include formal action items; they do not provide information on other issues that were discussed, including those raised by the HRAC. It is important to elevate HRAC issues to the level of formal action items.
- Councilman Kutz agreed that the HRAC's priority issues should percolate up to the STAC. It is important to be strategic about what to elevate.
- Chairman Payment said it would be helpful to have information on the disposition of issues raised at HRAC meetings.

Councilwoman Cowan Watts noted the need to formalize the relationship between the HRAC and the STAC. This could be done through (1) a formal structure for ongoing dialogue and (2) a mechanism for the HRAC to make formal presentations to the STAC once a year.

Councilman Kutz asked whether a formal relationship would be possible under the by-laws for the two groups. CDR Branch stated that one reason for the charter revision was to align the charge for all four tribal advisory groups.

Ms. Sylvester added that HRAC members also serve on the CDC Tribal Advisory Committee and the STAC. If these groups are looking at common issues, members should be able to coordinate how those issues are addressed.

Councilwoman Cowan Watts summarized action items from this discussion:

- Chairman Payment will email the list of STAC priorities to Ms. King Bowes and Mr. Haverkate, for distribution to Council members. (This was done during the course of the meeting.)
- Councilman Kutz and Chairman Payment will identify items from the STAC priorities to present to the HRAC for consideration at a future meeting.
- HRAC members will review the list of STAC priorities to identify cross-cutting issues and highlight any issues that are missing.

Council members should send their comments on the STAC priorities to Chairman Payment and Councilman Kutz, with "STAC" in the subject line.

Election of HRAC Co-Chairs

Facilitator: Rick Haverkate

Councilwoman Cowan Watts thanked the Council for the honor and pleasure of serving as Co-Chair. She noted that she had served on the Council since its inception and would remain an active member.

Mr. Haverkate and Councilman Kutz thanked Councilwoman Cowan Watts for her service as Co-Chair and her contributions to the HRAC.

Mr. Haverkate called for a motion to close nominations. Councilwoman Cowan Watts made the motion, which was seconded by Councilman Marcellais.

Mr. Haverkate called for a vote to approve Councilman Kutz and Chairman Payment as Co-Chairs of the HRAC. The motion carried by unanimous voice vote.

Identification of Research Projects for Potential Funding

Facilitator: Cara Cowan Watts

Councilwoman Cowan Watts asked HRAC members to identify two or three research priorities that would have the greatest impact on Indian Country if funds were available at the end of the fiscal year.

Chairman Payment proposed qualitative research on the origins of historical trauma. A pilot project with focus groups might guide a comprehensive study.

Ms. Sylvester echoed the need for qualitative research. She noted that tribal leadership has identified priorities of suicide, substance abuse, and depression and these all go back to historical trauma.

Ms. Mitchell-Enos proposed funding for a Native research database/clearinghouse and a mechanism for tribes to own research data.

Chairman Payment emphasized the need to build capacity for tribal communities to collect general data on their membership. It is critically important for the HRAC to play a role in tribal ownership of data.

Councilman Kutz cited two priorities: (1) qualitative research to demonstrate the impact of loss of family units, loss of land, and loss of culture and language, and (2) data on suicides in tribal communities.

Ms. Antone Nez cited four priorities: (1) research on the long-term impact of uranium mining on Navajo land, (2) tribal ownership of data, (3) behavioral health studies on the incidence of suicide among young AI/AN people, and (4) recognition of TECs as public health authorities.

Dr. Omohundro stressed the importance of baseline data and identified two mechanisms to collect it: (1) increase the sample size for the Behavioral Risk Factor Surveillance System (BRFSS) and Youth Risk Behavior Survey (YRBS) to include tribal populations, and (2) require states to share vital statistics with tribes as a condition of their contracts with the National Center for Health Statistics.

Ms. Antone Nez stated that the Navajo TEC was looking at steps to build a health surveillance system that has culturally appropriate tools to collect baseline data.

Councilman Marcellais said that he works primarily with youth. He noted that proper nutrition is a challenge for low-income families in tribal communities, resulting in high rates of obesity. He also called for shifting the focus from detention to rehabilitation, with an emphasis on exercise and proper nutrition.

Councilwoman Cowan Watts noted that the Council had previously discussed the need for research to identify the benefits of a traditional diet and lifestyle. The issues raised by Councilman Marcellais could be linked to that priority.

