

National Institutes of Health Tribal Consultation Session

8th Annual Tribal Public Health Summit

Session Date: June 6, 2017

Prepared by the National Indian Health Board

On Tuesday, June 6, 2017, the National Institutes of Health (NIH) hosted a Tribal Consultation Session at the National Indian Health Board's (NIHB) 8th Annual Tribal Public Health Summit in Anchorage, Alaska. During this Tribal Consultation Session, tribal leaders and other representatives learned more about the NIH programs relevant to tribes and tribal organizations, as well as NIH's Tribal Consultation Policy.

I. TRIBAL CONSULTATION SESSION PARTICIPANTS

The following individuals attended the NIH Tribal Consultation Session:

A. Tribal Leaders (at the table and on the phone)

- Patrick Anderson, Tribal Health Director, Makah Nation
- Brian Bainbridge, Chairman, Cliff Lake Band of Lake Superior Chippewa Indians
- Lynn Malerba, Chief, Mohegan Tribe
- Gloria Simeon, 1st Vice Chair, Yukon-Kuskokwim Health Corporation
- Larry Wright Jr., Chairman, Ponca Tribe of Nebraska

B. NIH Staff

- Juliana Blome, Ph.D., M.P.H., Chief of Staff, Environmental influences on Child Health Outcomes (ECHO)

C. Tribal Moderators and Speakers

- Andy Joseph Jr., Board Member, NIHB and Business Council Member, The Confederated Tribes of the Colville Reservation
- Walter Phelps, Council Member, Navajo Nation Council and Navajo Area Delegate, NIH Tribal Advisory Committee (TAC)
- Denise Dillard, Ph.D., Director of Research, Southcentral Foundation (SCF) and Alaska Area Delegate, NIH TAC

D. Attendees

- See addendum for list of additional attendees

TRIBAL CONSULTATION SESSION PROGRAM

On June 6, 2017, the NIH held a Tribal Consultation Session at the NIHB National Tribal Public Health Summit from 10:00 a.m. – 12:00 p.m. in Tikahtnu Ballroom E. Tribal consultation was held to discuss research priorities and concerns for NIH's first strategic plan of the Tribal Health Research Office. The following is a comprehensive recap of the NIH Tribal Consultation Session.

A. Welcome

The NIH Tribal Consultation Session moderator Andy Joseph, an NIHB Portland Area representative and business council member, The Confederated Tribes of the Colville Reservation, called the session to order and offered the opening prayer.

B. Introductions

Following the prayer, Walter Phelps introduced himself as a representative of the Navajo Nation Council, and a member of the NIH TAC. Councilman Phelps then stated that the director of NIH's Tribal Health Research Office, Dr. Dave Wilson, would not attend the session because of travel complications. Councilman Phelps then introduced Dr. Juliana Blome, chief of staff of the NIH Environmental influences on Child Health Outcomes (ECHO) program. Councilman Phelps also introduced Dr. Denise Dillard as an NIH TAC member representing Alaska.

Councilman Phelps shared his experience with the NIH and the NIH TAC, praising the NIH student internship program in Bethesda, Maryland. Councilman Phelps encouraged the audience members to tell their family members about the available internship opportunities at NIH. He also stated that there are opportunities for tribal communities to get involved with research studies and to develop Institutional Review Boards.

Councilman Phelps commented that the Navajo Nation is both trying to promote cancer awareness and research the disease. He stated that Tuba City is trying to create a resource in the tribal communities of Western Navajo and Tuba City in order to build an oncology center and treatment program.

Councilman Phelps encouraged tribal leaders to engage the people that are involved in health care throughout Indian Country. He further commented that elected tribal leaders represent the TAC to help develop protocols and processes.

After Councilman Phelps' remarks, Dr. Blome introduced herself and noted changes to the day's schedule. Dr. Blome then read a brief statement on behalf of Dr. Wilson. Dr. Blome indicated that NIH is strongly committed to meaningful engagement with tribal nations. Dr. Blome stated,

“the consultation session is very important and will provide information valuable to the development of an effective strategic plan that will best serve tribal nations.”

NIH Overview

Dr. Blome recapped the structure of NIH and the 2016 FY budget; she stated that NIH funding of over \$181 million was spent on health research for American Indians and Alaska Natives (AI/ANs) and \$160 million a year in that area since 2012. Dr. Blome also stated that NIH funds research on a variety of topics designed to improve health and reduce health disparities in AI/AN communities including: cardiovascular disease; environmental health; drug and alcohol abuse; and diabetes. Programs are designed to empower individuals and communities with the information they need to improve the health of their community and prevent disease and injury. The NIH funds programs that encourage AI/AN students to enter biomedical research careers, join the biomedical workforce, come back to their communities and contribute their knowledge, as well as support AI/AN investigators who are leading their own biomedical research programs and labs.

