



Meeting Summary

Tribal Data Sharing and Genetics Policy Development Workshop

August 30 – September 1, 2017
UNM Comprehensive Cancer Center
Albuquerque, NM



The University of New Mexico (UNM)
Community Environmental
Health Program

Tribal Data Sharing and Genetics
Policy Development Workshop
UNM Comprehensive Cancer Center

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MEETING SUMMARY

*NIH Tribal Health Research Office and
National Human Genome Research Institute*



National Institutes of Health
Turning Discovery Into Health

**The University of New Mexico (UNM)
Community Environmental Health Program
Tribal Data Sharing and Genetics
Policy Development Workshop**

UNM Comprehensive Cancer Center
1201 Camino de Salud
Albuquerque, New Mexico

August 30 – September 1, 2017

WORKSHOP PRESENTERS AND PANELISTS

Wednesday, August 30, 2017

Preworkshop Session: Basics of Genetics

Nanibaa' Garrison (Diné), Ph.D., Assistant Professor, Department of Bioethics and Humanities, University of Washington (UW); and Beverly Becenti-Pigman, Chair, Navajo Nation Human Research Review Board (HRRB)

Katrina Claw (Diné), Ph.D., Postdoctoral Research Fellow, Department of Pharmaceutics, UW

Thursday, August 31, 2017

Welcome from the UNM Comprehensive Cancer Center

Johnnye Lewis, Ph.D., Director, Center for Native Environmental Health Research Equity, NIEHS, NIH, and Professor, College of Pharmacy, UNM Health Sciences Center

Welcome from the Navajo Nation

Russell Begaye (Diné), Honorable President, Office of the President and Vice President, Navajo Nation

The Charge for This Workshop

Walter Phelps (Diné), Delegate, 23rd Navajo Nation Council

Previous Genetics Research with the Navajo

Clarita Lefthand-Begay (Diné), Ph.D., Assistant Professor, Department of American Indian Studies, UW

History and Context of the Moratorium

Nanibaa' Garrison (Diné), Ph.D., Assistant Professor, Department of Bioethics and Humanities, UW; and Beverly Becenti-Pigman, Chair, Navajo Nation HRRB

Big Science Initiatives and Genomic Analyses

Vence Bonham, J.D., Senior Advisor to the Director on Genomics and Health Disparities, Office of the Director, National Human Genome Research Institute (NHGRI), NIH; and Juliana Blome, Ph.D., Chief of Staff, Environmental influences on Child Health Outcomes (ECHO) Program, Office of the Director, NIH

Panel: Cultural and Spiritual Perspectives on Genetics

Moderator: David Begay (Diné), Ph.D., Research Associate Professor, College of Pharmacy, UNM Health Sciences Center, and Member, Navajo Nation HRRB

Panel Members:

Jonathan Hale (Diné), Chair, Health, Education, and Human Services Committee, 23rd Navajo Nation Council

Beverly Becenti-Pigman (Diné), Chair, Navajo Nation HRRB

Michelle Kahn-John (Diné), Ph.D., R.N., Diné Hataaʼii Association

Steve Benally (Diné), Azee' Bee Nahagha of Diné Nation

Panel: Patient/Family/Community Perspectives

Moderator: Nanibaa' Garrison (Diné), Ph.D., Assistant Professor, Department of Bioethics and Humanities, UW

Panel Members:

Yolanda Sandoval-Nez (Diné), Senior Advocate, Native American Disability Law Center

Dorey Nez, Navajo Parent; Janene Yazzie (Diné), Participant, Navajo Birth Cohort Study, and Co-Founder and CEO, Sixth World Consultants

Edith Hood, Community Organizer, Red Water Pond Road Community Association

Friday, September 1, 2017

Session II: Alternatives and solutions

Panel: Moving Forward—Integration of Genomics into Health Care

Moderator: Walter Phelps (Diné), Delegate, 23rd Navajo Nation Council

Tuba City Regional Health Care Oncology Program Planning

Lynette Bonar (Diné), M.B.A., R.N., CEO, Tuba City Regional Health Care Corporation (TCRHCC)

Child and Adolescent Development and Genetics

Allanceson J. Smith (Diné), M.D., Child and Adolescent Psychiatry Fellow, Langley Porter Psychiatric Institute, University of California, San Francisco

National Cancer MoonshotSM Initiative

Michelle Bennett, Ph.D., Director, Center for Research Strategy, Office of the Director, NCI, NIH

Non-Panel Presentations

Alaska Native People's Perspectives on Biospecimen Use in Research and Genetic Research

Vanessa Hiratsuka (Diné), Ph.D., Senior Researcher, Centers for American Indian and Alaska Native Health, Colorado School of Public Health; and Denise Dillard (Inupiaq Eskimo), Ph.D., Director, Research Department, Southcentral Foundation (SCF)

The NIH and Health Research in Tribal Nations

David R. Wilson (Diné), Ph.D., Director, Tribal Health Research Office (THRO), Division of Program Coordination, Planning, and Strategic Initiatives, Office of the Director, NIH

Discussion and Next Steps

Moderator:

Walter Phelps (Diné), Delegate, 23rd Navajo Nation Council

MEETING SUMMARY

Wednesday, August 30, 2017

PREWORKSHOP SESSION: BASICS OF GENETICS

Prior to the official start of the workshop, several of the meeting participants met to discuss the basics of genetics. The learning goals and objectives for the session were to: (1) provide an overview of cell biology, genetics, DNA, and inheritance; (2) describe how genetic variation occurs and how it results in different observable characteristics within individuals; (3) describe how genetics relates to health and disease; and (4) discuss ethical issues and concerns that arise when examining genetics and health in Native American communities. The presenters asked the participants to consider two bioethics questions: Are we giving everyone a chance to live a healthy life? How can this affect Native communities and families?

For the purposes of this workshop, the following definitions were presented:

Cell: A microscopic unit that contains a variety of organelles (e.g., mitochondria, endoplasmic reticulum, nucleus, cell membrane, nuclear membrane) that contribute to help the human body function. Human bodies are composed of a variety of different cells (e.g., skin, blood, liver, heart).

Cell membrane: The phospholipid bilayer that surrounds the cell. Phospholipids do not dissolve in water.

DNA (deoxyribonucleic acid): The most basic molecular block of life. It provides information about the physical and personality traits of an individual, as well as about that individual's susceptibility to disease. DNA is contained in chromosomes, of which humans have 23 pairs, and is made up of four nucleotides (adenine [A], guanine [G], cytosine [C], and thymine [T]) that pair to form DNA's double-helix shape. One chromosome is inherited from the mother and one from the father. All chromosomes are found within each human cell, with the exception of red blood cells.

DNA sequence: The order of nucleotides along each strand that forms the DNA double helix. Humans have more than 3 billion different nucleotide pairs that make up their DNA sequence. Only some of these pairs contain the information needed to create a protein.

Endoplasmic reticulum: An organelle that helps to create proteins.

Genetic variation: The differences in genes (nucleotide pairs) that occur between individuals. Differences in single nucleotides (called SNPs ["snips"], which stands for single nucleotide polymorphisms) are the most common type of genetic variation among people. Humans have approximately 3 million SNPs.

Mitochondria: Organelles that provide energy.

Mitochondrial DNA: The small amount of genetic material contained in the mitochondria; this type of DNA is inherited from the mother.

Nuclear membrane: A lipid bilayer that surrounds the cell's nucleus, which contains most of the cell's genetic material.

Phenotypes: Differences in genetic traits that can be seen (e.g., hair color, eye color).

The participants engaged in an activity that allowed them to extract and visualize DNA from either a strawberry or a watermelon. Strawberries are octoploid, with eight DNA copies in each cell. (watermelons being diploid or triploid if seedless have fewer DNA copies per cell) As a result, participants found that much more DNA was extracted from the strawberries than from the watermelon. Plant cells are surrounded by a cell wall in addition to the cell membrane; human cells do not have a cell wall. Participants used detergent to break open the cell membrane, salt to create holes in the nuclear membrane, coffee filters to separate the solid cell components, and rubbing alcohol to separate the DNA from the other components.