Chairman Payment added that tribal communities have the highest rates of high school dropouts than any other population, but there are no data on the incidence of attention deficit hyperactivity disorder (ADHD) and autism in tribal communities.

Councilwoman Cowan Watts stated that the need for a Native research database/clearinghouse was a key issue for her community. She also noted that environmental justice included many issues and could be relevant to any agency.

Councilwoman Cowan Watts proposed to look at grant applications submitted by tribes that were approved but not funded due to the lack of quantitative data and see if qualitative methods could provide the missing data. Another priority could be to fund research fellowships for AI/AN candidates in order to develop the research infrastructure in Indian Country.

Councilman Kutz asked if collecting data that are required to run a tribal program was an essential government service. If so, development of a data collection infrastructure should be built into contract support costs. Chairman Payment stated that any position that provides essential services can be funded that way. His tribe hired an institutional researcher this year using tribal funds; they treated it as a central administrative function, since the tribe is required to evaluate its programs.

Ms. Antone Nez proposed to allocate additional funds to the 12 TECs because they are established as public health authorities, they play a significant role in data collection, and they know the local priorities. This would elevate the issues of data access, oversampling, and data infrastructure. It could also address the issue of a Native research database/clearinghouse.

Councilman Kutz summarized the priority issues that emerged from the discussion:

- Research to validate historical trauma as a causal factor in health disparities
- Research on causality of suicide and depression

- Native research database/clearinghouse
- Environmental justice, including long-term impact of uranium mining in the Navajo Nation
- Research on autism in tribal communities (incidence and causality)
- Research on the potential impact of traditional diet and lifestyle on reducing obesity
- Qualitative research on best practices to build resilience in communities.

Councilwoman Cowan Watts clarified that this agenda item was intended to identify priorities for end-of-year funds, if they are available.

Chairman Payment proposed a qualitative pilot study on historical trauma to conceptualize potential future research.

Ms. Mitchell-Enos stated that development of a clearinghouse could impact many communities. She felt that funding the TECs was too broad for end-of-year funds.

Councilwoman Cowan Watts proposed that the HRAC request funding for a Native research database/clearinghouse as the first priority. Most agencies would be willing to support it, and it would affect all tribal communities. Preliminary work has already been done and it could be started with a small amount of funding. HRAC members concurred, with no objections.

Councilwoman Cowan Watts asked for recommendations for the second and third items to recommend for funding. She stressed the importance of projects that were “shovel-ready” and could demonstrate success quickly.

Ms. Antone Nez stated that the Navajo Nation TEC was a “shovel-ready” project. The surveys are ready to go, and funding would allow for oversampling and data collection. The TEC has also developed a suicide surveillance tool.

Chairman Payment asked how the objectives and outcomes of the Navajo project would benefit other tribal communities. Ms. Antone Nez replied that the Navajo Nation has over 300,000 members, and primary data collection had never been done. The door-to-door data collection methodology could serve as a model for other communities to collect tribe-specific data that do not simply duplicate states vital statistics. Optional components could be modified to include questions about historical trauma. Some TECs serve multiple tribes.

Hearing no objections, Councilwoman Cowan Watts confirmed that funding the Navajo TEC survey would be the second item on the list of proposed projects.

HRAC members agreed that the third item would be to review tribal applications that were approved but not funded due to lack of data and then work with the tribe and/or a TEC to collect qualitative data.

Review of HRAC FY 2014 Priorities and Identify Priorities/Activities for the Upcoming Year

Facilitator: Cara Cowan Watts

Councilwoman Cowan Watts listed the new issues that emerged during the previous discussion:

- Historical trauma
- Autism
- Environmental justice
- Traditional diet and lifestyle and how they translate to modern diet and lifestyle.

Councilman Kutz proposed that the Council carry forward the priority issues related to NIH. Research conducted by NIH must have support from tribes in the area where research is conducted. NIH needs to complete its tribal consultation policy. NIH should fund more AI/AN researchers.

To facilitate the transition to new leadership at both HHS and the HRAC, Councilwoman Cowan Watts asked Mr. Haverkate and Ms. King Bowes to create a table listing: (1) the HRAC priorities; (2) what has been done to request action on each priority, and when; (3) what response was received; and (4) contact information at the relevant HHS agency.