NIH Tribal Consultation Guidance

Dr. Blome read the tribal consultation protocol, stating that the session would be recorded and transcribed. Dr. Blome detailed that the structure of NIH’s Tribal Health Research Office was established in 2015. Dr. Blome stated that the Tribal Consultation Session would discuss research in Native American communities and the strategic plan guiding NIH’s activities for the next 4 to 5 years. Five recommended priorities have been developed through consultation with NIH leadership and the NIH TAC: enhance communication, build research capacity, expand research, evaluate progress, and cross-cutting areas of cultural competency and community engagement.

Tribal Introductions

Patrick Anderson: Mr. Anderson introduced himself as a Tlingit from Alaska and appointed tribal health director for the Makah Nation in Neah Bay, Washington.

Brian Bainbridge: Chairman Bainbridge introduced himself as chairman of the Red Cliff Band of Lake Superior Chippewa Indians. Chairman Bainbridge felt it was important that he travel to voice his concerns and become educated. He noted the high instances of cancer in his area and wanted to find the root of it, referencing mining operations in his community. Chairman Bainbridge noted that he has yet to see research investigating the high rates of cancer in his area.

Lynn Malerba: Chief Malerba introduced herself as a member of the NIH TAC and stated that she was interested in listening to tribal leaders who are not on the committee.

Larry Wright, Jr: Chairman Wright introduced himself as the chairman of the Ponca Tribe of Nebraska and an NIH TAC alternate of the Great Plains Area.

C. Biomedical Research and Tribal Communities Presentation

Dr. Denise Dillard introduced herself as Inupiat Eskimo. She is the Alaska Area delegate on the NIH TAC. She is also the director of research at the SCF. SCF is a tribal health organization based in Anchorage and she has worked for SCF for 16 years. She was asked to talk about some of the research that has occurred and is occurring in Alaska. She added that her presentation was in no way meant to be comprehensive, but would provide a sense of what is being undertaken and how SCF has influenced how research is conducted in Alaska.

In 2004, SCF made the decision to create its own research department and the overall mission of that department is to respond to the priorities identified by tribal leadership through listening to community concerns.

SCF has a multi-step tribal research review and approval process and this process is required whenever any AI/AN people are invited to participate in a study within an SCF facility or on the Alaska Native Medical Center campus. The tribal review process is required before application for funding. This is called “concept approval” and it was something tribal leadership wanted to initiate.

SCF has a guideline for research document which researchers are required to sign. It states that the researcher agrees that all data is owned by SCF and the people who have contributed their information rather than the researcher or by the funder and that they are agreeing to go through all of these different steps of tribal research approval, not only for the current study but also in any future studies that might use some of the data that was obtained, and requires that results be disseminated back to SCF, to the community, and also to providers in case there is any change to clinical processes that might be warranted.

Dr. Dillard noted that there is a Specimen Bank on the Alaska Native Medical Center campus where specimens have been stored since the 1960's. In the early 2000's, the Centers for Disease Control and Prevention (CDC) asked the tribal leadership to join in co-management of the Specimen Bank. There were several questions that tribal leadership had about the Specimen Bank and research helped to facilitate obtaining some of the answers to those questions.

One set of questions was about how the bank came to be and they helped to document some of the history. They also helped to document what was stored in the Specimen Bank, how samples came to be placed into the bank, and what regions of Alaska the specimens came from. They went to 14 different regions of Alaska and spent time with community members and leaders asking them about the idea of a Specimen Bank storing specimens for future research.

Key findings were that a lot of people are not aware that there is a Specimen Bank in Anchorage and there were some concerns about how consent is obtained and how leadership and communities will be involved in guiding this research moving forward.

There were also views that such a resource could be beneficial in research if appropriately overseen in terms of being able to look back at changes in environment and looking at other biological markers of early disease. People also had a lot of questions about the Specimen Bank and the operation itself.

In 2010, SCF began a series of pharmacogenetic research studies looking at how people's genetics may influence response to medications. They started off this set of studies by asking people what they thought about this type of research and then they collected DNA and other information to look at response to Warfarin and Tamoxifen.

Both the Warfarin and Tamoxifen studies had a separate consent to store specimens of people who were willing and they also did agree that should they do any future studies that they would go back and re consent people every time that those specimens were accessed.

They found in focus groups and interviews that there was concern about information being used to stereotype people. There were also questions about how much would this type of research or clinical care cost, and concerns that this needs to be balanced with the many health needs of the community. There were also questions concerning what are the benefits for people. It might be of benefit to the small number of people who participated in the study, but what about the rest of the community.