The participants then took part in activity that allowed them to identify their own genetic traits through a survey. A group exercise allowed them to compare their surveyed traits within their group. Each group's genetic variation then was compared to the general population.

Genetic tools and research can help researchers predict susceptibility to certain diseases (e.g., cancer, type 2 diabetes) and screen newborn babies for diseases that can be treated early in infancy. An example pertinent to the Navajo Nation is severe combined immunodeficiency (SCID) disorder, which causes babies to be born without immune systems. With screening, newborns with the disease can be identified and undergo a stem-cell transplant early in life that could cure the disease. In response to a question regarding genetic testing for SCID occurring in Navajo Nation hospitals, the presenter explained that because of the moratorium on genetic research studies on the Navajo Nation, an innovative blood test has been developed that examines a molecular byproduct rather than the DNA itself. A participant asked how rare the SCID disorder is in the Navajo Nation. The presenter responded that it is rare, but clusters of Navajo families on the western side of the reservation have higher incidences of the disease compared to the general population.

Vaccine therapies, which use information derived from genetic research, can be used to treat or cure some diseases. Some epigenetics studies have focused on chronic stress, and studies have been proposed to investigate historical trauma in Native Americans to determine whether past trauma could have effects on DNA that affects future generations. For example, research has indicated that the grandchildren of populations that have undergone severe famine have increased disease susceptibility, even though they personally have not experienced famine.

Pharmacogenomics (the study of how a person's genetic makeup affects how they respond to medications) can be used to determine the best drug and/or dose to treat an individual's condition or disease. The blood thinner Warfarin is an example of this; some populations need a higher dose for therapeutic effects, whereas others need a small dose to avoid unwanted side effects. Pharmacogenomics also may allow health care professionals to tailor cancer therapies to each individual. Precision medicine is a new area of research being funded by the National Institutes of Health (NIH) to examine and understand genetic variation across different populations so that therapies and treatments can be targeted to individual patients to be the most effective.

Genetics research also helps researchers to understand the microbiome, which refers to all of the microorganisms living within an individual, and how it may interact with the environment. For example, changing one's diet can influence the microbiome. This could assist with the development of dietary interventions to improve health.

DNA can be used to study a variety of things. Some of these studies may offer benefits to communities, whereas others may not. Individuals must provide informed consent for their DNA to be used in research studies. Only a very small amount is needed for analysis during a study; with consent, leftover DNA may be stored in a biobank to be used for additional future research. Regulation of the use of this leftover DNA is important to ensure that the additional research is also beneficial to the original donor.

A participant noted that tribes that determine membership through blood quantum are becoming more interested in genetic information and testing. Parentage blood quantum tests differ from ancestry tests. No current DNA test will provide results that will indicate ancestry in a specific tribe. Some tribes are concerned that genetic research in relation to migratory patterns will conflict with their origin stories. Also, statistical probabilities used to determine genetic traits among populations can introduce error. Many genetics studies do not include a significant number of Native American individuals because, globally, indigenous peoples comprise only 0.05% of genome-wide association studies.

Genetic knowledge about a population can make screening and vaccines more effective in that population; the reverse also is true. For example, Native Americans were not included in the vaccine trial for human papillomavirus (HPV). As a result, the HPV vaccine is not as effective in Native American populations. Had Native Americans been included in the trial, it could have helped to lower cancer incidence in this population. It also is important to remember that different Native American populations may have considerable genomic differences. Finally, human beings are much more alike than different; these differences comprise one thousandth of a percent of the genome, and detecting such miniscule differences and understanding their meaning is difficult.

Thursday, August 31, 2017

Welcome from the UNM Comprehensive Cancer Center

Johnnye Lewis, Ph.D., Director, Center for Native Environmental Health Research Equity, National Institute of Environmental Health Sciences (NIEHS), NIH, and Professor, College of Pharmacy, UNM Health Sciences Center

Dr. Johnnye Lewis welcomed the participants to the workshop and thanked the workshop organizers and the organizations that had provided support, including the NIH and National Congress of American Indians. She recognized the tribal leaders and elders present. She emphasized that the input and opinions of all participants will be important for the desired open dialogue. Decision-making must be based on sound information. The workshop is being livestreamed, and participants can provide comments and ask questions on Twitter using the tag #tribalgenetics.

Dr. Lewis introduced Dr. David Begay, who thanked the participants for their attendance and provided the opening blessing in the Navajo language.

Welcome from the Navajo Nation

Russell Begaye (Diné), Honorable President, Office of the President and Vice President, Navajo Nation

President Russell Begaye officially opened the meeting, noting that the workshop topic is important to Indian country and the Navajo Nation in particular. Many environmental issues exist on Navajo land, including contaminated water and areas made uninhabitable because of contamination. As a result of various medical research concerns, such as cloning and exploitation, the Navajo Nation instituted a moratorium on genetic research studies in 2002. President Begaye has been following a UNM study about the generational effects of uranium, which he has found interesting; studies on cattle and sheep also are being conducted. He described other research that studies the cells of individuals diagnosed with cancer to develop an individualized treatment plan. Research is very important so that individuals are not misdiagnosed or mistreated.

It is important to allow Navajo citizens who have medical skills and knowledge to perform preventative research and research on focused treatment for diseases that will benefit the Navajo Nation. Previous studies conducted on the Navajo people did not provide them with benefit. As a result, beliefs and attitudes toward research studies must be addressed. Navajo citizens have always viewed the body as sacred, and this belief must be honored and protected. Research must be protective of elders and children, as well. The Navajo Nation should establish a group to explore policies to guide genetic research studies on the Navajo people, manage Navajo intellectual property, ensure informed consent, address ethical issues, and describe storage and infrastructure solutions. Collaboration is also critical; groups that should be working together are working in their own silos.

Because understanding the importance and dynamics of genetic studies is crucial, the public should be educated in lay terms, including through a description of how these studies can help the Navajo Nation address important health issues. A lack of information exists about Native genetics and DNA, and this must be addressed. The Navajo people have specific susceptibilities to certain diseases, and more research must be performed to explore and manage these susceptibilities.

The Navajo Nation is developing a health system that should improve the quality of health of its citizens, including comprehensive tracking to ensure that each individual receives the best treatment possible. A Navajo college of medicine is being established and is expected to be completed during the summer of 2018. The goal is to begin to accept students as soon as possible after its completion. Currently, nine Navajo medical students attend the University of Arizona College of Medicine; four are being supported by the Future Navajo Physicians' Scholarship Fund.

President Begaye's goal is to open the door for Navajo citizens to come home to help other Navajo people understand why cancer and diabetes have become so prevalent within the community and to perform research to address these health issues. It is time to open the door for the Navajo people to research their own genetics.

The Charge for This Workshop

Walter Phelps (Diné), Delegate, 23rd Navajo Nation Council

Delegate Walter Phelps welcomed his fellow delegates, the Navajo Nation HRRB members, and NIH staff. The charge for the workshop is to find answers to address disease in Native American populations. Navajo and Native American mortality rates are higher than those for the general U.S. population in all age groups. The participants are on a journey together to diligently find solutions.

Previous Genetics Research with the Navajo

Clarita Lefthand-Begay (Diné), Ph.D., Assistant Professor, Department of American Indian Studies, UW

Dr. Clarita Lefthand-Begay described previous federal Indian policies that resulted in the disruption of tribal cultures and languages and the turbulent dynamic between the U.S. government and tribes. Tribes in the United States have experienced a number of traumas, including forced removal from their homelands. In the historical relationship between researchers and Native peoples, Natives have been seen as objects of science and absent of any knowledge or understanding to contribute to science or research. Flawed craniometry methods were used to “prove” that Europeans were superior to any other racial group. Samuel Morton’s 1839 work, *Crania Americana: A Comparative View of Skulls of Various Aboriginal Nations of North and South America*, is considered to be the foundation of anthropological interest in studying deceased Native Americans and opened a floodgate for researchers seeking cultural data on Native peoples. In one example, a researcher casually published his method of obtaining Navajo skulls from a sacred burial ground. As late as the 1970s, Native American women were undergoing forced sterilization without informed consent, which further injured the relationship between health care providers and Native peoples. In 1989, Arizona State University began a genetics study on the Havasupai people; ultimately, the DNA was used for purposes outside the original study without the knowledge or consent of the participants.