Ms. Antone Nez asked if the Council wanted information on uranium mining. Councilwoman Cowan Watts requested that she send the information to OMH.

HRAC Charter Revisions

Facilitator: CDR Tracy Branch

CDR Branch noted that the HRAC's charter was last revised in 2010. The goal is to bring all of the tribal advisory committees and councils into greater alignment with the STAC. To that end, HRAC and the other advisory committees have been asked to revise their charters to align them with the STAC charter.

HRAC members currently participating in the work group include Councilman Kutz, Councilwoman Cowan Watts, Chairman Payment, Councilman Antone, and Mr. Anderson. Councilman Marcellais volunteered to join the work group. CDR Branch requested that proxies ask their leadership if they would be interested in serving on this work group.

The work group will meet monthly, with iterations being circulated via email. The proposed revisions should be ready for the HRAC to review at the next quarterly meeting.

Work group members agreed to hold their first meeting on Monday, July 28, at 4 p.m. EDT.

Federal Partner Updates

ACF

- The agency was not represented at the meeting and did not provide a written update.

AHRQ

- Dr. Wadhvani reported that the agency has a new Director and Deputy Director, as well as new research priorities.
- AHRQ has funding to support both quantitative and qualitative research on patient-centered outcomes to improve access, affordability, equity, and quality of health services.
- The briefing document provided in the meeting materials included a list of current funding opportunities. HRAC members should encourage researchers in their communities to apply for these opportunities, including:
 - PA-13-045: AHRQ Health Services Research Projects (R01)
 - PA-13-046: AHRQ Health Services Research Demonstration and Dissemination Grants (R18)
 - PA-13-039: AHRQ Mentored Clinical Scientist Research Career Development Award (K08).
- HRAC members are encouraged to propose qualified investigators from tribal communities who could participate in grant review committees. AHRQ provides an extensive orientation for new reviewers.

Assistant Secretary for Planning and Evaluation (ASPE)

- ASPE was not represented at the meeting.

CDC

- Ms. Satter reviewed a number of items from the briefing document that was included in the meeting materials.
- The CDC's Tribal Advisory Committee met in February. Several members of that Committee also serve on the HRAC. The next TAC meeting will be held in August in Acme, Michigan. Agendas for TAC meetings are developed by Committee members.
- CDC held a general listening session at the Northern Cheyenne Nation.
- CDC and the Native Research Network held a listening session at the Native Health Research Conference that focused on the issue of Native American research specimens. The goal was to develop a CDC policy that will govern the respectful stewardship and disposition of those specimens. The next listening session will be held at the annual meeting of the Association of American Indian Physicians (AAIP) in July.
- CDC has many scholarships and career development opportunities, including internships for AI/AN students at the high school, undergraduate, graduate level, and post-doctoral level. Information is available at www.cdc.gov/tribal/training_career/index.html and www.cdc.gov/fellowships/. Interested students may contact Ms. Satter for help in navigating the system.
- CDC established a five-year cooperative agreement with the American Public Health Association (APHA) to provide capacity building TA for tribal public health authorities.
- CDC created a limited eligibility mechanism that allows tribes to apply directly for CDC grants, without having to compete with states or other jurisdictions. A template is available that may also work at other HHS agencies.

- CDC utilizes special grant review panels where half of the members are AI/AN subject matter experts, and half are CDC scientific experts. The need for Native experts to participate in review panels came from advisory committee recommendations such as the HRAC which helped to justify this expense.
- CDC provides TA and training throughout Indian Country. Examples were provided in the briefing document.
- CDC collaborated with AAIP on a Data into Action training program to develop Native research infrastructure.
- CDC is developing a Native American public health program at the University of Arizona. Traditional healers were involved in developing the curriculum.
- CDC partnered with the University of Washington to develop a grant writing training manual for tribal applicants and Native organizations, to complement the online trainings developed with NIH funding. The program is available online at <http://nursing.washington.edu/building-sustainable-indian-tribal-infrastructure-translational-research/news-training>.
- Open funding opportunity announcements (FOAs) for which tribal entities are eligible are listed at www.grants.gov. A number of funding announcements were listed in the briefing document, along with contact information.