If pharmacogenetic testing could more quickly get people onto the right medication, then this could potentially save the system money in the long run. This type of research could help develop the community in terms of developing research capacity within the AI/AN community.

They found in some of the genetic research that there is the presence of some variance genetically that have been found in other populations, which would influence the dosage. Warfarin is a blood thinner used within cardiovascular disease and Tamoxifen is a medication used in breast cancer treatment. The dose may need to be modified for some women with breast cancer and there may be a need to alter the dose and start at a lower dose.

Then this built on to some current research that they are doing, which is the Southcentral Foundation Research Center for Alaska Native Health. This is funded through the Native American Research Centers for Health at NIH. They have undertaken two types of pharmacogenetics studies. One is looking at how pharmacogenetics could be used to guide the selection of tobacco cessation agents. Some people metabolize tobacco faster than others. So, whether somebody is on the patch or on a medication may vary in terms of what some of their genetic background may be.

D. Tribal Comments

Gloria Simeon: Ms. Simeon introduced herself and stated that she has learned much during her time on the Yukon-Kuskokwim Health Corporation. Ms. Simeon stated she wanted to provide background on her organization's genetic studies. Ms. Simeon commented that nearly half the number of tribes in the United States are in Alaska; her region of 56 villages comprises approximately one-tenth of the tribes in the country. Her community has been studied by

researchers for decades. Ms. Simeon stated that her question referred to a time when her community was not allowed to give informed consent on the collection of their blood and body samples. Of the 100,000 or so samples in the Alaska serum bank, almost half of those are from the same region as Ms. Simeon. The Indian Health Service (IHS) did not ask permission for many of those samples that are still currently being accessed and utilized to determine health outcomes. In fact, one study, the infant morbidity and mortality study, has been going on 60 or 70 years, tracking about 600 or 700 babies that were born back in the 1950's. Ms. Simeon doubted that participants have been made aware that they were being tracked or had been part of the study. So, there are many loose ends. Also, Ms. Simeon stated a concern mentioned by Dr. Dillard that communities need to be aware of the studies that are going on with their people, to protect the research resulting from those studies. Much is going on in the study of their community's genetics. As Dr. Dillard mentioned, their bodies react differently to mainstream, Western medicine. The community has been communicating to its providers "this isn't working," and the providers have not listened. There are significant enough differences in their people's genome that their bodies process Western medicine differently. The right levels are for the most part, unknown. The more that is known, the more people can be helped and protected. The Yukon-Kuskokwim Health Corporation ensures its board has information to make good decisions on what research is allowed in the region. A basic understanding of what people need to know is very important, especially with the studies that are occurring. Also, a partnership exists between the states of Alaska, Washington, and Montana in childhood obesity studies, with \$22 million available for research in that area. Ms. Simeon had hoped Dr. Dillard would be able to expand on that area, because there are issues with obesity and diabetes among her people. This is important because there are possible benefits, but also potential for great harm.

Walter Stickman: Mr. Stickman stated that his question was being asked on behalf of his sub region regarding cancer. Both the young people and elders in different situations are being diagnosed. For example, an elder man with cancer in his lungs does not have much time left. And a young lady in her late 20's has been diagnosed. The same is happening to people in other villages too. Mr. Stickman stated that his people are trying to figure out if it is the flood systems, coming down their water system and getting into the land and fish being eaten. Mr. Stickman asked if research could be done to help people find ways to avoid and prevent cancer.

Steve Tetlow: Mr. Tetlow introduced himself and his organization, which opened a hospital in July 2016. Mr. Tetlow stated the research presented during the Tribal Consultation Session was a good presentation and that tribes should be concerned with research. Research has been happening for so long in many different areas that Mr. Tetlow was unsure if its impact was positive or not. However, in the business community, what is studied are projects to determine the strengths and weaknesses, identifying opportunities and threats. Mr. Tetlow thought that most of what had been shared were strengths of the research, but not enough about the weaknesses. Therefore, Mr. Tetlow wanted to know, "what are the risks [of the research] that impact tribes?" Mr. Tetley also recommended that research focus on current, real risks of tribes. A few years ago, there was a lawsuit in Arizona where one of the universities did not keep protocol for protecting the information of the tribes it had collected samples from. Mr. Tetlow

