

American Indian/Alaska Native Health Research Advisory Council (HRAC)
Quarterly Conference Call
Friday, February 7, 2014

HRAC Tribal Delegates and Alternates

Ileen Sylvester and Jay Butler, Alaska Area Delegate and Alternate
Aaron Payment and Renea Ditmer, Bemidji Area Delegate and Alternate
Daniel J. Calac, California Area Delegate
Sandra Yarmal, Nashville Area Delegate
Cara Cowan Watts and Tom Anderson, Oklahoma Area Delegate and Alternate
Stephen Kutz, Portland Area Delegate
Michael Peercy, National At-Large Member Delegate
Malia Villegas, National At-Large Member Alternate

HRAC Federal Partners

Kishena C. Wadhvani, Agency for Healthcare Research and Quality (AHRQ)
Katheryn Warren, Office of the Assistant Secretary for Planning and Evaluation (ASPE)
Delight Satter, Centers for Disease Control and Prevention (CDC)
Chrisp Perry, Health Resources and Services Administration (HRSA)
Elizabeth Carr, Office of Intergovernmental and External Affairs (IEA)
Susan Karol and Alan Trachtenberg, Indian Health Service (IHS)
Tracy Branch, Office of Minority Health (OMH)

Other Attendees

- Kendra King Bowes, Native American Management Services, Inc. (NAMS)
- Camila Santos, PSA

Call to Order and Introductions

- HRAC Co-Chairs Cara Cowan Watts and Stephen Kutz opened the call and welcomed participants. Councilwoman Cowan Watts conducted a roll call of tribal delegates and federal representatives.
- They deferred decisions on action items to the next meeting due to the lack of a quorum.

HRAC Updates

- Commander (CDR) Tracy Branch stated that she will send a marked-up version of the HRAC charter to all members of the Charter Workgroup soon and schedule a conference call to discuss the recommended changes. She asked workgroup members to perform an initial review of the document prior to the call, with an emphasis on the red-lined items. A number of issues may need correction; others have terms that need clearer definition. CDR Branch will manage the editing process and be responsible for version control of the document.
- CDR Branch announced that the Administration for Children and Families (ACF) is developing new research and data collection priorities and is seeking assistance from tribal communities. CDR Branch will get more information on the goals of the initiative and the

type of support that the ACF is requesting from the HRAC. She will send the information to all HRAC members to provide feedback.

Questions and Answers

- Chairman Aaron Payment recommended that Charter Workgroup members send their proposed changes to CDR Branch to incorporate them using the track changes function in Microsoft Word. CDR Branch agreed and said she will provide instructions for the editing process when she sends the document.
- Councilman Kutz requested a list of members who volunteered to serve on the Charter Workgroup. Kendra King Bowes stated that the workgroup included Cara Cowan Watts, Stephen Kutz, Aaron Payment, Chester Antone, Tom Anderson, and Tracy Branch (OMH). Jennifer Cooper of the National Indian Health Board (NIHB) also volunteered, but she is no longer at the NIHB.
- Councilwoman Cowan Watts asked if there was an actionable item related to the ACF research priorities. CDR Branch said she needed to schedule a meeting with the ACF representative to clarify what type of assistance they are requesting from the HRAC. Once she has that information, she will inform the HRAC of the nature of the request so members can determine how to respond.

HRAC September 2013 Quarterly Call Minutes Approval

- Action was deferred to the next quarterly meeting due to the lack of a quorum.

National Children's Study Updates

- Dr. Alan Trachtenberg announced that the National Children's Study (NCS) advisory group met in January to update the framework they will use for the study. The framework will define the higher-level functions of a normal 21-year-old and serve as a basis of comparison to evaluate outcomes for cohort members at the end of the study. Dr. Trachtenberg sent HRAC members a copy of the Request for Information (RFI) that solicits feedback on the framework. Dr. Trachtenberg asked HRAC members to review the framework and consider submitting comments regarding culturally-relevant or culturally-specific areas of health for American Indians and Alaska Natives (AI/ANs) for the attention of the advisory group.
- Dr. Trachtenberg did not have any additional information regarding the sampling system for the study, but he learned that the researchers do not intend to stratify the hospital- or birth-unit based samples. The random sample may or may not include any Indian hospitals. The advisory group is awaiting a report from the Institute of Medicine (IOM); they do not know what the report will recommend. In the meantime, if there is interest in promoting a stratified hospital sample with attention paid to types of hospitals that care for small, but important, parts of the population, this is a good time to submit that request. It is still possible that the NCS will stratify hospitals.
- Councilman Kutz stated that this will be a topic for the annual meeting. If the meeting does not occur in a timeframe that makes it possible to provide input, the HRAC might need to form a workgroup. The current model does not address the underlying issue of ensuring that geographic areas with the greatest health disparities are included in the sample. Dr. Trachtenberg noted that Alaska and the Great Plains Areas were no longer left out of the geographic sampling frame. The new sampling frame will assemble all hospitals listed by the American Hospital Association that do deliveries, which includes IHS hospitals. They are