HRSA

- Mr. Perry reported that he would be transitioning out of his current role. Lieutenant Commander Rose will take his place.
- The Bureau of Health Workforce (BHW) has a Geriatric Education Centers (GEC) program to improve education and training for health professionals and technicians in geriatric health. The GEC of Wyoming partnered with AARP to present a cognitive health workshop at the Wind River Reservation for Eastern Shoshone and Northern Arapahoe tribal elders.
- HRSA's Office of Regional Operations will host a webinar in collaboration with SAMHSA on July 24 for tribes in Regions VII and VIII. The webinar will focus on prescription drug abuse on tribal land and tribal health workforce strategy in the Great Plains Area. Details were provided on page 5 of the briefing document included in the meeting materials.
- HRSA's Office of Federal Assistance Management (OFAM) developed a listserv to communicate funding opportunities more effectively. To subscribe to the listserv, send an email to grantinfo@hrsa.gov.
- The BPHC issued a supplemental funding opportunity for eligible Health Center Program grantees to expand their services. Tribal grantees are eligible to apply. Applications are due by July 1, 2014.
- HRSA will conduct its tribal consultation on September 8, in conjunction with the National Indian Health Board Consumer Conference in Albuquerque, New Mexico. The consultation will focus on HRSA's tribal consultation policy. HRSA has issued the policy for review and looks forward to receiving feedback. Comments may be submitted to indianhealth@hrsa.gov.
- HRSA issued calls for nominations for the Tribal Advisory Committee and grant reviewers.

Councilwoman Cowan Watts and Dr. Gracia thanked Mr. Perry for his service and welcomed LCDR Rose.

Councilman Kutz requested clarification about the policy statement on page 1 of the briefing document, in the section on the NHSC: “The Affordable Care Act (ACA) permits Indian health facilities that serve only Tribal members to qualify as NHSC sites, extending the ability of IHS/Tribal facilities to recruit and retain primary care providers by utilizing NHSC scholarship and loan repayment incentives.” The statement implies that this policy extends only to clinics that serve only tribal members. However, the ACA authorized tribal facilities to provide care to non-tribal members, many tribal clinics serve family members who are not enrolled, and those in remote locations might be the only source of health care for the community. Mr. Perry said he would obtain clarification on the policy statement.

Chairman Payment said that he believed tribal clinics were required to provide opportunities for members of other tribes to obtain services. The statement might be a condition of HHS funding. Ms. Antone Nez asked if there was any flexibility on the July 1 due date for the BPHC funding opportunity. Mr. Perry was doubtful that it would be extended, but he offered to check with BPHC. He noted that HRSA conducts TA calls to help potential applicants complete the application process and meet the deadlines.

IEA

- IEA was not represented at the meeting. The HRAC requested that OMH send a note to IEA to encourage their participation at future meetings.

IHS

- Dr. Bartholomew reported that IHS sent more than 35 students and faculty to the Native Research Network conference.
- IHS is conducting an evaluation to demonstrate the impact of the NARCH program. IHS is looking for volunteer sites to test the data collection instrument and hopes to have a tool available by the end of 2015.

Councilwoman Cowan Watts noted that Dr. Alan Trachtenberg had taken a new position at FDA. Mr. Mose Herne, who is Division Director for Evaluation and Research at IHS, would represent IHS on the Council going forward.

Councilwoman Cowan Watts asked if IHS had any information about best practices to capture information on suicide and attempted suicide. Dr. Bartholomew said he would look into this matter and report back to the Council.

Councilwoman Cowan Watts asked about the impact of budget negotiations on the IHS scholarship program.

Councilman Kutz requested more information about the NARCH evaluation tool. Dr. Bartholomew said it would consist of a survey that would be used to develop an annual report for Congress.

NIH

- Dr. Hunter reported that in FY 2013, NIH spent \$160 million in 687 projects and 531 institutions in 36 states for AI/AN research, interventions, research training, and infrastructure and outreach.
 - Research was conducted in diverse areas, including social determinants of health (SDH) that have an impact on biological health.
 - Interventions were designed to reduce smoking, alcohol, and substance abuse; increase cancer screenings; and address historical trauma and mental health.
 - Research training is preparing a diverse workforce for the next generation in health science education, handling hazardous materials, environmental health, maternal and child health, gerontology, and neurological sciences.
 - Infrastructure and outreach activities include infrastructure, research capacity, emergency preparedness information, health planners, and grant writing workshops. The National Institute on Minority Health and Health Disparities (NIMHD) has a mandate to establish an endowment to support this function.
 - Information on NIH-funded projects is available at NIH Research Portfolio Online (RePORT): <http://projectreporter.nih.gov/reporter.cfm>.