said that tribes are always concerned for the potential risk of private information being released, even though this has been refuted, the risk is always there. People are concerned and want to know what is causing cancer in the community. Cancer did not occur in the old days of the Apaches and the Warrior Societies. The San Carlos Apache are in eastern Arizona, and the Gila River comes through their community. It goes down to Coolidge Dam and into Phoenix Valley. In the 1960's, the U.S. government sprayed the river with dioxin, a derivative of Agent Orange, to defoliate all the trees, the conduits and willows, and everything along the river. This was done so that rivers of the San Carlos and Gila would run down into the valley for the farmers downstream, not Indian farmers. Agent Orange or dioxin, is something that was sprayed in Vietnam also. The elderly present are Vietnam War veterans. There are problems among these veterans because if they handled Agent Orange, they are affected by a lot of health issues now. Because of the Warrior Society days, veterans are given high esteem and should receive the best care available. Mr. Tetlow stated that maybe more research needs to be done in San Carlos about what the government did and that the government activity is a form of research. Apaches are going to be affected for the worse because of the water systems. It is said that it is still in the water and the land; it is still in the sand. Maybe there are opportunities for research or strengths that can help. Mr. Tetlow stated that tribes need to be protected first; the other priorities can be research. If the utmost protection is given to tribes in the research, benefits can be found.

Madison Fulton: Ms. Fulton introduced herself and commented that her former professor, Debra Harry (Northern Paiute), is the executive director for the Indigenous Peoples Council on Biocolonialism. As an international advocate against biocolonialism, which is the patenting of intellectual property rights, cultural property rights, and also Indigenous peoples' genome, blood samples, etc., a huge concern is the political risk of genome research used to discredit Indigenous peoples' origins and their inherent rights to the land, community, and natural resources. The lawsuit mentioned by Mr. Tetlow is the *Havasupai v. Arizona Board of Regents*. A community member attended a briefing of the research and discovered their information was being misused. Biocolonialism occurs when researchers do not offer free, prior informed consent in patenting the intellectual property rights of songs, prayers, the information where to find certain things, medicine, and ceremonies. Ms. Fulton stated that there is "a lot of baggage" regarding the term research and said she is grateful because not many institutions or researchers even address the issue. Ms. Fulton stated, "here is a flipside to conducting research in tribal communities."

Rupert Steele: Councilman Steele introduced himself and his tribe, stating that a few years ago the University of Utah's Huntsman Cancer Institute came to his tribe to do research. The researchers wanted to help find out if cancer was part of the reason his tribe's people were dying mysteriously. Councilman Steele stated that his people are located "downwind" from the Nevada test site in Las Vegas, with the mountain ranges to the north and south. The tribe entered into an agreement with the University of Utah that was similar to the agreement between the Havasupai Tribe and Arizona State University (ASU). Councilman Steele stated that he brought it to the attention of his tribal members, advising them to sign consent forms because the research may be used differently than what tribal members were being told. Councilman Steele stated that research of his people has been happening for a long time and many do not want to give consent.

Councilman Steele stated that some studies are important but could be misused. Councilman Steele is worried that research can be used to support claims against tribes. Therefore, Councilman Steele thought that when these studies are done, information should be returned to the tribe to maintain confidentiality. Councilman Steele stated that his tribe had to threaten a lawsuit before the blood samples of his tribal members were returned to them by the University of Utah. It took nearly 2 years for the tribe to receive the samples. It is unknown what happened to the samples during this time and it remains a large concern. Councilman Steele commented that research is important but should be approached carefully. Another issue Councilman Steele wanted to discuss was nonpoint contamination. Councilman Steele commented that tribes should be informed of the contaminants in their air, water and land and this is not being discussed for national security purposes. The Training and Test Range of the Dugway Proving Grounds is on the eastern border of Councilman Steele's reservation, where many chemicals have been tested. Testing could affect Councilman Steele's community [members], whom are different and will react differently to the medicine.

Matilda Hardy: Ms. Hardy introduced herself and stated that her community was also concerned with the diagnosis of cancer. Ms. Hardy stated that there should be further consideration when a patient goes in for the treatment of illnesses or cancer at hospitals. There are many diagnosed with cancer in the region. And when individuals are studied, instead of holding the information for years, tribes should be informed when the studies go out. Ms. Hardy further stated that more should be done for the people by supporting the Certified Nursing Assistants (CNAs) in each village, helping to relieve the health aides or whoever works in the villages; the CNAs go in after an operation to help relieve a patient that needs medical care.

Mae-Gilene Begay: Ms. Begay introduced herself and thanked NIH for its funding to continue the Navajo Birth Cohort Study. Ms. Begay stated that she wanted to know what kind of impacts President Trump's Administration would have on current research projects that are being funded. Ms. Begay also stated that she would like to comment on research study dissemination. Ms. Begay was unsure of the protocols on research study finding, but said it should be mandatory for the researchers to disseminate information back to respective tribal communities. Tribal communities are not aware that these studies should be shared with them, so dissemination should be mandatory. Ms. Begay also asked, "Do you have archives of all the studies that have [been] made on Indian nations and do we have access to those studies?"

