

NIH Tribal Consultation Advisory Committee Meeting
September 29-30, 2015
National Institutes of Health
Bethesda, MD 20892

Day 1 – September 29, 2015

Invocation

Walter Phelps, Council Delegate

Councilman Phelps opened the meeting with a traditional Navajo invocation.

Welcome and Introductions

Kathy Etz, PhD, Senior Advisor for Tribal Affairs, National Institutes of Health (NIH)

Aaron Payment, MPA, Chairperson, Sault Ste. Marie Tribe of Chippewa Indians, TCAC Bemidji Area Delegate

Dr. Etz welcomed participants to the inaugural meeting of the NIH Tribal Consultation Advisory Committee (TCAC) and thanked NIH Director, Dr. Collins, and NIH Principal Deputy Director, Dr. Tabak for their support.

Chairperson Payment reviewed the technical procedures for the meeting. He noted that TCAC was exempt from the provisions of the Federal Advisory Committee Act (FACA). Due to the government-to-government nature of TCAC meetings, guests may not participate in open discussion. However, TCAC members may yield their time to alternates, technical representatives, or guests. If a TCAC member is found to be in violation of these rules, HHS might not be allowed to rely on any data from the meeting in making decisions, which could jeopardize past and future actions of the TCAC.

Chairperson Payment led a round of introductions of committee members, alternates, technical advisors, and staff. Following the introductions, Dr. Etz reviewed the meeting materials and invited those on the phone to introduce themselves.

Opening Remarks and NIH Orientation

Lawrence Tabak, DDS, PhD, NIH Principal Deputy Director

Dr. Tabak provided an overview of the structure and mission of the NIH:

- NIH is part of the Department of Health and Human Services (HHS). Its mission is “to seek fundamental knowledge about the nature and behavior of living systems ... and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.”
- NIH consists of 27 Institutes and Centers, with an overall budget of \$30.5 billion. Each Institute and Center is a discrete entity and receives its own funding from Congress.
- The research portfolio includes intramural research conducted at NIH (11 percent of the budget), and extramural research (80 percent of the budget). More than 60 percent of NIH funding supports investigator-initiated research; the remaining 40 percent supports

research conducted in response to Funding Opportunity Announcements (FOAs). Funding decisions are based on scientific merit; scientific opportunity; public health needs; and the current portfolio of funded work.

- Funding decisions for investigator-initiated research are made as follows:
 - A researcher initiates a grant proposal for a new or continuing project.
 - A scientific review panel evaluates the scientific merit of the proposal. Criteria include significance, investigator, innovation, approach, and environment.
 - The Institute's program official serves as the main contact for the applicant and helps to interpret results of the peer review.
 - The Institutes' National Advisory Councils assess programs and approve applications.
 - The Institute director makes the final selection.

Dr. Tabak emphasized that NIH is committed to enhancing the diversity of its workforce through training and infrastructure development. Initiatives include:

- **Building Infrastructure Leading to Diversity (BUILD):** Supports undergraduate institutions and their pipeline partners to design, implement, and evaluate innovative strategies to transform undergraduate research training, address barriers to participation, enhance faculty development, and strengthen institutional Infrastructure.
- **National Research Mentoring Network (NRMN):** Provides support for the development of a national network of mentors and mentees from all disciplines relevant to the NIH mission to enhance training, preparation, and career development of individuals from diverse backgrounds in biomedical research.
- **Coordination and Evaluation Center (CEC):** Coordinates consortium-wide activities for BUILD and NRMN, evaluates the efficacy of training and mentoring approaches developed by BUILD and NRMN, and disseminates information.
- **Native American Research Centers for Health (NARCH):** Supports collaborations between federally recognized American Indian/Alaska Native (AI/AN) tribes and tribal organizations and research-intensive academic institutions. Promotes the training of a cadre of AI/AN scientists and health professionals and supports health research projects prioritized by tribal communities.
- **Institutional Development Award (IDeA) Networks of Biomedical Research Excellence:** Funds multi-disciplinary research networks to provide research opportunities for students from undergraduate institutions, community colleges, and tribal colleges and universities (TCUs) and serves as a pipeline for these students to continue in health research careers within IDeA states.
- **Native Investigator Development Program (NIDP):** Prepares postdoctoral AI/AN researchers to become self-sustaining independent investigators conducting research on the interface of culture, aging, and health.

Research opportunities at NIH include a Summer Internship Program (SIP), Undergraduate Scholarship Program (UGSP), post-baccalaureate Intramural Research Training Award (IRTA), and Graduate Partnerships Program (GPP), and a research program for students attending

community colleges. Dr. Tabak urged TCAC members to encourage young people from their communities to apply for these programs (<https://www.training.nih.gov/programs>).

Dr. Tabak encouraged TCAC members to contact him directly if they have questions or want to bring any matter to his attention (Lawrence.Tabak@nih.gov).

Discussion

- Chairperson Payment stated that it is important for grant reviewers to acknowledge Indigenous knowledge and understand the world views of other cultures. He suggested that review panels should include individuals with Indigenous background knowledge and recommended that tribal voices be included at various intervention points.
 - Dr. Tabak identified three avenues for providing input: serving on a scientific review panel; consulting with the NIH program official to provide context for a research project; and public comments at meetings of NIH advisory councils.
- Councilwoman Malia Villegas asked where policy change and development occur at NIH.
 - Dr. Tabak stated that policy development happens both formally and informally. The Office of Science Policy within the Office of the Director plays a primary role in formal policy development, and each Institute and Center has individuals who develop policies related to its research priorities. There are also many informal avenues of policy development.
- A TCAC member asked what relationship exists between the colleges and universities involved in the Native Investigator Development Program and how NIH connects with those programs.
 - Dr. Etz noted that this program is an investigator-initiated program that was developed at the University of Colorado-Denver, led by Dr. Spero Manson.
- Councilman Phelps asked for examples of the types of research priorities that have been addressed through the NARCH. He noted that water infrastructure is the priority for the Navajo Nation due to the Gold King mine spill that contaminated a primary water source. They are exploring how the Environmental Protection Agency (EPA) can work with the Navajo Department of Health to address that issue.
 - Dr. Tabak yielded the floor to Sheila Caldwell. Dr. Caldwell stated that the NARCH was giving power back to Native communities to determine the kinds of research that are important to them, rather than priorities of NIH or the Indian Health Service (IHS). The National Institute of Environmental Health Sciences (NIEHS) supported several NARCH studies on health outcomes of environmental disasters.
 - Dr. Tabak noted that NIEHS partners with EPA on a number of projects. A staff member from NIEHS stated that the Institute received two time-sensitive grant applications responding to the effects of the Gold King mine spill. These are under review at NIEHS. NIEHS also supports two Environmental Health Disparities Centers of Excellence at University of New Mexico and University Arizona that both focus on tribal environmental health disparities research. These centers are co-funded by NIMHD and EPA.