Councilwoman Cowan Watts asked several questions:

- How does NIH recruit Native researchers?
- What is the status of the tribal consultation policy?
- How has NIH responded to the Cherokee Nation's complaint about an NIH-funded researcher who claimed to be Cherokee, but is not a citizen of the Cherokee Nation, Eastern Band, or United Keetoowah Band?

Councilwoman Cowan Watts noted that the individual in question conducted research with the Cherokee Nation and Choctaw Nation, but no IRB has seen him or is aware of what he is doing. The HRAC is very concerned about researchers who claim to be AI/AN in order to conduct research in tribal communities.

Dr. Hunter stated that NIH does not award grants based on nationality, and it is not standard process to require verification of the nationality of a Principal Investigator. The researcher would have been required to go through the IRB of his institution. NIH would only have looked into it if the study involved human subjects, which was not the case for that particular grant. If someone wishes to question the basis on which a grant was awarded, they may file a formal letter of complaint with the Office of Research Integrity (ORI).

Chairman Payment suggested that it might be useful to review the IRB document to determine whether it was submitted under false pretenses, such as a claim of cultural competency.

Councilwoman Cowan Watts stated that the issue of pursuing complaints regarding research integrity should be on a future agenda. She would report back to the HRAC regarding how the Cherokee Nation handles this issue.

Regarding tribal consultation, Dr. Hunter stated that NIH developed a guidance document describing how the HHS tribal consultation policy would be implemented at NIH; the document

was approved in 2013. The NIH website was revised to include a list of tribal contacts at the various Institutes and Centers (<http://www.nih.gov/about/tribalcontacts.htm>) as well as the tribal guidance document (<http://www.nih.gov/about/tribalconsultationpolicy.htm>). NIH is in the process of forming a Tribal Advisory Council, as required by the HHS tribal consultation policy. Dr. Hunter said she would provide an update on the status of that activity.

Regarding recruitment of tribal researchers, Dr. Hunter stated that NIH Institutes and Centers recognize the importance of a diverse research workforce and the importance of having researchers who understand the communities where studies are conducted. Most of them have made a concerted effort to recruit Native researchers. However, the Office of General Counsel will not allow any announcement that targets specific populations. There is a broad effort to conduct technical workshops and presentations at regional meetings and to recruit Native researchers for review panels. NIH is making inroads in this area.

Ms. Satter recommended that the Cherokee Nation contact the Office of Human Research Protection (OHRP) regarding its concerns about the research that is being conducted in their community.

Dr. Gracia noted that the ORI and OHRP are housed within the Office of the Assistant Secretary for Health. OMH can help to streamline communications with those offices.

Dr. Hunter recommended that Councilwoman Cowan Watts contact the Institute that funded the application and the NIH ORI before going outside of NIH. They would provide a response and would also consult with the NIH Office of General Counsel.

Councilwoman Cowan Watts stated that the Cherokee Nation had raised this issue more than once and did not want this individual to be funded by any agency. It is a serious issue and needs to be addressed outside of NIH.

Ms. Satter noted that this issue affects both the application process and human subjects protection. She recommended adding this issue to the agenda for the Research Roundtable the following day.

Review of Day, Next Steps, Closing Comments, and Closing Blessing

Facilitator: Cara Cowan Watts

Councilwoman Cowan Watts stated that the items on the agenda had been reviewed throughout the day.

Next steps include the Research Roundtable on June 24, quarterly conference calls for the full HRAC, and monthly meetings for the charter revision work group. Councilwoman Cowan Watts noted that all future actions would be led by Councilman Kutz.

Councilwoman Cowan Watts offered several suggestions regarding communications, in response to Dr. Gracia's request:

- Information on grant opportunities should be sent directly to TECs and other interested institutions, rather than going through HRAC members.
- Communications between the HRAC and the STAC need to be formalized.
- Preparation for and follow-up after the HHS Annual Tribal Budget and Policy Consultation held in March/April needs to be improved.

Councilwoman Cowan Watts asked HRAC members to submit written suggestions to improve communications with OMH.

Chairman Payment offered a closing prayer.

Councilwoman Cowan Watts adjourned the meeting 4:45 p.m.