Patrick Anderson: Mr. Anderson stated that he would like to propose that NIH look at the association between adverse childhood experiences, unresolved childhood trauma, and cancer. For years, staff at the State of Alaska Department of Health have attempted to collect data regarding adverse childhood experiences among the Alaska Native community. Authorization was granted to put questions into the Behavioral Risk Factor Surveillance System (BRFSS). In 2013, a report by Pat Sidmore indicated that Alaska Natives were at double the risk of having four plus adverse childhood experiences. In 2015, Dr. Vincent Felitti addressed the National Congress of American Indians regarding the story of Mary Elizabeth Bullock, a former federal

civil rights judge with multiple adverse childhood experiences. As an adult, Judge Bullock had four different kinds of cancer, recurring four times, and two autoimmune diseases.

Dr. Felitti made the point that when you have a state of continued toxic stress throughout your life, the impacts on the body are suggestive of growth of cancers and autoimmune diseases. A recent article in the medical journal Pediatrics included a finding on an association between adverse childhood experiences and risk in cancer, recommending greater research. If Alaska Natives have four plus adverse childhood experiences, it is likely that the population attributable to risk of adverse childhood experiences contribute to increased cancer. In cases of true prevention, resolving the toxic stress of childhood acquired trauma by providing resources and parenting support is long term, but an area that should be worked on as a part of the NIH research agenda.

Kanaelani Davis: Ms. Davis introduced herself and asked that NIH recognize her people. She is Kanaka Maoli Native Hawaiian. Ms. Davis stated that a systematic inquiry or investigation does not occur very often and the sight of the observations have been lost. It is understood by Indigenous people that with grandparents and the elders, people are not researching but observing; because what is seen is not the whole picture, especially when looking at diseases and the health of her people. Ms. Davis stated that the observations she did as a young child are not the same today. Like the ocean in front of her house, the tides are very different. Ms. Davis commented that the trees that bloomed once a year now bloom four times a year. Ms. Davis stated that she was unsure when mango season is because it comes when it comes. Therefore, research is constantly looking for certain things that are particular to one thing and the whole picture is never seen. Ms. Davis encouraged observations of the Native Hawaiians to be included as part of the strategic plan. Ms. Davis also encouraged cultural health integration, though it is not profitable. Ms. Davis stated that she would like to see requirements for providers to both understand and become part of the community through observations of its people when they enter small Indigenous communities. Ms. Davis asked, “How can an apple tree be orange if the apple has never seen an orange before?”

Eric Hardy: Mr. Hardy introduced himself and thanked the Indigenous people of the area for allowing him to visit. Mr. Hardy commented that he wanted to reiterate much of what had been said and that part of the conversation when it comes to research is the colonial project history. Indigenous people are the most researched people in the world, and now that Indigenous people are part of the conversation, the conversation of research methodologies has been brought to the forefront. Mr. Hardy asked, “How are we defining and designing our research methods?” When health is discussed, such as diabetes and cancer, those are very Western concepts. This is not to say that those issues do not affect [our] communities. However, the way they are discussed is from a Western framework. It is important to bring up communities when discussing methodology, as the Hawaiian relative [Ms. Davis] was talking about. Research studies from the Indigenous perspective, such as intellectual property rights and cultural property rights, need to have their methodologies discussed in a way that makes sense to the Indigenous ways and

knowledge so that tribes can build capacity in their communities. Tribes need to protect their communities in the ways they are supposed to be protected, through ceremony and prayer, for example, but also other Western frameworks. There are other conversations that also need to be talked about, especially in the context of health disparities. Maggie Walter, an author from the University of Tasmania, is talking about quantitative research methodologies and reframing the approach on quantitative research as a Western space to redefine an Indigenous space. The way disparities are discussed is top-down, like something is wrong with Indigenous people. But looking at it from an Indigenous perspective, you shift the conversation to, “Is the Western lifestyle good for us?” Another part of this is understanding that privilege when it comes to research. Many in attendance have degrees and classes where months are spent talking about these things, exploring these conversations. But to be honest, when it comes to community members, the conversation also needs to go back to methodologies and reframing the conversation about the ones that are qualified to talk about research. “Are we referring to our doctors, our scientists to kind of define things? Are we talking about our elders, our ceremonial people, or the experts?” If this is going to be an Indigenous-centered approach, reframing conversations about “what kind of research” also needs to be part of this conversation. “Who are we talking to when we talk about these health issues? Are these experts?” Mr. Hardy stated that the last thing he wanted to mention refers to Ms. Fultons’ comments between ASU and the Havasupai Tribe. It should be recognized that when it comes to creating knowledge and protecting knowledge, institutions have control. This also gets back to the idea of creating knowledge. Indigenous people create knowledge all the time, just as good if not better than universities.