A historical legacy exists of research that does not fit the needs and well-being of Native peoples, and this must be corrected. Researchers acknowledge that research has been done inappropriately in the past and are working to find ways to address issues in a culturally appropriate and empowering manner. As expressed in Linda Tuhiwai Smith’s book, *Decolonizing Methodologies: Research and Indigenous Peoples*, the term “research” has become a dirty word to many indigenous peoples. James Watson, one of the discoverers of DNA structure, recently stated that “DNA is no longer a matter of interest only to white-coated scientists in obscure university laboratories; it affects us all.” Native peoples must remember their past but also not be guided by fear. As sovereign nations, tribes must strive to better understand how the genetic revolution and genomic-based health care can work to benefit their citizens.

Discussion

A participant noted the importance of developing data-sharing policies so that research can be beneficial to tribal communities. Establishing ownership of what belongs to tribes is paramount. Tribes should take ownership of their health care systems. How do Native peoples best control their destiny? This is a critical question as tribes begin to take control of their own destinies. Dr. Lefthand-Begay agreed, especially in terms of establishing data ownership and ensuring that data are appropriately managed over time. Tribal members must have access to research results so that they can determine how the research can be of the greatest benefit to the community it is meant to serve.

A participant described a conversation with a spiritual practitioner about past research that had not been effectively understood by the Navajo participants. The Navajo have certain words and phrases to describe these types of traumas. It is because of situations like these that the Navajo people are hesitant to seek medical services, even when not seeking them may result in dire consequences.

A participant commented that many early studies examining genetic factors come back to the story of the great internment at Fort Sumner. Many genetic disorders have been linked to that period because a

high concentration of Navajo families was interned during that time. She encouraged the current generation of researchers to examine new and historical data in a meaningful way.

A participant described himself genetically in terms of his clans. He recommended that when speaking about genetics, Native peoples should ask the following questions: Who are we? Where have we come from? How were we created? Songs, chants, and narratives also must be considered. It is important for Native peoples to understand these things because Natives have been so integrated within the dominant society. Clans also have recognized the need for intermarrying to “bring in new blood” and avoid deformities. The genome and the imprint of each chromosome encodes the ceremonies, rituals, and narratives of a people and is written in each body, encoding everything individuals do.

History and Context of the Moratorium

Nanibaa’ Garrison (Diné), Ph.D., Assistant Professor, Department of Bioethics and Humanities, UW; and Beverly Becenti-Pigman, Chair, Navajo Nation HRRB

Dr. Nanibaa’ Garrison explained that a number of previous genetic studies have been performed on the Navajo people, including those focused on SCID, Navajo hepatoneuropathy, Athabaskan brainstem dysgenesis syndrome, poikiloderma with neutropenia, Lynch syndrome, microvillus inclusion disease, metachromatic leukodystrophy, and oculocutaneous albinism type 2. Many of these diseases are highly prevalent or over represented in Navajo populations. The Navajo Nation HRRB noticed that it was receiving an increasingly large number of genetic research proposals, and questions arose about their appropriateness, expertise, and oversight. The Navajo Nation produced and released a 40-minute documentary, *The Gift of Life*, that focused on Navajo views of genetics and origin stories. Ultimately, the Navajo Nation recognized a lack of policies or guidelines existed for genetic research protocols. As a result, in April 2002, the Navajo Nation approved a resolution (HSSCAP-20-02) of the former Health and Social Services Committee of the Navajo Nation Council (now the Health, Education, and Human Services Committee of the Navajo Nation Council), which placed a moratorium on genetic research studies conducted within the jurisdiction of the Navajo Nation until such time that a Navajo Nation Human Research Code has been amended and approved by the Navajo Nation Council.

Ms. Beverly Becenti-Pigman explained that when the HRRB began to receive the increased number of research proposals, it consulted with the (then) Health and Social Services Committee of the Navajo Nation Council. Community conversations were held with Navajo Nation leadership, the Diné Hataalii Association (Navajo Medicine Men’s Association), the Native American Church, traditional healers, and individuals with Western scientific training. More than 100 medicine men provided input regarding how genetic issues needed to be addressed. Some discussions were captured in the documentary, which is spoken in the Navajo language with English subtitles. The documentary was then shared to obtain additional input. Ms. Becenti-Pigman also appeared on a radio show to solicit further input from the community; most of the responses indicated a lack of support for Navajo genetic research. Now may be the time and the opportunity for the Navajo Nation to begin developing rules to address genetic studies.

Dr. Garrison provided additional context for the moratorium, which was initiated as a result of concerns raised by Navajo decision makers and tribal members about possible stigmatization, biased interpretations, and a lack of direct benefits of the research. Many tribes at the time were wary of genetic research and researchers because of a historical legacy of exploitation and distrust. For example, in 2004, the Havasupai Tribe filed a lawsuit against researchers at Arizona State University for misuse of Havasupai DNA samples. The case raised a number of ethical issues about appropriate and inappropriate use of genetic samples.

The next steps are to develop educational workshops and conferences such as this one, study the community's attitudes and opinions about genetics, develop policy, and consider a legislative change to lift the moratorium on genetic research.

Discussion

A participant asked about the specifics of the moratorium and how it affects Navajo citizens wanting to participate in genetic research. Ms. Becenti-Pigman responded that the moratorium applies only within the boundaries of the reservation, and Navajo citizens can choose to participate in research off of the reservation. If a Navajo person is harmed as a result of poor research protocols, however, the Navajo Nation will address the matter through the Navajo court system and not the local, state, or federal court system. The Navajo Nation HRRB works with principal investigators to ensure that protocols for non-genetics-related research completed on the reservation are appropriate and culturally sensitive.

A participant asked whether the data collected from voluntary Navajo participants off of the reservation are the property of the Navajo Nation. Ms. Becenti-Pigman responded that they are not because the Navajo Nation does not have jurisdiction.

Big Science Initiatives and Genomic Analyses

Vence Bonham, J.D., Senior Advisor to the Director on Genomics and Health Disparities, Office of the Director, National Human Genome Research Institute (NHGRI), NIH; and Juliana Blome, Ph.D., Chief of Staff, Environmental influences on Child Health Outcomes (ECHO) Program, Office of the Director, NIH

Mr. Vence Bonham stated that the NIH is ready to work with the Navajo Nation as it considers changing the moratorium. He explained that his work focuses on ensuring that genomics, including research supported by NHGRI, benefits all populations. In 2003, the human genome was mapped for the first time. Since then, the cost of sequencing a person's genome has been reduced from \$1 billion to less than \$1,000. Hundreds of thousands of people have had their genome sequenced, which has provided powerful information to better understand the variation in the genomes of individuals and how this information may be important for health and disease. Significant advances have been made in understanding how genomics contributes to disease.

Genomic medicine includes a number of different research areas. Cancer genomics is leading the way in understanding disease and treatment of disease. Pharmacogenomics, which includes delivering the right drug to the right person at the right time, is just behind cancer genomics. Epigenetics, another exciting area of research, explores how DNA is expressed and how the environment may influence this expression and an individual's genome. Sequencing genomes has increased knowledge about rare genetic diseases. Big data helps health care providers to interpret information to improve clinical care. Health equity is achieved when each individual has the opportunity to experience the best health possible without being affected by socially determined circumstances. The goal of genomic medicine is to ensure that everyone benefits and has health equity. Mr. Bonham described a case study in which a misdiagnosis occurred regarding a genetic variant's relationship to heart disease, highlighting the fact that without information in clinical laboratory data sets, we do not have the ability to understand human variation in a way that can improve health for everyone.

Although NHGRI supports a number of big science and genomics programs, the majority of NIH genomics research has been integrated across the 26 other Institutes, Centers, and Offices (ICOs). Biomedical research at the NIH has integrated genomics to examine specific organ systems, diseases,

and environmental and other issues to better understand disease. One NHGRI program, Clinical Sequencing Evidence-Generating Research, aims to increase the diversity of populations in genomics research, include diverse health care settings, and study and address barriers to health care. Another NHGRI program is the Undiagnosed Diseases Network, supports a number of sites across the country with researchers working to better understand undiagnosed diseases and improve treatment for individuals with these diseases.