- Councilwoman Villegas asked what the Office of the Director hoped the TCAC would achieve and what opportunities were available to leverage the insights of TCAC members.
 - Dr. Tabak said he hoped the TCAC process would become a dialog that would provide a deeper understanding of what is important to tribal communities, and why it is important. It is not possible to advance understanding of health and disease until you understand the context and issues.
- Councilman Phelps asked how issues are prioritized in the annual report that NIH submits to Congress and where tribal concerns fit in that report. He reiterated that clean water is an important priority for tribal communities and expressed a hope that the TCAC could be a voice to increase awareness of that issue.
 - Dr. Tabak noted that the report to Congress is a public document.
 - In addition, there is a searchable database with information on all NIH grants available online at <https://projectreporter.nih.gov/reporter.cfm>.
 - Chairperson Payment suggested that the TCAC could be a voice to identify areas where additional research is needed. Any items that are broader in scope could be taken to the Secretary's Tribal Advisory Committee (STAC).
- Councilman Chester Antone asked about the extent to which research funded by IHS regarding traditional herbs and medicines would fit within NIH priorities.
 - Dr. Tabak stated that this issue would be addressed on the second day of the meeting.
- Mr. Jace KILLSBACK stated that most nations have tribal colleges that can be a pipeline for researchers. The ability to utilize investigators is a challenge for tribes.
 - Dr. Tabak stated that NIH would like to optimize the linkage with tribal colleges.

Highlights of Selected NIH Programs

Native American Research Centers for Health (NARCH) Program

Sheila Caldwell, PhD, National Institute of General Medical Sciences (NIGMS)

Dr. Caldwell provided an overview of the NARCH program, which is funded through NIGMS:

- NARCH helps to build a cadre of biomedical researchers within tribal communities; it also helps to develop research infrastructure in those communities.
- NARCH is a unique model within NIH because it is focused on the health research needs of the community, rather than a single disease.
- A NARCH application may include a student development project, a faculty development project, a capacity-building project, or a research project, in any combination.
- Examples of NARCH projects include:
 - Oklahoma Native American Research Centers for Health: Conducting research to identify autoantibody associations among Oklahoma tribal populations with rheumatic disease.
 - Southwest Tribal American Research Center for Health (Albuquerque Area Indian Health Board): Offer research internships for AI/AN graduate students and

provides mentoring and social support to AI/AN undergraduates pursuing health science degrees.

Other programs funded through NIGMS that support AI/AN research include:

- Institutional Development Award (IDeA)
 - Provides state-level grants to a) broaden the geographical distribution of NIH research funds, b) increase the competitiveness of investigators, and c) serve unique populations.
 - IDeA Networks of Biomedical Research Excellence (INBRE) program supports the development of research capacity and infrastructure within a state. More than 20 tribal community colleges are networked through INBRE grants.
- Research Supplements to Promote Diversity in Health Related Research
 - Supplements research grants to support recruitment and training of students, postdoctorates, and eligible investigators from underrepresented groups in health-related research.
- NIH Visit Week
 - NIGMS Center for Research Capacity-Building, in collaboration with the Office of Intramural Training and Education, conducts a week-long program to expose American Indian and Alaska Native and other students to biomedical research and career opportunities.

Discussion

- Dr. Alison Barlow asked how tribes can support the NARCH to ensure that its funding will be stable.
 - Dr. Caldwell stated that the NARCH program has been revised over the years. The NIGMS director wants to expand the program and increase involvement from Institutes and Centers across NIH.
 - Chairperson Payment noted that TCAC members can advocate for additional funding for their priorities and needs.

Native Interventions Funding Opportunity Announcement

Shobha Srinivasan, PhD, National Cancer Institute (NCI)

Dr. Srinivasan described the Intervention Research to Improve Native American Health (IRINAH) program and noted that a list of IRINAH grants was included in the meeting materials.

Key points of Dr. Srinivasan's presentation were as follows:

- Numerous Institutes across the NIH support the program. The IRINAH group meets by phone once a month to collaborate on projects and develop publications.
- Developed to adapt, develop, and test interventions in AI/AN and Native Hawaiian populations.
- Requires researchers to partner with communities, incorporate concerns of the community, adopt methodologies that are relevant to Native American populations, and

implement appropriate study design. A Tribal-Researcher agreement is required, when needed (may not be needed when working in urban areas).

- The project is focused on health promotion and disease prevention to reduce mortality and morbidity in Native American communities.
- Although it is a R01 program, it does not require previous pilot data from the community or tribe to be studied – pilot data can come from another source. There is no requirement for the study to be generalizable to other communities across the U.S., although there is an expectation that the results will discuss lessons learned.
- IRINAH encourages a community-based participatory research (CBPR) approach, with a focus on community strengths and resiliency.
- The community is expected to participate in recruitment of individuals and communities, develop intervention protocols, provide oversight to ensure that research is conducted in a culturally appropriate manner and takes place within the agreed-upon timeline.
- The project is expected to have a clear protocol for ownership, control, and storage of data, which is an important issue for many tribes.
- Conducting research and addressing design issues with small populations requires innovative approaches.

Further details are at: <http://cancercontrol.cancer.gov/nativeamericanintervention/index.html>.

Discussion

- Chairperson Payment expressed appreciation for IRINAH's use of the CBPR approach and respect for tribal sovereignty regarding data.
- Dr. Etz noted that most large NIH research grants require investigators to have pilot data included in the grant application. This program utilizes a protected review, in which the review committee reviews applications in response to this funding opportunity announcement. All reviewers have expertise in conducting research in AI/AN communities or in the content area of the proposed research.
- Mr. Killback asked who would drive the research if the capacity did not exist at the local level and noted that tribal communities are often intimidated by research institutions. He emphasized the importance of culturally appropriate methods of data collection. He also noted that the Northern Cheyenne Tribe recognized the importance of developing its data management capacity. He added that the Northern Cheyenne were beginning to focus on behavioral health.
 - Dr. Srinivasan acknowledged the challenge of building research capacity within tribes. She noted that the IRINAH program was conducting training on how to write a successful application for NIH funding.
 - Dr. Etz hoped that TCAC members would help NIH do a better job of providing information on research opportunities to Indian Country. She noted that for NARCH grants, the tribal organization is the grantee and distributes funds to academic institutions. That approach is unique to this grant program. Responding to the comment on behavioral health, she noted that the NIH

understands that behavioral health research is an important area for tribes, and several Institutes have made that a priority.