Aren Sparck: Mr. Sparck commented that he wanted to discuss investing in Indian Country research, because right now the epidemiology centers are handling the epidemiological needs of the Native population. Most of them are on a regional basis throughout the United States with the tribes or urban populations that they represent. Tribes would very much like to see an increased collaboration investment from all HHS agencies. People see an IHS mandated aspect; but working with the Office of Minority Health (OMH), NIH, or CDC, the actual investment of working together and collaborating for research in Indian Country has to happen. Mr. Sparck commented that his peers work in silos, not necessarily talking to one another. But if everybody is seen together at the same table, “To see that there's research being created by Native people, with Native people, and for Native people, we're going to get to a place where we're not necessarily talking about research as a dirty word anymore.” Mr. Sparck said he wanted to ask if more could be done to work together and understand that the research centers created by Native people, for Native people are something tribes would like to see invested in more at the federal level.

Ellen Provost: Dr. Provost commented that she would like to expound on an issue of concern which may be unknown. Every IHS area has a Tribal Epidemiology Center (TEC). Dr. Provost encouraged attendees to visit <https://tribalepicenters.org/> to learn more about the services available in the Indian Health Care Improvement Act, which was permanently reauthorized in March 2010 as part of the Patient Protection and Affordable Care Act. TECs were given public

health authority designation and are responsible for epidemiologic and technical assistance services: answering data requests; putting together reports and presentations; and answering questions from federal partners, the communities, and tribal leadership. The NIH has provided funding for TECs for a very long time. Initially, it was about \$100,000 per TEC per year until the sequestration in 2013, when that amount was cut in half. Her organization just received notice in the middle of this funding year that the funding amount from NIH will be zero in FY18. Dr. Provost stated that she was informed it was because of a problem with the IHS' interagency agreement. Dr. Provost stated that when she last checked, she was informed there would be nothing for FY18. She said \$50,000 is almost a whole FTE for TECs. The activities and services provided will be gone and hard to replace again in the future. Dr. Provost asked, "What is the NIH's plan to ensure continuity of funds to TECs for FY18?" Dr. Provost said that she understood that there may not be an answer given immediately, but she wanted to ensure that her question was recorded.

Juliana Blome: Dr. Blome thanked attendees for their comments and attention, stating that she attended the March meeting of the NIH TAC and the budget issue mentioned by Dr. Provost was discussed briefly. Dr. Blome was unable to provide an answer at the time, but stated that she would return to NIH and bring it to the attention of NIH senior leadership and Dr. Wilson. Dr. Blome stated that they would find out what the options were and what could be done. It was in the interest time that Dr. Blome decided to not present on the ECHO program, though she would be available to answer questions and talk.

NIH Strategic Plan

Dr. Blome introduced the five priorities of NIH's draft strategic plan for the Tribal Health Resource Office, developed in consultation with NIH leadership and the NIH TAC. Dr. Blome stated that she would like to hear from the participants about their opinions on these priorities. NIH had several questions put together and invited audience members to come to the microphone to speak on the outlined priorities.

Mr. Anderson thanked Dr. Blome and introduced himself as the tribal health director for the Makah Nation. Mr. Anderson stated that he liked category 3 and 5, expand research and cross cutting across areas of cultural competency. He indicated that for about a decade he wanted to see research that was cross-disciplined and seeking a root cause of a multitude of areas where AI/ANs are heavily impacted and essentially building on the adverse childhood experience study and a multitude of negative behaviors [that] occur. Mr. Anderson also indicated that he believes there are neutral and positive behaviors that help people negotiate the range of choices that one can make in terms of support. He also referred to things like drug abuse, an individual's attempt at self-medication, and said he believes this is not just true with the selection of drug use, but the opioid epidemic. Mr. Anderson remarked with his research there is about 33,000 deaths caused annually, and dopamine receptors that are affected by opioid use are also affected by tobacco use, of which there are approximately 80,000 deaths attributed to annually and alcohol abuse

with over 480,000 deaths annually. He also commented that nutritional supports are not integrated into most of their studies. Mr. Anderson continued to summarize additional studies conducted by NIH in the impact of Omega 3 supplementation on achievement among the lowest 20 percent of academic achievers within primary care facilities. Mr. Anderson also noted the impact of vitamins D3 and B regarding depressive symptoms. He continued to go into the aspects of holistic views of healing by Dr. Peter Levine, recognizing how the body responds to toxic stress, and biofeedback methods. Mr. Anderson stated that we need to research whether current mechanisms are successful and we should be targeting people based on the evidence of their exposure to toxic stress and behaviors that they develop and high-risk populations, including those with adverse childhood experiences. Mr. Anderson continued to discuss his involvement with suicide prevention, citing Alaska suicide rates. He said 80 percent of successful suicides occur in the younger population, while women attempt more but are less successful. He also referenced a study coming out of the University of Alaska for depression and alcohol abuse in regard to suicide prevention and screening for adverse childhood experiences. Mr. Anderson indicated that he would like to see the NIH TAC consider including these areas as a part of the strategic plan as research areas for the future.