Mr. Bonham closed with a quote from Dr. Martin Luther King, Jr.: “We cannot walk alone, and as we walk we must make the pledge that we shall always march ahead. We cannot turn back.”

Dr. Juliana Blome provided an overview of the NIH’s ECHO program, the mission of which is to enhance the health of children for generations to come. The program’s overall scientific goal is to answer crucial questions about effects of early environmental exposures on child health and development. These exposures are examined in a holistic manner from the macro to the micro levels. The program focuses on five key high-impact pediatric outcomes: upper and lower airway; obesity; pre-, peri-, and postnatal; neurodevelopment; and positive child health, which is related to resilience. The study tries to meet scientific needs and inform programs, practice, and policy through long-term studies and a clinical trials network.

The program includes 83 cohorts, including the Navajo Birth Cohort Study, and plans to weave together the information of all of these cohorts to increase the ability to address important research questions. ECHO cohorts have existing and new data that are placed into a central repository and encrypted. The program will collaborate with the Navajo Nation and other tribes to ensure that all concerns are addressed and that the Navajo Nation and other tribal communities can benefit from the research conducted under the ECHO program.

Discussion

A participant asked whether NIH genomics researchers collaborate and how cultural, data ownership, and other concerns are addressed on a national level. Mr. Bonham responded that NIH researchers collaborate with one another in a variety of ways and discuss a number of issues, including data ownership and sharing. The participant was concerned that the NIH has only one tribal liaison to represent more than 500 tribes and recommended expanding the number of representatives. Mr. Bonham replied that NHGRI seriously considers these types of recommendations.

A participant asked how the NIH allows enough time to provide a meaningful consultation with tribes. Mr. Bonham explained that taking the time to ensure that the community is engaged in research is an important issue. NHGRI allows modification of timelines when researchers request additional time to engage with communities; the ability to do this is included in funding announcements. NHGRI understands that not all research will move at the same pace, and there is a need to educate communities, which takes time.

A participant asked whether an initiative will be established to develop equal partnerships with tribes that will allow traditional healers to be part of the decision-making process. For example, the Navajo Nation has some of the most brilliant traditional healers and has developed one of the best traditional healing programs in the country. Mr. Bonham responded that he would like the participants to discuss specific opportunities for such collaboration during the workshop, and that Dr. David Wilson’s presentation, the following day, provides another opportunity to address this issue.

SESSION I: RESEARCH AND CULTURAL PERSPECTIVES

Panel: Genetics Research—What We Can Learn

Moderator: Clarita Lefthand-Begay (Diné), Ph.D., Assistant Professor, Department of American Indian Studies, UW

Pharmacogenomics with Northwest and Alaska Tribes

Katrina Claw (Diné), Ph.D., Postdoctoral Research Fellow, Department of Pharmaceutics, UW

Dr. Katrina Claw explained that pharmacogenomics is the study of how a person's genetic makeup affects how they respond to medications to allow the development of effective, safe medications and doses for personalized precision medicine. This knowledge can help health care providers determine whether to treat an individual with a conventional drug or dose or an alternative drug or dose; these determinations must balance benefit and risk. Much of the interindividual variation is based on protein activity, including those at the site of action or in clearance.

Dr. Claw's work focuses on human genetic variation. Each individual's genes differ from the genes of other human beings by approximately 0.1%. Genetic variation in drug response is responsible for up to 30% of all adverse drug reactions, which creates a relationship between genetics and outcome. Little is known about the pharmacogenomics of Native Americans. Of the 11 studies on pharmacogenomics genes in indigenous peoples conducted between 1969 and 2005, six took place in Canada, and five occurred in Central and South America. No studies were conducted on American Indian/Alaska Native (AI/AN) populations. The studies found that allele frequencies are highly variable, with no consistent similarities to frequencies in other ethnic or racial groups. Therefore, insufficient data were available to generalize.

The Northwest-Alaska Pharmacogenomics Research Network (NWA-PGRN) focuses on genomic medicine for underserved and disadvantaged populations. The group focuses on two questions related to the development of health applications from genomic research: How can we assure that everyone benefits? How can we assure that disadvantaged populations are not harmed? The network is partnership-based, with tribal, academic, and other partners in Montana, Alaska, and Washington. The deliberative process in establishing the partnerships was based on building trust and ensuring that learning was mutual. The research process is aimed at correcting historical precedents and includes shared power and participation in research design, analysis, and dissemination. NWA-PGRN engages in community-based activities to examine the genetic and environmental effects of antiplatelet therapies, management of warfarin therapy, and management of vitamin D deficiency and health outcomes.

Dr. Claw summarized that pharmacogenomics and precision medicine can affect Native communities, and knowledge integration will lead to better health outcomes. These affect AI/AN health research by increasing the number of Native researchers, building tribal research capacity, and bringing precision medicine to tribal communities.

One Health Initiative: Interdisciplinary Collaborations and Communications in All Aspects of Health Care for Humans, Animals and the Environment

Gilbert John (Diné), Ph.D., Assistant Dean for Research, College of Veterinary Medicine and Biomedical Sciences (CVMBS), Colorado State University (CSU)

Dr. Gilbert John explained that the One Health concept was introduced in 2007 among a variety of disciplines with the belief that the health of people is connected to the health of animals and the environment. It brought together human and animal medical professionals, accelerated biomedical research discoveries, and improved veterinary and human health. The One Health concept rediscovers global Native knowledge.

The mission of CSU's CVMBS is to help animals, people, and the planet through research on environmental health, infectious disease, and cancer. When the NIH's National Cancer Institute (NCI) established the Comparative Oncology Program in 2003, CVMBS joined the Comparative Oncology Trials Consortium, which includes 20 veterinary schools, and established its cancer research program. CVMBS also focuses on translational research; the CVMBS Flint Animal Cancer Center's mission is to improve the prevention, diagnosis, and treatment of cancer in pets and translate this knowledge to benefit humans diagnosed with cancer. Veterinary studies of pets with cancer are combined with human clinical trials in an integrated and comparative approach to drug development that aims to accelerate the development of new human cancer drugs.

Genes that encode for certain cancers are similar in humans and animals. Additionally, several animal genetic disorders resemble human conditions. The environment and physical stresses can influence these conditions similarly in humans and animals. Comparative medicine and translational medicine will play an important role in animal and human health in the future. Moving forward, CVMBS is exploring the intersection of animal health, human health, and the environment. The One Health Initiative allows physicians, veterinarians, and biomedical researchers to work together to improve human and animal health.

Mine Waste Exposures, Epigenetic Changes, and Risk

Johnnye Lewis, Ph.D., Director, Center for Native Environmental Health Research Equity, NIEHS, NIH, and Professor, College of Pharmacy, UNM Health Sciences Center

Dr. Lewis became involved in this effort in 2000 when 20 chapters of the Navajo Nation approached her about determining whether unregulated drinking water contained uranium, which could contribute to the high rates of kidney disease on the reservation. The partnership, the Diné Network for Environmental Health, took 4 years to develop. In 2004, funding was obtained for the first-ever study on community exposures (in Navajo adults) that result from the 1,100 waste sites on the Navajo Nation that contain a mixture of heavy metals. The study has evolved since then, adding a birth cohort study in 2010 and an assessment of young adults in 2015. In 2016, the birth cohort was expanded as part of the ECHO program to allow children to be followed to the age of 5 years instead of the original 1 year. A recently funded study will examine interventions to reduce risks from heavy metal exposure.

The Navajo Birth Cohort Study/ECHO participants will be asked if they are willing to share their data for combined national analyses if the moratorium is lifted; the discussions occurring at this workshop will have future effects. Participants will be enrolled in a culturally respectful manner and will provide informed consent. The diversity in cohorts, if shared, will allow researchers to examine the interactions of genes, the environment, and epigenetic changes and evaluate these interactions in outcomes that

happen with very low frequency. Being part of such a large study will allow Navajo researchers to examine the interactions of multiple factors, such as how the same genes or exposures can have different outcomes.