- Councilman Phelps asked which Institute was responsible for the grant awarded to the Rand Institute for motivational interviewing.
 - Dr. Srinivasan said that program was conducted under the auspices of the National Institute on Alcohol Abuse and Alcoholism.
 - An NIH staff member stated that the focus of the project was to prevent alcohol use and involvement among urban NA youth.
- Beverly Cook asked whether the requirement to have prior data was new or if it had always been part of the grant application.
 - Dr. Srinivasan replied that R01 research generally requires prior data. The waiver of the requirement to have pilot data from the same population being studied in the new application for IRINAH projects is new. Applicants have now begun to demonstrate that the proposal is grounded in valid research that will benefit the community.
 - Dr. Etz clarified that the IRINAH program still requires pilot data, but it does not need to be from the tribal community.
 - Chief Cook stated that there are different ways of knowing in tribal communities, such as Indigenous knowing, that cannot always be described.
 - Dr. Srinivasan said that some studies are using a mixed-method approach that combines evidence-based protocols with Indigenous ways of knowing.
 - Lynn Malerba stated that the tribes that most need research grants do not have the infrastructure to conduct the studies. She suggested that tribes could describe their communities and their needs and NIH could determine which funding programs would be the best fit, similar to the common application for colleges and universities.
- Dr. Alison Ball referenced grants for suicide prevention that used evidence-based interventions, but the studies found that those approaches were not effective in tribal communities. She emphasized that it is important to find interventions that are meaningful and can be used in NA communities.
- Chairman Jeromy Sullivan stressed the importance of collaborating with other tribes. He worked with a neighboring tribe that developed a culturally appropriate, prevention-based curriculum for a youth project in partnership with NIH. The curriculum built on existing knowledge and was delivered in a non-classroom setting.

President's Precision Medicine Initiative (PMI)

Kathy Hudson, PhD, Office of the Director

Dr. Hudson described the new Precision Medicine Initiative that was announced during the State of the Union address in January 2015. Key points were as follows:

- The PMI consists of two parts: 1) advances in cancer diagnosis and treatment, and 2) the creation of a large research cohort to expand knowledge of precision medicine approaches for all diseases.
- The proposed budget for fiscal year 2016 is \$215 million.

- NIH formed a PMI Working Group of the Advisory Committee to the NIH Director, charged with developing a vision and design for the research cohort.
- Inputs for the cohort project have included four public workshops; Requests for Information (RFIs); a survey of public perceptions of a precision medicine cohort; and White House Privacy and Trust Principles.
- Scientific opportunities for the research cohort include the ability to develop quantitative estimates of risks based on both genetic and environmental factors and the ability to identify individual variations in drug response, among others.
- The PMI cohort will consist of one million or more volunteers who agree to provide health data and a biospecimen and to participate in a longitudinal study with continuing interactions.
 - Methods of recruitment include direct volunteers and referrals from healthcare provider organizations.
 - The cohort will broadly reflect the diversity of the U.S., including underrepresented groups.
- The Foundation for NIH conducted a survey on public attitudes toward a large precision medicine cohort. The representative sample of 2,600 individuals included 51 AI/AN respondents. Similar to findings for the entire sample, 79 percent of AI/AN respondents felt the PMI cohort should be created, 52 percent said they would probably or definitely take part if asked, and 82 percent said they would be interested in receiving information about themselves and about the study.
- The PMI Cohort Program (PMI-CP) will be a highly interactive model, with participants involved in governing, implementing, and evaluating the project. Talking about participants rather than patients or subjects has been a notable shift for NIH.
- The Working Group is committed to participants controlling how their information is used and shared. Depending on their preferences, participants may receive individual data, individual health information, ongoing study updates, and aggregated results.
- The Working Group submitted its report in September, and the NIH director approved the recommendations.
- A director for the PMI-CP has been named, and activities will begin in the next fiscal year if the budget is approved.

Discussion

- Dr. Denise Dillard noted that most consent models are based on obtaining individual consent rather than tribal consent. Tribes are concerned about the impact on the community.
 - Dr. Hudson stated that the White House was convening groups to discuss aspects of engaging specific communities. There are plans for additional meetings at the highest level.
- Councilwoman Villegas asked if there were international models for this work and asked where and how decision making would occur, since the program involves the White House as well as NIH.

- Dr. Hudson stated that the two issues the president mentions frequently are climate change and precision medicine. NIH is working closely with the White House Domestic Policy Council, the Office of Science and Technology, the Chief Data Scientist, and senior advisors to the president.

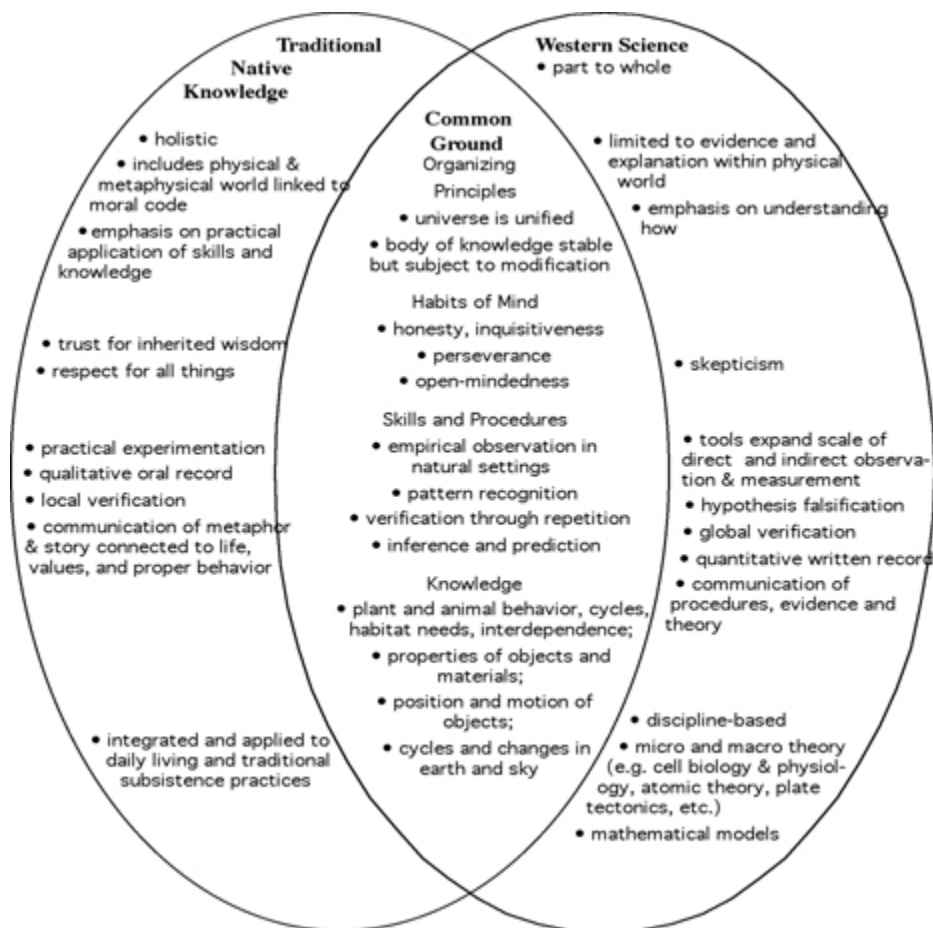
AI/AN Ethical Research

Malia Villegas, PhD, Councilmember, Village of Afognak, and TCAC National At-Large Member Delegate