also sampling out-patient prenatal care providers who perform deliveries at the selected hospitals. Councilman Kutz stated that this will address one of the HRAC's primary concerns. He asked who will be in charge of sampling within those hospitals and how that task will be organized. Dr. Trachtenberg stated that the hospitals had not been selected yet. He noted that the selection will not be done on a regional basis. Comments should be directed to Dr. Hirschfeld.

- Councilman Kutz suggested the HRAC ask the National Congress of American Indians (NCAI) to let their citizens know to identify themselves as AI/AN when they enter civilian hospitals to deliver. Dr. Trachtenberg suggested the HRAC ask the NCS to do as much as possible to identify participants who are Native.
- Councilwoman Cowan Watts noted that there was still an opportunity to provide input on the NCS. She sent the RFI to tribes in the Oklahoma Area and urged all HRAC members to send it out in their respective areas.
- Councilwoman Cowan Watts said it was her understanding that the Affordable Care Act (ACA) definition of AI/ANs might be changing again. She asked if the HRAC should recommend that the Department of Health and Human Services (HHS) and the NCS use a consistent definition. Councilman Kutz stated that it was important to ensure that the definition is clear. Hospitals and birthing centers do not do a very good job of identifying AI/ANs, and the extent to which the study is diligent in identifying participants will be a factor in the effectiveness of the study. There is always a tendency for researchers to make assumptions based on their accent or how they look. The performance standards for determining the identity of people in the study will be of great importance.
- Councilwoman Cowan Watts asked Dr. Trachtenberg to request clarification from the NCS regarding how they will identify AI/ANs. Dr. Trachtenberg said he is willing to do that, but he will first ask Teshia Solomon if she addressed that issue in the work that she did with the NCS.
- Dr. Trachtenberg asked for clarification about the changing definition of AI/ANs under the ACA. Chairman Payment stated that the current definition is based on membership in a federally-recognized tribe, which is problematic for tribes that do not have lineal descent. There has been a push among tribes to base the definition on tribal membership and the two subsequent generations, so that a child and grandchild of a tribal member will receive coverage through the ACA. He believed a legislative or an administrative fix to address that issue was underway. Dr. Malia Villegas said that the issue of urban Indians had come up in certain states, especially California, but she did not have specific information. Chairman Payment said that he might have more information following the Secretary's Tribal Advisory Committee (STAC) meeting, which will be held the week of February 10.
- A HRAC member asked about the timeframe for the NCS rollout. Dr. Trachtenberg replied that Congress prohibited any activity until the release of the IOM report. That report is expected in August, so the preliminary study will probably begin in the fall. The NCS does not have funding for the main study. Dr. Trachtenberg said that the ACA definition of AI/ANs may be useful in defining participants for the NCS, because women will learn how to identify themselves when they go to clinics for prenatal care.
- Councilwoman Cowan Watts stated that the proposed definition described by Chairman Payment will fit with the cultural affiliation among federally-recognized tribes. She asked if other HRAC members agreed. Councilman Kutz said he believed the HRAC was advocating for the NCS to use the IHS definition and wondered how that will change the definition.