Epigenetic changes can be explained as an additional layer of instructions outside of the genetic code that controls how DNA is interpreted and expressed. These changes are not transient, often are induced or removed by environmental exposures (either increasing or decreasing the expression of certain genes), and can be passed from generation to generation. For example, an exposure to uranium two generations ago may cause markers to appear two generations later despite the lack of exposure in that generation. Metals are known to induce epigenetic modifications, which can alter developmental pathways even if the genetic code remains unchanged. Understanding the difference helps to identify risk and design appropriate interventions. Pre- and perinatal exposures may provide a window of opportunity to achieve this.

Dr. Lewis and her colleagues investigate how metals enter the body, the amount of metals that influences disease, which metals or metal combinations cause disease, and how metals change cells in the body and whether these changes affect future generations; the ultimate goal is to develop interventions to tip the balance back toward health. The researchers have found metal effects on kidney and cardiovascular diseases and an increased likelihood of developing multiple chronic diseases. The results showed evidence of immune dysfunction and an increased prevalence of autoimmune markers. Arsenic, uranium, and possibly other metals block the process of routine DNA repair by displacing zinc. In animals, supplementing with zinc can restore DNA repair in animals. Other possible mechanisms of disruption include oxidative stress and the loss of DNA repair enzymes. Identifying all mechanisms will allow designing more effective interventions that address multiple pathways.

Panel Discussion

A participant noted that sheep have a shorter gestation period than humans, and effects are seen sooner as a result. Also, as market preferences changed, fatter lambs were selected, and Navajos began consuming more fat. Sheep diets also have changed to be corn-based, which has affected their nutrition and health. The participant wondered whether Navajo citizens are eating diabetic sheep and if that contributes to human pancreatic cancer. He also stated that contaminated water on the reservation contributes to disease.

A participant asked the panel members to share their opinions on the Navajo Nation's moratorium on genetic research. Dr. John responded that he thought that the moratorium needs to be reevaluated and modified to allow the Navajo people to benefit from science; currently, the opportunity exists on the reservation to achieve this. Several experts are in attendance who can help develop protective, culturally appropriate policies. Dr. Claw explained that she had always had an interest in genetics and pursued this interest as a career. She would like to come back to the reservation and use her education, knowledge, and experience to help her people with her holistic perspective. She has not participated in any external genetic research out of respect for the moratorium. Ultimately, she would not have obtained a doctorate in genetics if she did not see the potential for genetic research to be beneficial. Dr. Lewis commented that she is happy to hear these discussions; research partners must follow the Navajo Nation's lead on this. All of the participants can provide input into the process and help make the decision. The Navajo Nation must be comfortable with any negotiated policy, and that policy must address any Navajo concerns.

A participant stated that a disaster occurred on the reservation in the 1970s that was worse than the Three Mile Island incident, but the contamination remains. School children were exposed to uranium in contaminated water for a long time until testing was performed and the school installed a filter. A filtration system is a “bandage”; the mining waste must be cleaned up. Uranium levels remain high and pose a danger to the Navajo people. Future generations must be protected and not exposed to these heavy metals. County, state, and federal government, including the U.S. Environmental Protection Agency, must provide assistance. Dr. John agreed and explained that he would like to see a comprehensive study to understand the process, share information, and address the contamination.

Panel: Cultural and Spiritual Perspectives on Genetics

Moderator: David Begay (Diné), Ph.D., Research Associate Professor, College of Pharmacy, UNM Health Sciences Center, and Member, Navajo Nation HRRB

Panel Members: Jonathan Hale (Diné), Chair, Health, Education, and Human Services Committee, 23rd Navajo Nation Council; Beverly Becenti-Pigman (Diné), Chair, Navajo Nation HRRB; Michelle Kahn-John (Diné), Ph.D., R.N., Diné Hataalii Association; and Steve Benally (Diné), Azee’ Bee Nahagha of Diné Nation

Dr. Begay introduced the panel on cultural and spiritual perspectives on genetics. Mr. Jonathan Hale emphasized the need to determine how to better grasp these issues as a people. He noted that elderly individuals often must endure significant numbers of medical procedures, but few data are available about AI/AN populations. Mr. Hale noted the importance of data to any federal initiative. He also recommended better definition of the terms used to avoid multiple interpretations and legal conflicts.

Ms. Becenti-Pigman commented that in a traditional system, human life should be in harmony with the natural universe, and she asked how to balance this with genetics. She explained a system for healthy families based on the four directions. In Navajo culture, east is the direction of ethics and values, thinking, and the beginning of life. In this direction, healthy families should value children, provide a healthy start during pregnancy, and build a strong foundation in strong character and values. South is the direction of economics, livelihood, and planning. This direction focuses on the development of physical wellness, including opportunities for learning about a healthy life, working with communities to create healthy environments, and encouraging young people to become involved. Healthy families in this direction are physically active together and prepared for future challenges. The west relates to family and community, and this direction focuses on the development of social competence and relationships. Healthy adults in this direction recognize the need to take time for themselves to stay healthy. North is the direction of the environment, as well as hope, life, and harmony. The nation completes the cycles of life in harmony and balance, and Navajo people have strength and healing in the winter of their lives. This direction relates to the development of emotional well-being and respect for nature. In this direction, healthy families learn from their experiences and share them. Healthy families also include roles for all ages, including the elderly.

Ms. Becenti-Pigman asked how genetics fits into these four directions, emphasizing that what is desired in each direction is healthy families, so when one thinks of genetics, one should think of healthy families.

The four directions are the lifeline of Navajo people. She noted that the Belmont Report¹ emphasized doing no harm and protecting and respecting traditions; these principles will lead to benefits.

Dr. Michelle Kahn-John commented on the honor of speaking on behalf of the Diné Hataaʼii. She noted that the Diné Hataaʼii Association is very open and includes members with many roles and specialties, and the association welcomes new participants. Its mission is to preserve and protect spiritual practice and, through that, protect health. Dr. Kahn-John noted that the association has approved almost every research proposal that has been presented to it; the association is very supportive of research. She emphasized that researchers need to prove that they can function as positive members of the tribal community, adding that humbling oneself is a critical component. Researchers also must understand the complexity of the tribal community.

The foundational philosophy of the community is *hózhó*, the journey of walking through life harmoniously. Dr. Kahn-John noted that many members of the younger generation, including herself, cannot grasp the richness of the concept that elders can convey, especially in Navajo. The collective wisdom of the Diné Hataaʼii Association also emphasizes the interconnectedness and holistic nature of everything. The Diné Hataaʼii are open, supportive, and ready for collaboration, and they provide much teaching and guidance. They believe that a solution always exists. Dr. Kahn-John presented several Diné Hataaʼii opinions on genetics. One medicine man was curious but cautioned that it should be done thoughtfully, with prayers and ceremony, emphasizing constant grateful exchange. Another was more hesitant, emphasizing the importance of protecting knowledge and ways, although he also agreed that it should go forward with the appropriate caution.

The Diné Hataaʼii Association, as a whole, recommends cautious forward action, with a Hataaʼii expert included on the planning committee. The association wants to ensure that findings will be protected, but the ultimate goal is health and well-being for tribes and the world. Dr. Kahn-John emphasized that a cultural wisdom document—the Substance Abuse and Mental Health Services Administration’s [The National Tribal Behavioral Health Agenda](#)—could be consulted and adapted for use in proposals.

Mr. Steven Benally explained that he is from a long line of medicine people and has visited with his advisors about genetics. All discussions return to one central purpose: healing. Mr. Benally emphasized the need to help those who need help. He explained that, in the Indian worldview, all life is alive, and people can talk to it. Through this method, they can ask for help in diagnosing illness, identifying imbalances, and asking for ways to approach illness and help people regain the health that they have lost. All ceremonies are created for the purpose of healing. He asked how to preserve these traditions and ensure that they will be carried down to future generations, so they can help themselves when in need.