Councilwoman Villegas facilitated a discussion of research partnerships with AI/AN communities and noted that this issue is a priority for the National Congress of American Indians (NCAI).

Detailed information was included in the meeting materials. Key points were as follows:

- Tribal communities have always been scientists, with Indigenous knowledge and traditional ecological knowledge.
- The Alaska Native Knowledge Network (ANKN) developed a Venn diagram showing the qualities associated with traditional knowledge and Western science (http://www.ankn.uaf.edu/curriculum/Articles/BarnhardtKawagley/Indigenous_Knowledge.html)



- NCAI's curriculum, *Research that Benefits Native People*, is available online (<http://ncaiprc.org/research-curriculum-guide>). It is based on the following principles:
 - Indigenous knowledge is valid and should be valued.
 - Research is not culturally neutral.

- Responsible stewardship includes the task of learning how to interpret and understand data and research.
- Tribes must exercise sovereignty when conducting research and managing data.
- Research must benefit Native people.
- Opportunities to shape policies regarding research ethics with AI/AN communities include:
 - Data sharing and management
 - Benefits to Native people
 - Understanding how to operationalize culture
 - Development of policies and protocols
 - Identification of Indigenous people in datasets
 - What kind of research is funded
 - Investments in capacity-building.

Discussion

- Chairperson Payment noted that early research was often conducted by ethnographers and missionaries, which includes numerous layers of cultural bias.
- Chief Mark Romero appreciated the statement that Indigenous people are scientists. He noted that his grandmother used traditional herbs and traditional healers. Many natural medicines are controversial, but they need to be considered in Native communities and more research is needed in this area.
- Mr. Kilsback noted that the regional institutional review board (IRB) that was developed for research conducted with multiple tribes in his area was taken over by the regional health board, with no funding. Many tribal members signed up for research that degraded tribal women and traditions, because the studies were based on Western-centric protocols. Protection of life includes a wide range of agencies; it is important to network those agencies and overcome silos in order to address health disparities. Implementing ethical codes would empower tribes to determine what types of research will be conducted in their communities. Researchers have disrupted entire tribes because their approaches were not reviewed in the context of traditional tribal law.
- Councilman Phelps emphasized the need to understand the intentions of researchers and the research community. Researchers and health advocates lobby tribal councils when they receive grants, which can cause divisions and imbalance within a community.
- Dr. Etz noted that questions about policy would be addressed in the afternoon session. The NIH initiative on big data might be relevant for a future meeting. NIH is working on the issue of tribal IRBs. The TCAC might wish to consider what kinds of training materials should be available for NIH staff.

Policies

NIH Policies

Carrie Wolinetz, PhD, Office of Science Policy (OSP)

Dr. Wolinetz described OSP's role in developing research policy at NIH. A fact sheet was included in the meeting materials. Key points of her presentation were as follows:

- OSP's activities include policy advice and analysis for NIH leadership, policy development, review of emerging technologies, internal and external engagement, and data analysis and innovation policy.
- OSP's policy portfolio includes five priority areas:
 - Clinical and healthcare research policy
 - Technology transfer and innovation policy
 - Biosecurity, biosafety, and emerging biotechnologies
 - Collaboration, coordination, and reporting
 - Data sharing.
- Opportunities for engagement in the policy process include:
 - Reactive vs. proactive
 - Priorities for the agency, administration, U.S. government
 - Driven by and in service to the science
 - Opportunities for input: Public comments, in-person engagement and discussion, communications tools (e.g., blog, Twitter), and workshops.

Discussion

- Councilwoman Villegas asked what outcomes Dr. Wolinetz would like to see from this initial meeting.
 - Dr. Wolinetz stated that policy setting is a collaborative effort at NIH, and TCAC members are stakeholders in the research. She hoped that this collaboration would help give Native communities a voice in the process of developing policy in NIH priority areas. She noted that it was particularly challenging to develop policies regarding precision medicine and genomic data sharing. It is important to hear from people who are interested in how data are generated.
- Councilman Phelps noted that significant resources are allocated for health research in other countries, while Native communities feel neglected. It is important to find a balance.
 - Dr. Wolinetz noted that OSP does not set policies for funding, and there are few resources for setting international health policies. She agreed that it is critical to think about and avoid unintended consequences of policies. Engaging with communities can help in that process.
- Councilman Antone expressed concern about sharing tribal data in publications that do not benefit tribes.
 - Dr. Wolinetz replied that NIH is focused on engaging participants from the outset, which is a significant shift. There will be a learning curve, and researchers will need to work in collaboration with study participants. Everyone will benefit from mutual dialog and learning.

Genomic Data and the Genomic Data Sharing (GDS) Policy

Laura Lyman Rodriguez, PhD, Division of Policy, Communications, and Education, National Human Genome Research Institute (NHGRI)

Dr. Rodriguez provided an overview of genomic data and the GDS policy at NIH. A fact sheet was included in the meeting materials, along with the full text of the policy. Key points of the presentation were as follows:

- The genomic data sharing policy starts from values that are intrinsic to NIH (stimulate research to improve human health, respect research participant interests, promote public benefit, and responsible stewardship of public investment).
- Special features of genetic/genomic data include stability over time, unique for each individual, probabilistic and complex information, familial implications, effect on reproductive decision making, group/community implications, and cultural meaning.
- What is different about the genomic sequence from a policy perspective:
 - Issues are now more “concrete” than in the past
 - Privacy concerns
 - Uncertain risks, including the potential for incidental findings
 - Potential for significant benefits.
- It is essential to sequence the genome for as many individuals as possible in order to understand the biology of disease and the range of genetic variability so that researchers can develop treatments and cures.
- Challenges
 - Forty percent of the U.S. population is of non-European descent, but 96 percent of studies to date were conducted with European populations—the cohort needs to be more diverse and inclusive.
 - Recruitment of participants from underserved populations can be more difficult.
 - Approaches will need to reach beyond genomics.
- NIH needs to address its history related to use of specimens and data collected from AI/AN communities and other populations.
- Proposed changes and informed consent in the Common Rule
 - Proposes a new requirement for informed consent for the use of biospecimens and information sharing in research
 - Focuses on autonomy of the participant, rather than “identifiability”
 - Proposes an HHS template for broad consent for future use of data
 - Proposes a length of time for which informed consent is valid
 - The comments period is open until December 7, 2015. NIH would value feedback from TCAC members.
- Understanding and working with communities
 - Working with NCAI to develop the AI/AN Genetics Resource Center
 - Exhibition at the National Museum of Natural History, with dialogs hosted by tribal organizations
 - Partnership for Community Outreach and Engagement in Genomics to bring cultural perspectives into research.