Madison Fulton introduced herself as an employee with the Inter Tribal Council of Arizona. Ms. Fulton indicated that enhanced communication and coordination needs to happen at the community level. Ms. Fulton commented that they work with 13 tribes and need to do outreach with the tribes to be effective in their work. She urged the panel to work with the community for dissemination and implementation follow up, especially regarding tribal research. She stressed the point that dissemination and implementation of tribal based research must happen at the community level. Ms. Fulton commented that they have gotten feedback from community members who are reluctant to give information for surveys because they feel the information never gets back to them. Ms. Fulton again stressed the importance of having information come back to the tribal communities; when studies don't return with information, it leaves community members upset. Information needs to be community owned, community controlled. Ms. Fulton provided cautions when discussing tribal capacity growth for tribes and stated that we should think critically and not just from an accumulation and material growth perspective. Ms. Fulton recommended that NIH ask the fundamental questions of how does the research benefit tribes, who does the research benefit, and how the institutions will inform the tribes of results. Ms. Fulton indicated that a tribal Institutional Review Board should be the top priority and occur before all the other ones, citing tribal sovereignty and Indigenouslyness. Ms. Fulton noted that it is all about maintaining respectful partnerships, and maintaining the connection/relationship building that is a core value of Indian people.

Comments on the NIH Strategic Plan

Male Speaker (name and affiliation unavailable): The male speaker commented that priority number one, communication, and number five might have to be exchanged. The speaker stated that he thought that the approach to research with tribes should be the tribes having final say on

research and to establish protocols on how the tribes are approached and decide where the research will go. The speaker also commented on the aspects of tribal sovereignty and how switching priorities one and five would allow this to occur. The speaker discussed that priority one would become priority two and two would be three, building research capacity, and four would be expanding research with evaluation as the last priority.

Mr. Eric Hardy, with the Inter Tribal Council of Arizona, indicated that research should be considered as a means to protect and express tribal sovereignty. Mr. Hardy also commented that there is an understanding that research is inherently seen as Western in tribal communities. Mr. Hardy commented that we should be having conversations understanding what research is and reframing the conversation for a tribal context. Mr. Hardy commented that tribes don't have a lot of the capacity that Western institutions have.

Ms. Deborah Scott introduced herself as a grant writer and evaluator working with BeLIEving In Native Generations, a nonprofit in Anadarko, Oklahoma. She suggested that expanding research means not having the topic decided prior to coming to tribal communities, meaning the needs of the tribal community are not included. Ms. Scott called for a more organic approach of deciding how research was selected and done for a broader understanding of reports on the need and how it can help community research-based programs.

Chairman Brian Bainbridge asked if the priorities were ranked in order of importance and how NIH would follow the priorities. He cautioned NIH to not lump everyone into the same group because they don't all live the same. Chairman Bainbridge commented that tribal communities have different environments that affect them in different ways and listening to everyone is important to drive the research, referencing priority five. Chairman Bainbridge mentioned that whether funding sources are competitive or not, it's important that the research is meaningful and addresses problems or issues. Chairman Bainbridge stressed number five of the NIH strategic priorities, basing it off community concern and needs.

Dr. Juliana Blome commented that she was not sure if they were prioritized and added that they are all areas of focus for discussion. She also asked about what kind of objectives should be in each of the areas and how success should be defined.

Chairman Bainbridge responded that it should be defined, first, by looking at what is at the bottom versus what is at the top. He questioned who defined the goals and objectives of the project.

Dr. Blome indicated that she wanted to ensure she was listening actively. She stated that it sounds as if number five is really foundational to everything that NIH would do and should come as number one if the items were to be ranked.

Chairman Bainbridge indicated that the priorities should revolve around first establishing a relationship and meaning with the people and the culture and not adapting to the Western one first. Chairman Bainbridge commented that there should be care taken to see who Native people are and then set the course for whatever there is; it should be a standard practice.

Dr. Blome responded that it is not really a priority per se, but more of a guiding principle for how to interact with tribal nations and asked if that would be fair.