Mr. Benally noted that current concerns are not the same as they were in the past, including health and the environment. He asked what nations, families, and individuals will be subject to without the right interventions. People want to be part of efforts to fix problems, so he supports lifting the moratorium with certain reservations. He hoped that this will be moved forward by the right people in the right way and for the right reasons, but he also emphasized the importance of keeping the sacred, sacred. He noted that cultural identity is sacred to the community. Exact strategies to address these problems have

¹ The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1979. [The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research](#). April 18. Washington, D.C.: Department of Health, Education, and Welfare, Office of the Secretary.

yet to be developed, which is related to elders' concerns about how everything will be done. On a personal note, he described several relatives' experiences with cancer and diabetes and wondered if their treatments would have been more successful or less painful if they had been aligned to their individual genetics rather than a one-size-fits-all method. He added that the community has reservations about being told what is good for it from the outside when the community members always have been able to help themselves.

Discussion

Dr. Begay invited questions, and a participant asked for his opinion. He commented on the difficulty of moving from one language to another, whether that translation is between Navajo and English or between scientific and Native worldviews. This is a complex process that has not been adequately communicated, but all parties have done their best so far. Dr. Begay emphasized the importance of continued work to cultivate the relationship between scientific and indigenous communities, noting that the contrasts in worldview also have posed problems for other indigenous societies, such as Native Hawaiians and Maori. The indigenous world is holistic, while Western thought is rooted in the Cartesian mind, a very different system of thought that emphasizes certain places for everything. Dr. Begay noted that spirituality is one of the first aspects to be discarded in the scientific laboratory, whereas in the Native worldview, it is the key ingredient of the human mind and body. Although the Western world is reductionist, the Native perspective works within the complexities of the healing process and can create connections necessary to heal that the medical profession cannot. He noted the difficulty of connecting intuitively with those who were not raised within indigenous culture, as well as the difficulty of explaining genetics to elders.

A participant asked how indigenous knowledge, which largely focuses on ways to make people healthy, can be translated to prevention strategies. Dr. Kahn-John agreed with the attendee that policy is important, noting that many Native researchers work in this area, and restrictions against bringing traditional healing into research agendas have decreased. She emphasized that progress is occurring, but it is slow. Components of traditional medicine are related to physical health and also to environmental and social health. She emphasized the importance of gaining the input of the community.

A participant commented that as the community moves forward, it must ensure fair practices for those individuals who have gone out into the Western world in search of more opportunities and those who remain on the reservation and follow more traditional ways of life. She recommended promotion of herbal medicine and spirituality as components of healing.

A participant commented on the multilevel communication process required to achieve healing. Common knowledge and basic language are shared every day, such as asking a neighbor how they are feeling. The second level is ceremonial process and exchanging esoteric knowledge. The attendee emphasized the importance of protecting some knowledge of the sacred. Research facilities can be locations of ceremonial processes and esoteric knowledge, but it should be in service of reaching a place of healing. He recommended cautious support and ensuring that biological information provided for research is not used improperly.

A participant questioned how to determine personal risk factors and acquire enough data to change policies. Mr. Hale commented that only official policies have weight, despite the amount of discussion that surrounds them. He recommended asking governments to provide documentation and ensure that

all relevant aspects are included in the official policies, including ethical and financial considerations. He added that policies in “black and white” are the only products he can take back to the community.

A participant suggested that a good starting point for doubters is to consider what would happen if the moratorium is not lifted. Some families may not be able to receive treatment, so the attendee recommended taking a chance to improve health if it is offered. Additionally, she commented on certain medical issues that are more common in the Native community, such as injuries and conditions that may occur in bullriders, and need further study.

A participant referred to a presentation during the morning session that addressed systems perspectives, including the genetics of humans, the environment, and livestock. The attendee noted that the current discussion centered on health, but other domains must be considered, including government. He emphasized the cause-and-effect relationship inherent in all aspects of the issue, including economic development, social ills, housing, and alcoholism. He emphasized that sustainability policy is needed and that this is a new paradigm that many institutions and governments at all levels are incorporating. He wondered how to couple genetics with sustainability. Dr. Kahn-John responded that sustainability and genetics are directly correlated, but any program needs data. She noted that sustainability gives control back to the people, and the Native community needs well-thought-out sustainability plans to overcome disparities.

Dr. Kahn-John explained to a participant that she would take a discussed agreement back to the Diné Hataaʼii Association and the other groups with which the association works. She noted that many models of collaborative health care exist, especially in the Indian Health Service, although she acknowledged that that service is not always ideal. She explained a study demonstrating that a traditional ceremony was more effective at helping individuals heal, and when people were asked why they had not sought traditional treatment earlier, answers ranged from lack of funds to not speaking Navajo or not knowing how to access a medicine man, so much teaching remains to be done.

Dr. Begay commented that this is “the tip of the iceberg,” and there are few ways to communicate about this. He noted that real communication happens when all parties put everything on the table. This session was successful in juxtaposing the real Native mind and the Western mind and fostering intellectual dialogue.

Panel: Patient/Family/Community Perspectives

Moderator: Nanibaa’ Garrison (Diné), Ph.D., Assistant Professor, Department of Bioethics and Humanities, UW

Panel Members: Yolanda Sandoval-Nez (Diné), Senior Advocate, Native American Disability Law Center; Dorey Nez, Navajo Parent; Janene Yazzie (Diné), Participant, Navajo Birth Cohort Study, and Co-Founder and CEO, Sixth World Consultants; and Edith Hood, Community Organizer, Red Water Pond Road Community Association

Dr. Garrison introduced the panel, explaining the importance of gathering the firsthand perspectives of people who are thinking about genetics through personal experience or how to navigate the world of cancer.

Ms. Yolanda Sandoval-Nez explained that she and her husband are the parents of two deceased children with a rare genetic disorder. She commented that the experiences of parents are rarely heard, and she hoped that the past experiences of the Navajo people will not dictate what they do in the future. She

added that the moratorium made it challenging to get her children the treatments they needed. Ms. Sandoval-Nez and her husband participated in a documentary ([Sun Kissed](#)) about their experience to highlight the importance of their voices. She noted that there are always challenges in adhering to traditional values. Mr. Dorey Nez added that as he became more involved in genetics, he often was the only Navajo in the room, and others often would think he represented the entire tribe. Researchers assumed that he was making excuses for the tribe not to be involved in research. He emphasized that the Navajo people have experiences to share that can make research less one-sided.

Ms. Janene Yazzie explained that she is both a participant in the Navajo Birth Cohort Study and a community organizer.

Ms. Edith Hood explained that her hometown has significantly contaminated soil and water from local uranium mining. Their area is the number one Superfund project on the Navajo reservation. She explained that she both worked in a mine and lived in the contaminated area. She added that the town had three medicine men who taught everything they could. She wondered where the sacredness is in genomics.

Ms. Yazzie explained that this is an exciting time in that tools are being developed to examine practices already known in Native knowledge, and these studies are highlighting interconnections always known to the Navajo people. She commented on the concept of environmental injustice, or the exploitation of Native lands, resources, and people. Many worldviews are centered on honoring water, a sacred element. Water, however, has become a conduit for the spread of contamination. In the east, hydraulic fracturing (fracking) sites are affecting the environment and causing social and economic stresses. This affects cultural, mental, and spiritual health. Areas in the south are contaminated by uranium mining; the runoff from a 1979 spill affected rivers, and the contamination is controlled by a system that values exploitation. In the west, wastewater is used to create artificial snow on sacred peaks, and in the north, unreclaimed mines leach metals, leading to the Gold King Mine wastewater spill.

These situations influenced Ms. Yazzie to become a participant in the Navajo Birth Cohort Study, because it is imperative to work faster to understand what affects the Navajo community. She emphasized the difference between Western and indigenous research. For example, at the Gold King Mine, federal agencies assessed the spread of contamination via hikers using personal water filters, but indigenous community discussions highlighted much more dynamic pathways of exposure. They had a more comprehensive understanding of the views of this river and its effects.