- NIH GDS Policy
 - Announced August 27, 2014, effective January 25, 2015
 - Guiding principle is to maximize public benefit. Key elements include respect for participants, data sharing, and freedom to operate
 - Established a community resource to promote maximum public benefit and provide transparency for the public and investigators
 - Overarching framework will keep the policy current with scientific advances and ethical conversations
 - All comments that were received during the public comment period expressed support for the general principle of data sharing and the benefits of genomic data for advancing science, and nearly all expressed support for the policy.
- Informed consent: The GDS Policy has an explicit standard of consent for future genomic research and broad sharing.
- Data access: A two-tiered system (controlled and open access) will respect data use limitations established by the research institution and its IRB while protecting privacy.
- Institutional Certification
 - Tribal law was added to the list of laws and regulations to be considered in the submission of data to NIH, based on comments from NCAI.
 - IRBs must specifically consider potential risks to individuals and their families as well as to groups and populations when developing data use limitations.
- Data management experience to date
 - Issues are identified by Data Access Committees (DACs), users, and others
 - Response and penalties are managed through DACs and coordinated centrally. NIH is vigilant in monitoring how researchers use data to which they have access.

More information is available at <http://gds.nih.gov> or gds@nih.gov.

Discussion

- Chief Malerba asked about the policy for community data.
 - Dr. Rodriguez said that the GDS policy asks researchers to consider group and population-wide issues when developing data use limitations. Current regulations do not include a formal mechanism to ensure that. NHGRI has addressed it from a policy perspective and would like to engage in a dialog with TCAC regarding how to resolve this issue.
- Councilwoman Villegas noted that the Proposed Changes to the Common Rule includes some elements that NCAI had identified as problematic when they commented on other policies. She also expressed concerns about enforcement and accountability when investigators or research institutions do not follow the data sharing policy.
 - Dr. Rodriguez stated that the policy includes clear procedures for addressing incidents of misuse of data. The updated GDS policy attaches the terms and conditions to grant awards. NIH is exploring how to further strengthen those protections for the PMI, either through administrative rules or legislative activities. With regard to the Proposed Changes to the Common Rule, the

comments received to date represent a wide range of perspectives. Dr. Rodriguez advised the TCAC to submit comments and engage in consultation on the policy. Ongoing dialog is important for policy decisions.

- Dr. Etz said NIH would like the TCAC to inform the understanding of when it is appropriate to engage in consultation with the TCAC regarding policy development. She noted that Dr. Wolinetz expressed interest in developing an infrastructure for that process.

TCAC Discussion: How NIH Can Partner with Tribal Epidemiology Centers (TECs)

Selina Keryte, Indian Health Service

Dr. Etz noted that a factsheet on TECs was included in the meeting materials. Key points from the discussion were as follows:

- The National Institute on Minority Health and Health Disparities (NIMHD) co-funds the TECs. The NIH also supports the TECs indirectly through the NARCH program.
- Ten of the 12 TECs serve individual IHS service areas. The Inter Tribal Council of Arizona serves both Tucson and Phoenix, and the Urban Indian Health Institute serves 34 urban Indian health organizations across the country.
- TECs approach all activities in a culturally appropriate manner. They work with tribes and tribal organizations to overcome the historical mistrust of scientists and researchers among AI/AN people.
- The Indian Health Care Improvement Act designated TECs as public health authorities, which authorizes them to access data.
- The Affordable Care Act outlined seven core functions for TECs:
 - Collect data and monitor progress toward meeting the health status objectives of IHS, Indian tribes, tribal organizations, and urban Indian organizations
 - Evaluate delivery systems and data systems that impact the improvement of Indian health
 - Assist in identifying highest-priority health status objectives and services needed to address them
 - Make recommendations for targeting needed health services
 - Make recommendations to improve healthcare delivery systems
 - Provide epidemiologic technical assistance (TA) to tribes, tribal organizations, and urban Indian communities
 - Provide disease surveillance and assist tribes, tribal organizations, and urban Indian communities to promote health.

Discussion

- Chairperson Payment noted that some TECs are more cooperative than others about reporting data and communicating directly with tribes. He did not know of any TECs that made recommendations for health service needs and asked about the methodology for doing that.
 - Ms. Keryte replied that each TEC has an advisory council. Concerns may be communicated to them or to the TEC director.

- Chairperson Payment said the TEC advisory council would have greater impact if it reported directly to the Secretary.
- Mr. KILLSBACK stated that the Billings Area health board serves as the advisory board for the TEC. They establish health priorities for the area and work closely with TEC director on strategies to achieve those goals. The biggest hurdle when developing a health code was the inability to finalize a data sharing agreement due to a conflict with IHS. The Northern Cheyenne Tribe utilizes the TEC for data to support grant applications and to document health disparities. It has been challenging to find a qualified individual with cultural and linguistic competency to serve as TEC director, especially when the salary is not competitive.
- Councilwoman Villegas stated that in 2014, some TECs were in a position to establish cooperative agreements with state and regional public health entities that would allow them to access data. She noted that NCAI convened TEC directors when they were developing tools for diabetes prevention for tribal youth. TECs are looking for more opportunities to collaborate in that way.
 - Ms. Keryte noted that there would be a meeting of TEC directors and epidemiologists in Phoenix in March 2016.
- Dr. Etz stated that it is important to determine overlapping functions when developing partnerships. It might be helpful for NIH to provide more TA to assist TECs when they develop applications for the NIH.
 - Ms. Keryte noted that the TECs are in an excellent position to build capacity for CBPR, because they already have strong partnerships with tribes and a high level of trust.
- Councilman Antone stated that the TECs, NIH, and the STAC need to be connected in a structure that is at a higher level than the individual TECs. Reporting to the STAC could be the responsibility of someone within that structure.
 - Ms. Keryte noted that most of the TECs have access to the IHS Epi Data Mart.
- Councilman Phelps noted that the Centers for Disease Control and Prevention (CDC) issued a disease finding several years ago regarding the risk of Rocky Mountain Fever within tribal communities. The Navajo Nation provided emergency funding to respond to that notice. Five federal agencies, including NIH, are working on the second five-year plan for the Diverse Cohort Study looking at the presence of uranium in the Navajo Nation, with funding from the EPA. The Navajo Nation recently submitted an inquiry following the Gold King mine spill; the EPA asked what type of study they wanted. There is a clear need to develop the infrastructure and capacity for tribes to respond to major outbreaks within their communities.

