

**American Indian/Alaska Native Health Research Advisory Council (HRAC)  
Annual Face to Face Meeting, Washington DC  
April 28, 2009**

**HRAC Tribal Delegates and Alternates**

- Donald Warne, Aberdeen Area
- Tim Gilbert, Alaska Area
- Emily Hughes, Alaska Area
- Kathy Hughes, Bemidji Area
- Tracy “Ching” King, Billings Area
- Jim Crouch, California Area
- Elizabeth Neptune, Nashville Area
- Madan Poudel, Navajo Area
- Roselyn Begay, Navajo Area
- Cara Cowan Watts, Oklahoma Area
- Violet Mitchell-Enos, Phoenix Area
- Stephen Kutz, Portland Area
- Chester Antone, Tucson Area
- Sarah Hicks, National Congress of American Indians
- H. Sally Smith, National Indian Health Board

**HRAC Federal Partners**

- Garth Graham, Office of Minority Health
- Wilbur Woodis, Office of Minority Health
- Wendy Perry, Agency for Healthcare Research and Quality
- Leo Nolan, Indian Health Service
- Alan Trachtenberg, Indian Health Service
- Ralph Bryan, Centers for Disease Control and Prevention
- Sue Clain, Office of the Assistant Secretary for Planning and Evaluation
- Ileana Herrell, National Institutes of Health

**Meeting Minutes**

- A quorum was reached, thus results from meeting are considered official.

**Opening Session**

- Invocation by Chester Antone
- Opening Remarks:
  - HRAC Co-Chairs H. Sally Smith and Cara Cowan Watts
  - HHS Deputy Assistant Secretary for Minority Health, Garth Graham
    - Comparative Effectiveness Research is a new area of research being developed in response to healthcare reform, and HHS has not received any feedback or comments from AI/AN communities. It will be looking at cost containment strategies centered around healthcare as well as what research methods and policies work. Right now they are in the stage of defining CER, but this is the time to get involved. As Dr. Graham states, we need to "Go on record and be a part of the evolution."

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- Two more Public Sessions will be held in Chicago on May 13 and in DC during the week of June 8th. The Federal Coordinating Council is tasked with presenting their recommendations/findings by June 30, 2009 to the President.
- Comments: Dr. Warne suggested that this provides more opportunities for research and a new way of thinking. Dr. Trachtenberg pointed out that there is no provision from the stimulus bill for IHS grants. Funding is lacking for evidence-based and culturally based practices. Also, IHS is not represented on the Federal Coordinating Council. AHRQ will be posting information on their website on CER.
- Next Steps
  - Schedule conference call to further discuss this agenda topic and compile an official response from HRAC.
  - Encourage NCAI, NIHB, Tribes, health boards and other stakeholders to submit comments as well.
  - Cara to send an email with request that IHS be added to the Federal Coordinating Council.

## **National Children's Study**

### **1. Presentation**

- Dr. Peter Scheidt and Dr. Jennifer Park provided an overview of the National Children's Study

### **2. Discussion**

- Does the study oversample for the AI/AN population?
  - The study doesn't oversample for any subgroup.
- Does the study sample across diverse groups of Tribal communities?
  - Yes, to an extent due to the sample itself. Sampling a majority of states where AI/ANs reside, but it doesn't include all groups. For example South Dakota and Alaska are not involved.
- Why was there no sampling in Alaska, where over 250 Tribes reside?
  - It's stratified. The sample is distributed by US population not by groups. Other states not involved are Nevada, Nebraska, and Vermont.
- What agencies are involved in the study, and who is funding the study?
  - Congress is funding the study. It's not funded out of existing operating budgets within NIH and HHS, but in addition to. CDC, EPA and Education are also involved.
- How will the data collected in Indian Country be used?
  - There are no plans to do a Tribal analysis at this time as this is a national study. Any requests would go through the Publications Committee and Data Access and Confidentiality Committee.
- Who will own the blood and tissue samples including cell lines?
  - The study will own the samples, however, subjects can ask for their samples to be withdrawn.

**American Indian/Alaska Native Health Research Advisory Council (HRAC)  
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- How long will the blood, tissue and cell lines be maintained?
  - Indefinitely, unless a request is made for the samples to be withdrawn.
- Will the samples be shared with other researchers or for future studies? If so, who?
  - The Sample Oversight Committee manages the sample from before collection to after the study. This committee would seek permission prior to any future use other than what was included on the original study documentation/release.
- How will information be shared with Indian communities?
  - Data safety monitoring committee and other committees have certain protocols in place to ensure the data is used responsibly. They will be willing to provide the local information if there are securities that the local groups will be using the data responsibly.
- Will at least one American Indian scientist sit on the Data Safety Monitoring Board?
  - Dr. Everett Rhoades (Kiowa) is on the National Children's Study Advisory Committee.
- Dr. Warne comments on how so many Tribes are left out of the study. Aberdeen is currently looking to acquire additional funds for a supplemental study. Perhaps HRACs role is to serve as an advocate for funding these additional studies.