- Councilman Kutz thanked Dr. Trachtenberg for his efforts to redirect the study. Dr. Trachtenberg replied that there is now a greater possibility that the HRAC will get what it wanted. Right now, it will be helpful to ask for stratification of Indian hospitals to ensure that some are included in the sample. Failing that, it will be possible to advocate for a portion of the 10,000. He urged the HRAC to keep its attention on this issue and respond to the RFI on using the composite outcome for the higher-level functions of a healthy 21-year-old person. February 24 is the deadline for receipt of comments.
- Councilman Kutz stated that responding to the RFI will have to be done on an individual basis, because it will be difficult to develop a common definition. Dr. Trachtenberg said providing input was more important than a common definition.
- Chairman Payment reported that he spoke with Cathy Abramson, who chairs the NIHB. Ms. Abramson said there was no update about changing the definition of Indian for the ACA, and she noted that the definition in the ACA leaves out some Alaska Natives. The administrative fix had been reviewed and did not appear to resolve the problem; however, there is broad support for a legislative fix. Chairman Payment stated that if the NCS uses the ACA definition, tribes that are not lineal descent will be left out. Dr. Trachtenberg replied that an epidemiologic study such as the NCS will not be bound to a definition that was developed to determine eligibility for medical care. The process for collecting information is still open to input.
- Chairman Payment suggested that tribal leaders on the call should weigh in on the matter. The Sault Ste. Marie Tribe is a lineal tribe, so the definition covers his people. If someone must be a tribal member, then a large number of Native children will be left out of the study. Erring on the side of counting study subjects as Native is preferable to using a definition that excludes them.
- Dr. Villegas noted that HHS has its own definition of Indian that is different from the ACA definition, and there is a range of definitions across HHS agencies.
- Dr. Trachtenberg suggested that a set of questions with yes/no or multiple choice answers record the information in a way that allows analysis of data according to the definition the researcher wants to use. Delight Satter stated that the California Health Interview Survey (CHIS) used that approach. Investigators asked if the participant was American Indian, enrolled in a tribe, in which tribe they were enrolled, and so on. The methodology has been used for more than 10 years and works very well. The material is available for public access. The approach does not address the problem of whether the sample is large enough for each sub-population to be generalizable, but it will be the most useful way to gather the data. Dr. Trachtenberg asked her to provide that information so he could submit it to the NCS for consideration.
- Chairwoman Cowan Watts summarized that the key issues for the HRAC are sampling and oversampling and how the NCS will identify AI/ANs. Dr. Trachtenberg noted that this might be a good opportunity to ask the NCS to consider the CHIS methodology. Councilman Kutz added that the HRAC prefers to help the NCS define their process, rather than reacting to what they design. Councilwoman Cowan Watts proposed to include a discussion of the CHIS methodology on the agenda for the next quarterly conference call. Delight Satter offered to make a presentation on the approach to the development of the methodology. She noted that UCLA validated the items with many cultural groups in California, including tribes, and across six languages.

- Dr. Daniel Calac noted that the CHIS website will give the HRAC a good idea of how they present the data. Ms. Satter said she will send CDR Branch a link to the website along with additional information about the CHIS.
- Ms. Satter emphasized that it is not enough to enroll Native populations into a study. Once they are enrolled, researchers need to ensure that the questions they ask are culturally and linguistically appropriate.

HRAC 2014 Priorities

- Councilwoman Cowan Watts noted that the meeting materials included a copy of the October 22 document on HRAC priorities, and she asked CDR Branch what input OMH wants from the HRAC.
- CDR Branch stated that the document was based on the HRAC's work during the previous year. She asked the HRAC to review the list and determine if there were any priorities that should be updated, removed, or added.
- Councilwoman Cowan Watts noted that the list included seven priorities, many of which had several ongoing activities. This level of activity reflects the hard work and commitment of HRAC members.
- Councilman Kutz noted that the HRAC had been working with the National Institutes of Health (NIH) to increase research conducted in Indian Country, by AI/ANs. He asked the HRAC if this should be added to the list of priorities. Councilwoman Cowan Watts asked if this could be included in the priority related to scholarship opportunities for AI/ANs in the health research sector.
- Ms. Ileen Sylvester proposed that the NIH should award extra points in the grant review process for research conducted by a tribe or a Native researcher, or provide a funding priority for organizations that develop Native researchers.
- Councilman Kutz proposed to include this issue on the agenda for the next annual meeting. Councilwoman Cowan Watts felt it was worth the HRAC's time to consider adding it to the list of HRAC priorities, because it could have a significant impact in Indian Country. She will add discussion of this issue to the agenda for the next quarterly meeting.
- Chairman Payment proposed that the priority on scholarship and research opportunities for AI/ANs include this issue. He suggested adding a priority to develop internal capacity within tribes to collect their own data.
- Dr. Villegas stated that the NCAI supported the development of data capacity and infrastructure within tribes to address the pervasive challenges of small sample sizes and hard-to-count populations. It is important to build capacity and methodologies that fit within Native communities and enable leaders to make decisions.

Wrap Up

- HRAC members who wish to propose agenda items for the next meeting should send them to CDR Branch.
- CDR Branch asked the HRAC members to respond to requests they receive from her or the contractor team.

The meeting was adjourned at 4:10 p.m. EST.