Health Disparities Strategic Plan

Eliseo J. Pérez-Stable, MD, Director, National Institute on Minority Health and Health Disparities (NIMHD)

Dr. Pérez-Stable presented an overview of the NIMHD and the strategic plan the Institute is developing for minority health and health disparities at NIH. Key points were as follows:

- NIMHD was established as an Institute within NIH in 2010.

- NIMHD is conducting a visioning process and developing a strategic plan for the Institute as well as a strategic plan for minority health and health disparities across NIH.
- NIMHD leads scientific research to improve minority health and health disparities. Minority health research investigates health by race and ethnic groups. Health disparities research addresses issues of traditionally disenfranchised groups where there are adverse health outcomes.
- Health disparities result from greater risk for certain diseases; higher incidence or prevalence of a disease within certain groups; earlier onset of illness; later diagnosis or worse health care; or poorer outcomes. Disparities may result from social conditions, lack of access, biology, or a combination of those factors.
- The Agency for Health Research and Quality (AHRQ) is charged with collaborating with NIMHD to define health disparity populations. Both organizations include low-income, socially disadvantaged, and rural populations. AHRQ includes other categories for which there is no consensus at NIH, including urban poor, sexual/gender minorities, child and adolescent health, immigrants and migrants, and special needs for those who are disabled or need chronic care.
- NIMHD looks at health determinants across the lifespan as well as the complex interactions between individual behavior, attitudes, and biology; the healthcare system; the environment; and the domains of disparities.
- NIMHD's strategic plan is an opportunity to influence NIH overall. All Institute directors at NIH have an interest in addressing health disparities. Many things can be done in a systematic, standardized way.
- The pillars of NIMHD's science visioning include the etiology of health disparities; standardized measurements and approaches; and implementation science.
- Criteria for scientific research include scientific importance, innovation and leverage, collaboration across Institutes, and translational impact.
- NIMHD solicited input for the science vision. Mechanisms included public comments, a working group for each scientific area (June 2015-February 2016), and a consensus meeting (Spring 2016).
- The NIH strategic plan will be completed in 2015. Dr. Pérez-Stable hopes to complete the NIMHD strategic plan and the trans-NIH strategic plan in 2016.
- NIMHD programs for AI/AN populations include the Collaborative Research Center for American Indian Health, the Indigenous Wellness Research Institute, and programs that address mental health, particularly among adolescents.

Discussion

- Chief Malerba stated that health equity and social justice are the key issues. Tribes are the only citizens with treaty rights to health, yet they have the poorest health status. She appreciated that NIMHD recognizes the systematic nature of care and the issue of timely access to care, and she noted that this meeting had not addressed prevention, primary care, or disease management. She felt the focus should be on the individual rather than on diseases, looking at health beginning with pregnancy.

- Dr. Pérez-Stable stated that health equity is the goal of NIMHD, and it is a matter of social justice. He agreed about the importance of primary care and noted that he was in direct practice as a general internist prior to coming to NIH.
- Chief Cook stated that AI/AN communities are not always disadvantaged, but they have a disproportionate level of adversity in their family and community histories. Those things will improve if the adversity in all areas and all stages of life is addressed.
 - Dr. Pérez-Stable noted that he worked with Indigenous people in northern Argentina. He pointed out that not all racial and ethnic differences are bad. For example, recent research found that Mexican-American women have a gene that is protective for breast cancer.
- Councilwoman Villegas stated NCAI shifted their focus from reducing the gap between Native populations and Whites to making Native-to-Native comparisons. She stated that a disparities lens can be used to identify things that can be leveraged in powerful ways.
 - Dr. Pérez-Stable stated that NIMHD and tribal communities have a lot to learn from each other and need to work together. The White population has been the reference point for disparities research. Differences between different tribal communities can provide important information.
- Mr. Killback stated that a 2013 report showed that American Indians in Montana died 20 years earlier than their White counterparts. The governor created an Office of American Indian Health to identify and address health disparities.
- Councilman Antone stressed the need to develop ways to measure social determinants of health for AI/AN and identify long-term expectations. The TECs could collect the data that would be needed. Tribes should create their own definitions of well-being and establish their own insurance plans. The focus should shift from disparities to the resiliency of tribes.
- Councilman Phelps noted that tribes have healthcare facilities, but they lack the expertise. Tribes need to find a way to bridge the gap and bring resources closer to home. Another goal is to increase the lifespan in tribal communities. The work of NIMHD is very important.
- Dr. Etz asked if the TCAC would have an opportunity to provide input for the NIMHD strategic plan.
 - Dr. Pérez-Stable replied that an input meeting would be held in the near future. He was interested in knowing what NIMHD can do to improve health and reduce health disparities for AI/AN populations.

Closing Comments and Blessing

Aaron Payment, MPA, Kathy Etz, PhD

Lynn Malerba, Chief, Mohegan Tribe, TCAC National At-Large Member Delegate

Chairperson Payment and Dr. Etz made several logistical announcements.

Chief Malerba closed the first day of the meeting with a traditional Mohegan blessing.

Day 2 – September 30, 2015

Invocation

Beverly Cook, Chief, Saint Regis Mohawk Tribe, Nashville Area Delegate

Chief Cook opened the meeting with a traditional Mohawk prayer.

Welcome and Introductions

Aaron Payment, MPA, Chairperson, Sault Ste. Marie Tribe of Chippewa Indians, TCAC Bemidji Area Delegate

Kathy Etz, PhD, Senior Advisor for Tribal Affairs

Chairperson Payment invited those who were not present on the first day of the meeting and those on the phone to introduce themselves. Following the introductions, he provided a recap of Day 1 and an overview of Day 2.

Dr. Etz noted that the STAC sends a letter to the Secretary following its meetings with a summary of their discussions and their requests. The TCAC might wish to consider doing that as a formal record. She stated that one goal of this meeting was to provide members with an orientation to the NIH and its research methods.