### **3. Next Steps**

- Dr. Warne and Tim Gilbert will head up the National Children's Study responses.
- Dr. Warne will draft a position paper and send to HRAC for review within 3-4 weeks and then a conference call will be scheduled to discuss.
- Find out if there is a communication mechanism between the Tribes that are currently in the study. If not, one may need to be established.
- A formal response to the National Children's Study to be created and submitted for the record, so HRAC can document involvement and attempt to address issues.
- Develop an Aberdeen/Alaska Children's Study proposal, as an adjunct study. (Great Plains/Alaska Native Study)

## **Proposed AI/AN Youth Behavioral Risk Survey**

### **1. Presentation**

- Dr. Robert Wm. Blum, of Johns Hopkins University's Bloomberg School of Public Health, presents "An American Indian-Alaskan Native Youth Health Survey: preliminary considerations"

### **2. Discussion**

- There is no national data for urban youth so this will establish baseline data.
- Any data captured on a national level is stripped of identifiers. However, the goal is to give back the information that was captured, complete with identifiers, to the local level.
- Funding has not yet been secured.
- A national advisory board will be established over the next several months.

**American Indian/Alaska Native Health Research Advisory Council (HRAC)  
Annual Face to Face Meeting, Washington DC  
April 28, 2009**

- A concern was brought up that data is being requested on youth for other studies with SAMHSA, Washington University, etc. Dr. Blum mentioned that a Native doctoral student will be spending the summer looking at other studies so this one is not duplicative. They will also discuss this with the advisory committee to find out what they are aware of.

**NCAI Policy Research Center**

**1. Presentation**

- Sarah Hicks spoke on the role of the research center, the research agenda, and current research projects.

**2. Discussion**

- An HRAC member suggested that the NCAI Policy Research Center could assist Tribes by having NCAI's researchers conduct a scholarly review of proposals and send the best to the Tribe for consideration, since Tribes lack the staff to do so.
- The Policy Research Center could assist Tribes by sharing templates for research and IRB policies and processes.
- It was suggested that NCAI PRC provide more training for Tribal leaders.

**3. Next Steps**

- Action items and partnership recommendations to be submitted to Sarah for future follow-up and consideration.

**Tribal Considerations in Research Regulations**

**1. Presentation**

- Puneet Sahota, Research Fellow at NCAI Policy Research Center, provided an overview of community research regulation tools, and presented questions for consideration when embarking upon Tribal research regulations.

**2. Discussion**

- Dr. Trachtenberg mentioned that NARCH grants do not require data sharing even though the grants come from NIH and now data sharing is negotiable. It was also mentioned that any Tribe can request review by the IHS IRB.
- An HRAC member suggested that NCAI advocate to funding sources that data sharing should not be required. The data enclave process still requires sharing just not as much.

**3. Next Steps**

- Questions and Recommendations will be collected and provided to Sarah Hicks.

**Johns Hopkins Center for American Indian Health**

**1. Presentation**

- Allison Barlow and Olivia Sloan provided an overview of the center and the various programs it offers

**American Indian/Alaska Native Health Research Advisory Council (HRAC)  
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**Federal Collaboration on Health Disparities Research (FCHDR)**

**1. Presentation**

- Jamila Rashid provided an overview of FCHDR

**2. Discussion**

- Department of Interior, Department of Justice and USDA do not currently have active representation within this group. Jamila welcomes any advice or contact suggestions for future participation.

**3. Next Steps**

- HRAC to provide Jamila with a list of recommendations for participation in the FCHDR. Dr. Warne agreed to develop a few sentences with recommendations that HRAC could submit.
- HRAC to submit research priorities individually or jointly with NCAI.

**Discussion Guide**

**1. Presentation**

- Kendra King Bowes, of Native American Management Services, provided an overview of the Discussion Guide results to date.

**2. Discussion**

- HRAC to work with NCAI to see if results are comparative and final results could be submitted to groups like the Federal Collaboration on Health Disparities Research. NCAI recommends we wait until the NCAI Mid-Year Session has concluded, as they will be revising the research agenda based on feedback from Tribal leadership.
- It was decided to keep the survey open to get more participation, as it should be a living document.
- Need to get researchers involved. There are really 3 pieces to this: Tribal communities; Researchers (NRN); and Funders (HHS). HRAC should engage the researchers by providing them with the main areas of concern identified by the discussion guide and have them suggest what areas need to be researched as it relates to cancer for example.

**3. Next Steps**

- Chester Antone, Tim Gilbert, and Sarah Hicks to discuss and compare findings once NCAI's research agenda is finalized.
- Create white papers based on the results to be provided to HRAC.
- Decide how to involve the Native Research Network.

**Outreach and Meeting Reports**

**1. Issues**

- HRAC Website

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- Wilbur Woodis provided a quick overview of the current website going over navigation of the site as well as content highlights.

**2. Discussion**

- Comments on the website are to be directed to Wilbur Woodis following the meeting.
- Consider adding the IHS 800 number for research risks/problems.

**3. Next Steps**

- Add Native Research Network, National Indian Health Board and NCAI Policy Research Center links on the website.

**Council Deliberation and Development of Priorities**

**1. Issues**

- Tribal Priorities to Date and Next Steps

**2. Next Steps**

- Cara Cowan Watts suggested that if anyone is interested in a specific priority to please contact her or Wilbur Woodis for further action.
- Education about and need for multiple IRB approvals is pushed to NCAI in concert with Alan Trachtenberg.
- Madan Poudel suggested having a panel presentation at the next meeting or conference call with Epi Centers on their activities and the roll they play with discussion on data issues that they have.

**Election of Officers**

- Cara Cowan Watts and Kathy Hughes elected as the new Co-Chairs.

**Review of Day and Closing Comments**

- Cara Cowan Watts provided a quick overview of the day and thanked everyone for their participation.