Ms. Yazzie emphasized the need for offerings to respect what is being taken from the bodies of research participants. When she participated in the birth study, she felt something was missing; she was giving living pieces of her and her daughter's bodies, and that needed to be honored. Partnerships are not sufficient to ensure data sovereignty, and researchers need to address the inequalities that already exist in this system. Study participants find it difficult to meet researchers' deadlines, and researchers do not understand the social, economic, and cultural factors that affect participants, such as unreliable transportation. Power dynamics occur between the researcher and participant. Ms. Yazzie noted that research often is framed as conducted as a "benefit for all," but participants do not control how "benefit" is defined, and medical advances often come from exploitation. Numerous ethical questions exist about the ownership of genetic materials. Indigenous people understand that genetic materials still are alive and carry connections to the donors and their ancestors. She noted that, in the case of Henrietta Lacks, the many scientific advancements developed from her cells did not lead to changes in

her own community, so donors need to be able to access advancements that may result from their contributions. Indigenous people must have equal representation as decision-makers and in discussions.

Moving forward, the Navajo people must engage in more internal discussions to settle questions before they engage in discussions outside the community, and they also should discuss these questions across other tribal nations. Ms. Yazzie emphasized the importance of standing united to facilitate the control of data. Future studies should be founded on respect and honor both individual rights and indigenous rights. Traditional knowledge and knowledge-keepers should be protected and respected. Ms. Yazzie added that these considerations apply not only to the moratorium; there are other discussions to be had and spaces to be created.

Dr. Garrison asked the other panelists to elaborate on their experiences at the personal and community levels. Ms. Sandoval-Nez wondered whether her children's rare condition truly is as rare as they were told, because not much information is available in their area. Her children were diagnosed with xeroderma pigmentosum and were required to avoid sunlight. This was eye-opening for her family, requiring a lifestyle change so they could do everything at night. Additional disabilities are associated with this condition, so Ms. Sandoval-Nez and her husband had to learn a lot very quickly. She emphasized the importance of the partnership with her husband, who grew up on the reservation and understood its systems better than she did. It was also critical to partner with outside groups to ensure that her family was well-informed about the conditions and all treatment avenues. She wanted to share with the Navajo tribe that they need to have a voice at the table. The moratorium was a challenge; they had to go outside of the Navajo Nation because the doctors did not know what xeroderma pigmentosum was. Advocacy efforts always focused on informing other parents. Ms. Sandoval-Nez and her husband created their documentary to help other Native families, and she hoped that it opened eyes and doors. She noted that the family walked the fine line between Western and traditional medicine. Her husband had to quit his job and become the caregiver for their children because childcare for children with complex health conditions is difficult to find. She and her husband wanted their children to know that their parents loved them, and they wanted to give them the best quality of life possible.

Mr. Nez added that they made their documentary because they live in two worlds—the Western world and Navajo culture. He explained that he became involved in genetics because researchers offered him the chance to know whether he would get cancer in the future, so he viewed it as a preventative measure.

Dr. Garrison asked Ms. Hood to share more of her story. She explained that there were two mines in her town. In the 1960s, the residents did not know what was happening when the mines moved in. The mines increased traffic and caused noise pollution, and the local livestock often were hit by large trucks hauling ore. In 1979, the dam broke and spilled 94 million gallons of contaminated water. She noted that her town was in the middle of all the dust and pollution. People had died working in the mines; she worked in the mine carrying an instrument to detect readings, and years later she developed lymphoma. She was given intense chemotherapy, which destroyed her immune system, and because she was working as a teacher at the time, she was unable to fight off illnesses from her students. As a result, she came down with shingles; she still feels pain from this illness. She explained that although her community was significantly affected by the uranium industry, nothing has been done. The community still is attempting to get the government to clean up the mess left by the corporations. Leaders do not aggressively pursue solutions. She also noted the environmental racism inherent in quickly cleaning up

other disasters, such as Three Mile Island, while the 1979 spill in her community remains. The contamination is in the ground and water; it spreads to the plants, and the animals drink the water and eat the plants. Humans then eat the animals; it is a cycle.

Panel Discussion

A participant commented that she had been hearing the moratorium discussed for the last 6 months. She asked the attendees to consider whether the discussion at the workshop focused on a policy that will help to guide all research on the Navajo Nation in general or whether it will be a specific policy that guides only genetics research on the reservation. She thought that lifting the moratorium would provide benefits to the Navajo Nation. She asked about the process and the timeline for lifting the moratorium because lives are at risk. Ms. Sandoval-Nez explained that she wanted to educate herself after her children were diagnosed, and her children's quality of life was paramount. She is pleased to hear that people are discussing the moratorium. The moratorium has been a challenge for her family, and it was necessary to leave the reservation to learn about her children's disease. Ms. Yazzie agreed with the commenter that time is an issue. Allowances should be facilitated and expedited so that families have access to necessary medical research facilities. The Navajo people cannot allow their vulnerabilities to be used against them and must address the prevalent structural injustices that pose threats to future generations. She is tired of seeing her relatives and community members die of cancer and other diseases. She also is tired of the tribe's vulnerabilities being used to force the members into situations for which they are not prepared; they also are not protected from the adverse effects. For example, the industries causing the contamination and disease exploited the Navajo Nation's vulnerability (unemployment) by promising jobs. Structural inequalities need to be addressed in every step moving forward. Ms. Hood thinks about the level of voluntary participation in medical treatment and research.

BREAKOUT SESSION: IDENTIFY NEEDS TO BE ADDRESSED IN DEVELOPING POLICY

The unique composition of scientists, tribal leaders, and community members met in five breakout groups to discuss the following five strands: (1) cancer diagnosis, prevention, and treatment needs; (2) policy development needs; (3) cultural perspectives to address; (4) biomedical ethics needs; and (5) tribal nations' needs. The breakout sessions were designed to help identify needs within cancer genetics that can lead to policy development. Attendees were asked: if the moratorium is lifted, what policies would need to be in place to make them feel safe to participate in genetic research that would benefit the individual, the family, and the community?

Report-out of the breakout session discussions can be found on page 25.

Friday, September 1, 2017

SESSION II: ALTERNATIVES AND SOLUTIONS

Panel: Moving Forward—Integration of Genomics into Health Care

Moderator: Walter Phelps (Diné), Delegate, 23rd Navajo Nation Council

Tuba City Regional Health Care Oncology Program Planning

Lynette Bonar (Diné), M.B.A., R.N., CEO, Tuba City Regional Health Care Corporation (TCRHCC)

Ms. Lynette Bonar reiterated that the Navajo Nation has had a moratorium on genetic research since April 2002. The workshop was developed because of increasing interest in evaluating whether the moratorium should be lifted. To lift the moratorium, a Navajo Nation Human Research Code, policy and procedures, and departmental oversight are needed. How can genetic advances help tribal community members' quality of life? How can research policy changes innovate future treatment protocols for chronic diseases? Currently, oncologists send individuals' tumors for testing, but the resulting data are not received by the Navajo Nation. Any program put in place must be culturally sensitive.

Data and research about Caucasians, who may be somewhat different from a genetic point of view, should not be applied to tribal members in terms of treatment protocols. Tribal institutional review boards (IRBs) and epidemiology centers should be strengthened by sourcing their own tribal data. The Navajo Nation Epidemiology Center produced an updated *Cancer Among the Navajo* report, which is an excellent resource for the Navajo people; TCRHCC had been waiting for this report to be released so that it could finish planning an oncology center. Compared to the results of the previous report, the updated report showed an increased incidence for prostate, breast, colorectal, and kidney cancers; increased local stage diagnosis for prostate and colorectal cancers; an increased screening rate for breast and colorectal cancers; and increased mortality for stomach, kidney, and liver cancers.

It is difficult to keep up with the pace of technology. The military, private corporations, cancer registries, and other entities have been collecting DNA for many years; the Navajo Nation should request to receive data about Navajo citizens that have been collected by these organizations. The Navajo Nation has the capability to build an NCI Center for Cancer Research and should do so.

Ms. Bonar showed a clip of a documentary that shows the distance that Navajo community members must travel to receive medical treatment. More than 100 abandoned uranium mines surround the area in which TCRHCC patients live (17 of these sites are within 200 feet of an occupied residence), and the area was affected by nuclear bomb testing, but TCRHCC does not have concurrent data on how or if this is affecting individuals diagnosed with cancer. The U.S. government has recognized its responsibility for assisting the populations affected by nuclear bomb testing in Nevada, Utah, New Mexico, and Arizona. In 2016, TCRHCC treated 649 individuals with a cancer diagnoses but not for cancer. Numerous TCRHCC patients live at the highest poverty levels, and as a result, many do not receive the treatment they need. TCRHCC is working with the Centers for Medicare & Medicaid Services to address this.