Chairperson Payment emphasized the value of cross-pollination between the TCAC and other tribal advisory groups to HHS. He and Councilman Antone serve on the STAC and could help bring research issues to the attention of the Secretary. Rick Haverkate from the HHS Office of Minority Health provides technical support for the AI/AN Health Research Advisory Council (HRAC), which is another avenue to bring issues to the attention of the Secretary.

Mr. Haverkate reported that the HRAC has vacancies for delegates from several areas. He would provide details to Dr. Etz.

Chief Malerba noted that she chairs the Tribal Self-Governance Advisory Committee for IHS.

Councilman Antone noted that he serves on the CDC Tribal Advisory Committee.

Dr. Etz reported on the first NIH Tribal Consultation session, which was held on September 21, 2015. She noted that the Centers for Medicare and Medicaid Services (CMS) and the Health Resources and Services Administration (HRSA) held their sessions at the same time. There were three presentations and no formal testimony. Dr. Etz stated that the summary report would be distributed to all TCAC members when it is available.

Mr. Killback expressed concern that the tribal consultation was conducted prior to this meeting. It would have been helpful to have the TCAC provide input on the inaugural session.

Councilman Antone stated that he attended the consultation session. During that meeting, he stated that he looked forward to NIH's contribution to the tribal behavioral health agenda, and

he stressed the importance of talking to tribal leaders to recruit participants for the PMI to understand the appropriate consent process.

Councilwoman Villegas stated that tribes would have concerns about what precision medicine would mean for their communities, especially with regard to how data would be used and reported.

Chairperson Payment noted that the definition of an American Indian for research purposes was a challenging issue. He also suggested that the TCAC could develop a tool to identify priorities across Indian Country. Responses could inform the agenda for the tribal consultations.

Mr. Kilsback supported the idea of a survey and felt that responses should be provided by tribal governments rather than individuals. He suggested that attendance at tribal consultations might have dropped off because many of the sessions had not been productive or meaningful.

Dr. Alison Ball stated that conducting a survey would be a way for more voices to be heard. She recommended that NIH should find ways to incorporate Indigenous knowledge in the NARCH grants, and she suggested that the TCAC could call attention to the issue that smaller tribes are not studied as often as larger tribes.

Dr. Dillard requested information about the number of applications submitted to NIH by an AI/AN investigator or involve AI/AN populations and the funding levels for those studies. She expressed concern about budget cuts for NARCH grants and emphasized that research in AI/AN communities can be more expensive due to the long distances between research institutions and tribal lands, which require travel. She asked whether the TCAC would need to align its efforts with other tribal advisory groups or if it could determine its own priorities.

Chief Malerba stressed that it would be important to know the level of funding available and what percentage of that funding is accessed. She noted that healthcare funding is scattered across the federal government, and it is difficult for tribes to access that funding. It would be important to find ways to break down the siloes and promote coordination and collaboration between various federal agencies. Continuity of funding is also important. Tribal governments do not want to begin a project unless it will make an impact in their community.

Chairperson Payment noted that the STAC developed a searchable grants database, which he would circulate to TCAC members. He stated that information on successful applications is good, but it is more important to know why other applications were not selected for funding. The purpose of the TCAC is to build capacity in Indian Country.

Dr. Etz summarized key issues from Day 1 for discussion with Dr. Tabak:

- The relationship between NIH and Congress and how NIH prioritizes its programs
- The relationship between NIH and the White House
- The status of research on traditional herbs and medicines at the FDA.

Chief Malerba noted that the issue of informed consent for access to data was referenced in several presentations on Day 1. This is an important issue for Indian Country, and it would be helpful if there were a uniform approach to obtain informed consent.

Councilwoman Villegas said it would be important to clarify the distinction between submitting comments and consultation with regard to the Proposed Changes to the Common Rule. She would circulate a series of comments that the NCAI had already submitted. Some of the comments were from specific tribes. She would also circulate a list of NCAI resolutions that include research elements.

Chairperson Payment said it would be important to avoid reinventing the wheel. Collecting and synthesizing input that had already been submitted would be a good starting point.

Mr. Killback stated that his region requests a matrix of comments from consultations aligned with action plans so they can determine whether agencies take any action in response to the comments. A similar spreadsheet for the TCAC would be useful.

Councilwoman Villegas stated that the White House Tribal Nations Conference would be held toward the end of the year. NCAI prepares a briefing book for the conference. She requested input from TCAC members regarding the section on research priorities.

Chairperson Payment reported that the STAC would meet on March 1-2, 2016. The HRAC vacancies are for the Oklahoma, Phoenix, Albuquerque, and Tucson areas.

Chairperson Payment noted that the U.S. Census would hold tribal consultation in an effort to improve its methodology to avoid an undercount. He emphasized that a discrepancy between the Census count and the number of enrolled members could impact transportation and housing funds, and he stressed the importance of participating in the consultation sessions. Dr. Etz would circulate the schedule.

TCAC Discussion: Setting Priorities and Next Steps

Committee members identified the following priority issues to discuss with Dr. Tabak:

1. Education and awareness of NIH
2. Research pipeline/students
3. Preservation of Indigenous knowledge and language
4. Role of helping to build and inform research policy
 - a. Data collection, sharing and ownership, stewardship, return of results
 - b. Informed consent
5. Engage the international community for oversight of policy; support US recognition of international protocols; be inclusive across borders
6. Funding levels for AI/AN and set-asides for tribal government, principal investigators, and matrix, encourage more funds for NARCH, TCAC to drive NARCH project, increase the Native Interventions program, influence additional PARs to look at resiliency

7. What is the NIH commitment? Is NIH willing to add an Indian desk that is fully integrated? Who is the contact/tribal liaison at NIH if issues arise? What is the commitment to the committee? Are there resources to support proposed activities?
8. Census
9. Manage data and facilitate access to data
10. Informing ethics
11. Overseeing outcomes and accountability (how many Native researchers, impact, benefits to Native communities)
12. Inform consultation with NIH
13. Measurement – appropriate comparisons, effective metrics and indicators
14. Capacity building – IRBs (resources), conducting census, etc.
15. Identification – definition of Indian
16. Tribal liaison at NIH
17. What can NIH do to help tribal communities? Feedback, communications, dialog
18. EpiCenter questions and communications and data sharing, EpiCenters could discuss role on future agenda
19. Prioritize topics every year for Indian Country
20. Involvement and expansion to more tribal colleges
21. Align efforts with other committees
22. How NIH works, breaking down silos, cross-Institute funding
23. Training for NIH leadership and program officers on cultural competency, trust and treaty obligations, and sovereignty
24. Time on main pillars/scope of NIH mission and work and how other agencies use NIH
25. What research is being conducted in Indian Country, and are they giving back information to communities?
26. Use of technology to get input from Indian Country to inform consultations
27. Build capacity at NIH, beyond cultural competency
28. Trust and good examples/models (e.g., Southcentral Foundation, Jeff Henderson, Johns Hopkins, Centers for American Indian Health)
29. How to conduct and define AI/AN research
30. Evaluating research through an Indigenous lens
31. Access to care research and what it means for AI/AN and economics
32. Pilot data and timing
33. More capacity for reviewers with AI/AN expertise (many conflicts with applications)
34. Training-more flexibility in modalities, such as in own communities
35. Study sections – CBPR and what it means; funding mechanisms with short-turnaround time do not support
36. Hear from program officers/champions regarding their thoughts on what is needed
37. Evaluation vs. research. Evaluation is the first step. Combined funding mechanism between CDC and NIH. Evaluation of program to develop research questions
38. How to improve the review process - junior investigators are not getting funding; training for seasoned reviewers
39. NARCH and how it is funded; more permanent source of funding, similar to NCI
40. How to measure and validate historical trauma