Male Speaker (name and affiliation unavailable): The speaker indicated that number one is where they had an issue and not to enhance communication, but establish cultural relevancy for the NIH and when it comes to research by enhancing collaboration, investment, communication, and coordination. The speaker stated that there are ways to talk to people, but that there is cultural responsibility for the people to trust NIH in the first place. When there are efforts made to invest in the areas, that is when the people will say “yes.” The speaker referenced the Havasupai people and DNA evidence that is happening right now. The speaker commented that we must create a form of cultural responsivity and respect first by enhancing those areas and to add investment and collaboration along with communication and coordination. The speaker mentioned that the foundational principles and standard operating procedure should be to understand who you are talking to first, before you come in with an idea about research.

Female Speaker (name and affiliation unavailable): The speaker commented that in her area they started steering away from the term cultural competency and moving toward cultural humility because they are recognizing that you can't be competent in another person's culture, you should be humble about it.

Addendum 1: Additional NIH Consultation Meeting Attendees

- Tony Abramson, Sault Tribal Health Center
- Cassandra Allen, Chinle Service Unit, Indian Health Service
- Paul Allis, Food and Drug Administration
- Yesenia Alvarez, Pascua Yaqui Tribe
- Eleanor Amaktoolik, Chinik Eskimo Community (Golovin)
- Charlene Apok, Southcentral Foundation
- Justice Beard, Tuba City Regional Health Care Corporation
- Mae-Gilene Begay, Program Director, Navajo Nation Department of Health
- Brandon Biddle, Alaska Native Tribal Health Consortium
- Alvin Blackgoat, Health Board Gallup
- Millie Brockie, Tuba City Regional Health Care Corporation
- Brian Brunelle, Leech Lake Band of Ojibwe
- Mary D. Charles, Norton Sound Health Corporation
- Jared Clayton, Confederated Tribes of Grand Ronde
- Kanaelani Davis, Kanaka Maoli Hawaiian, Molokai Community Health Center
- Colleen Dushkie, Association of Alaska Housing Authorities
- Carrie Eischens, U.S. Arctic Research Commission
- Joseph Fang
- Maria Fang
- Alice Fitka, Norton Sound Health Corporation
- Ms. Frank, Council of Athabascan Tribal Governments
- Cary Fremin, Southcentral Foundation
- Madison Fulton, Health Promotions Specialist, Inter Tribal Council of Arizona
- Laura Gon, Tuba City Regional Health Care Corporation
- Nicole Gurnoe, Red Cliff
- Patti Handy, Organized Village of Kake
- Eric Hardy, Health Promotions Specialist, Inter Tribal Council of Arizona
- Matilda Hardy, Norton Sound Health Corporation
- Lonnie Headdress, National Indian Health Board
- Taralyn Jones, Sacred Circle/Goshute
- Joanne Keyes, Norton Sound Health Corporation
- Chris Kolerok, Bering Straits Regional Housing Authority
- Bertha Koweluk, Nome Eskimo Tribe
- Hazel Kunalan, ASNe/Nun
- Dolly Lane, Tuba City Regional Health Care Corporation
- Jenny Lee, Norton Sound Health Corporation
- Sherri Lewis, Chinik Eskimo Community (Golovin)
- Michael Mercado, Gila River Indian Community
- B. Alex Montoya, Fort Defiance Indian Health Board, Inc.
- Sam Moose, Mille Lacs Band of Ojibwe
- Holly Mortinson
- Frederick Murray, Norton Sound Health Corporation

- Angela Nason, Leech Lake Band of Ojibwe
- Tincer Nez, Tuba City Regional Health Care Corporation
- Mollie Ningeulook, Norton Sound Health Corporation
- Alan Numkena, Tuba City Regional Health Care Corporation
- Ellen Provost, EpiCenter Director, Alaska Native Tribal Health Consortium
- Joseph Reeves, Ketchikan Indian Community
- Cecil Sanford, Mount Sanford Tribal Consortium
- Honalee Sanford, Mount Sanford Tribal Consortium
- Tara Schmidt, Center for Behavioral Health Research and Services, University of Alaska Anchorage
- Deborah Scott, Cherokee
- Aliassa Shane, Southcentral Foundation
- Marc Shuman, University of California, San Francisco
- Gloria Simeon, Yukon-Kuskokwim Health Corporation Executive Board
- Aren Sparck, Government Affairs Officer, Seattle Indian Health Board
- Rupert Steele, Council Member, Confederated Tribes of the Goshute
- Walter Stickman Sr., Representative, Tanana Chiefs Conference
- Emery Tahy, Inter Tribal Council of Arizona
- Steven Tetlow, Board Member, San Carlos Health Care Corporation
- Herman Tso, Tuba City Regional Health Care Corporation
- Kimberly Williams, Tuba City Regional Health Care Corporation//Navajo