41. Committee to develop list of priority topics recommended for funding
42. Communications and how committee meeting operates, processes, etc.
43. Required protocols for academic institutions and academic-based researchers wanting to work with tribal nations, attached to FOAs
44. Fundamental knowledge – resources to drive desires.

Discussion with NIH Principal Deputy Director

Lawrence Tabak, DDS, PhD, NIH Principal Deputy Director

Chairperson Payment described how the list of priorities was formed. TCAC members provided the rationale for each item.

Dr. Tabak replied as follows:

- NIH wants the committee to be meaningful and does not have a set plan for the number and frequency of meetings each year. Dr. Tabak hoped the committee would elaborate collectively what its value and function would be.
- NIH will have a full-time, dedicated tribal liaison. In the interim, Dr. Tabak will serve as the designated staff liaison for the TCAC.
- Good communication between NIH and the TCAC will be essential going forward.
- Training opportunities for students are critical. If students from tribal communities do not apply, they will miss the opportunities that are available at NIH.
- NIH makes arrangements to ensure that investigators make data available on request. There are three layers of access: 1) unidentified aggregate data available to the general public, 2) access to data on an application-only basis, and 3) access to the raw data to investigate new research questions.

Dr. Tabak asked Joyce Hunter to comment on how NIMHD supports TECs and uses TEC data. Dr. Hunter replied that NIMHD provided support to the TECs over many years. Going forward, they would like to be more involved in order to better understand what the TECs are doing and how that impacts the mission of the NIH.

Dr. Tabak noted that he asked NIH staff to review the literature on historical trauma. He viewed this topic as an important area for additional investigation and discussion.

Working Lunch with NIH AI/AN Scholars

TCAC members were joined by AI/AN scholars, who discussed their experiences at NIH. The following scholars participated in the session:

- Deana Around Him (National Congress of American Indians)
- Geanna Capitan (National Institute of Neurological Disorders and Stroke)
- Loretta Grey Cloud (National Institute of Dental and Craniofacial Research)
- Tamara James (Office of the Director)
- Naomi Lee (National Institute of Neurological Disorders and Stroke)
- Danielle Locust (National Institute of Neurological Disorders and Stroke).

Business Items

TCAC members elected Chairperson Payment and Councilwoman Villegas as chair and co-chair, respectively.

TCAC Discussion: Committee Planning

Future meetings

Committee members discussed the date for the next face-to-face meeting.

Dr. Etz stated that the contract for the first year included two face-to-face meetings at NIH. The committee could meet in Indian Country in subsequent years.

Committee members agreed that the next meeting should be scheduled before the STAC meeting on March 1-2, 2016. A Doodle poll would be conducted to determine the date.

Funding for AI/AN Researchers

Dr. Etz shared data on NIH grant awards to AI/AN and Native Hawaiian and Pacific Islander (NHOPI) researchers in FY2014, as follows:

- Total grant applications received: 74,989 (Funds requested: \$30.4 billion)
- Applications from AI/AN, NHOPI researchers: 658 (Funds requested: \$261,889,343)
- Grants awarded to AI/AN, NHOPI researchers: 131 (Total awards: \$46,680,165).

Dr. Etz noted that race and ethnicity of applicants was self-reported and not required.

Recommendations

- Establish an AI/AN desk
 - Report directly to Dr. Tabak
 - Facilitate co-funding of grants through the Common Fund
 - Serve as a clearinghouse for on- and off-campus activities
 - Provide outreach and support for AI/AN scholars
- Create new FOAs
 - Trans-NIH treatment intervention and health services research, modeled on the Native Intervention FOA, with no requirement for pilot data (could replace the OBSSR study on trans-NIH health disparities)
 - Research on AI/AN-relevant concepts, including culture as an intervention component
 - Must have tribal/community support.
- Tap the Common Fund
 - Use Office of Behavioral and Social Sciences Research (OBSSR) model
 - Fund a lab position for an AI/AN student in a lab position
 - Direct more funding to junior investigators.
- Establish the current state of AI/AN science and interventions

- Post results/findings of research on AI/ANs for all Institutes and Centers
- Post publications and provide access to research data.
- Create collaborative structures across HHS to analyze and publish existing data
- With permission of tribes, analyze studies funded by the Substance Abuse and Mental Health Services Administration (SAMHSA)
- Recruit young AI/AN investigators to conduct secondary analysis, learn the literature, and learn how to publish
- Bilateral education: NIH outreach to tribes through the TECs
- NIH staff who attend TCAC meetings report back to their Institutes
- Reactivate the inter-agency working group
- Enlist establishments in tribal communities to promote science
- Provide outreach and education to AI/AN professional organizations
 - American Indian Science and Engineering Society (AISES)
- Create a video on AI/AN scholars and researchers at NIH
 - Similar to the movie on Native physicians shown at the Association of American Indian Physicians
 - Disseminate through social media.
- Increase AI/AN staff at NIH at all levels, especially senior staff.

Wrap-Up, Next Steps, and Closing

Committee members discussed the process for developing a letter to document this meeting. They agreed that Aaron Payment, Denise Dillard, Malia Villegas, and Liana Onnen would review the notes from this meeting, prepare a draft letter, and circulate it to all members for review and feedback.

Chairperson Payment said he was encouraged by this inaugural effort and thanked NIH and the logistical contractor for doing an excellent job.

Mr. KILLSBACK shared a traditional Cheyenne blessing to close the meeting.

The meeting was adjourned at 3:00 p.m.

NIH Tribal Consultation Advisory Committee Meeting

September 29-30, 2015

List of Attendees

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