Navajo citizens do not have access to cancer treatments. For example, Phoenix, Arizona, has one oncologist for every 16,512 people, and Flagstaff, Arizona, has one oncologist for every 13,733 people. The Navajo Nation, however, has zero oncologists for 156,823 people. The Navajo Nation needs its own research center. Navajo citizens drive anywhere from 2 to 8 hours one way to obtain care and treatment. The TCRHCC will act on the following recommendations: expand collaboration to turn data

into action, continue partnerships with state cancer registries, promote research that examines risk factors and causes, increase culturally appropriate education and awareness, and increase education and training for health care providers. Currently, TCRHCC has completed a feasibility study for the oncology center and credentialed its physicians. It is working with its partners and third-party payers regarding funding. The vision is for the oncology center to eventually apply to be an NCI Center for Cancer Research.

Child and Adolescent Development and Genetics

Allanceson J. Smith (Diné), M.D., Child and Adolescent Psychiatry Fellow, Langley Porter Psychiatric Institute, University of California, San Francisco

Dr. Allanceson Smith explained that he would provide a clinical perspective about genetics. He gave a brief overview of medical genetics, explaining that humans have approximately 3 billion base pairs and 21,000 genes in their nuclear genetic material. The mitochondrial genome contains 17,000 base pairs. Genotype refers to a person's genetic makeup, whereas phenotype refers to expressed traits. Copies of genes (alleles) can be dominant, recessive, incompletely dominant, or codominant, which determines how they are expressed in the phenotype. In humans, expression of traits can be sex-linked. Genomic imprinting is an epigenetic phenomenon that causes genes to be expressed preferentially depending on the parent from which it is received. Polygenic inheritance occurs when one characteristic is controlled by multiple genes, and genetic heterogeneity is when a genetic disorder may be caused by a number of different copies of alleles. Pleiotropy refers to one gene or one allele affecting different features.

Development and the environment also play roles in gene expression. Some studies compare sets of identical twins raised together or apart to determine whether certain traits are genetically or environmentally influenced. The gene-environment interaction refers to a genetic predisposition that only has risk or has a stronger risk effect in the presence of an environmental factor (e.g., phenylketonuria). Also, genetic mutations occur in each generation; the average mutation rate is 100 to 200 new mutations per generation. Not all mutations may be expressed, and some may be beneficial.

Dr. Smith described several genetic disorders. Angelman syndrome occurs from a loss of function of genes on maternal chromosome 15. A loss of function from genes on paternal chromosome 15, however, results in Prader-Willi syndrome. Down syndrome occurs in individuals with three copies of chromosome 21. One type of genetic mutation on the X chromosome is called fragile X syndrome, an X-linked dominant trait expressed when an individual has more than 200 trinucleotide repeats. Mothers with a higher than normal number of repeats but less than 200 (i.e., not a full mutation) are more likely to have children with fragile X syndrome. Klinefelter syndrome results in individuals with one extra X chromosome, whereas Turner syndrome occurs in individuals missing one X chromosome. 22q deletion syndrome, resulting from 3 million missing base pairs on chromosome 22, may be expressed several ways and therefore has several different names.

Development can be affected by exposure. For example, fetal alcohol syndrome results from *in utero* exposure to alcohol. It is the most common environmental cause of intellectual disability. More than 100 genes have been implicated in the occurrence of autism, and children with older mothers and fathers are more likely to be diagnosed with autism. Complex disorders, such as autism, may have a genetic basis and a gene-environment interaction. Neurodevelopmental disorders are a group of conditions that have an onset in the developmental period and generally manifest before a child enters grade school. The disorders are characterized by developmental defects that produce impairments of

personal, social, academic, or occupational functioning; neurodevelopmental disorders frequently co-occur.

With advancing technology, more information is available about genetic disorders, which allows better genetic counseling. Pharmacogenomics can provide guidelines about how to treat individuals and intervene early. Genetic research will provide insights about the interactions of genetics and the environment. Genetic research on the Navajo Nation could help to identify whether exposure to heavy metals affects gene disorders or increases the risk of neurodevelopmental disorders.

National Cancer MoonshotSM Initiative

Michelle Bennett, Ph.D., Director, Center for Research Strategy, Office of the Director, NCI, NIH

Dr. Michelle Bennett explained that the National Cancer MoonshotSM Initiative was launched during the 2016 State of the Union Address when then-President Barack Obama asked then-Vice President Joseph Biden to lead a new, national “moonshot” initiative to eliminate cancer. The goals of the initiative are to accelerate progress in cancer research, care, and treatment, including prevention and screening; encourage greater cooperation and collaboration; and enhance data sharing.

A Blue Ribbon Panel was convened with 27 cancer experts; these experts invited approximately 100 additional experts to participate in working groups to identify opportunities in cancer research. The working groups focused on treatment types, clinical trials, data sharing, children, and understanding the biology on a deeper level. The Blue Ribbon Panel ultimately developed 10 recommendations with strong cross-cutting themes. One important theme discussed by all working groups was health disparities research. Prevention and cancer in children were two additional important themes. One recommendation focused on precision prevention and early detection, with the goal of spurring an initiative to improve the current state of early detection, genetic testing, genetic counseling, and the knowledge landscape of the mechanisms and biological markers associated with cancer development. One important aspect of this recommendation was to use current knowledge to prevent cancer through screening, vaccination, and tobacco cessation. Another recommendation, the establishment of a “National Cancer Data Ecosystem,” aligns with the workshop discussions about data sharing. Data generated from studies should be available to anybody who is interested in learning more.

The initiative was funded in December 2016 with \$1.8 billion dedicated to the effort over 7 years; \$300 million was allotted for fiscal year 2017. The NCI has spent the last 8 months actively engaged in planning and prioritizing to implement the various recommendations. Funding opportunity announcements are being released to the community so that research efforts can be initiated to address a number of these areas. Although policy discussions were beyond the scope of the Blue Ribbon Panel, policy concerns (e.g., medical care and reimbursement for preventive services and genetic counseling, facilitating and promoting data sharing) were relayed to the Office of the Vice President.

A number of opportunities exist under the National Cancer Moonshot Initiative, including cataloging genetic variation as a cell moves from normal to cancerous, associating clinical data and exposure/lifestyle data with molecular characteristics, exploring the power of data sharing and computational biology, informing approaches to develop targeted therapies for prevention and treatment, and detecting and intervening in cancer and other disease processes earlier. Additional information and the full Blue Ribbon Panel report is available at the [Cancer Moonshot Blue Ribbon Panel website](#).

Panel Discussion

A participant asked Dr. Smith about genetic markers changing as a result of historical trauma. Dr. Smith replied that he did not have specific expertise about historical trauma, but he had read a study about Jewish offspring with ancestors who experienced the Holocaust; these children and grandchildren have increased rates of depression and anxiety, and it is thought that this is a result of epigenetic changes stemming from the ancestral trauma.

A participant asked about Dr. Smith's thoughts about environmental exposures to fracking—which releases methane, hydrogen sulfide, and other volatile organic compounds—and the possibility that resulting syndromes could be seen in future generations. Dr. Smith responded that this is a possibility, citing exposure to tobacco that affects the health of future generations. These effects will not be identified until research is performed.

A participant observed that sharing knowledge through song, ritual, narratives, drawings, symbols, and so forth is a recitation. Energy contains data, information, and knowledge. It is a two-way understanding, and humans affect the environment and vice versa. Science is exploring something that has always been there; it is a rediscovery. Dr. Smith commented that sharing experiences in psychotherapy is similar to sharing experiences with a traditional medicine man.

Non-Panel Presentations

Alaska Native People's Perspectives on Biospecimen Use in Research and Genetic Research

Vanessa Hiratsuka (Diné), Ph.D., Senior Researcher, Centers for American Indian and Alaska Native Health, Colorado School of Public Health; and Denise Dillard (Inupiaq Eskimo), Ph.D., Director, Research Department, Southcentral Foundation (SCF)

Dr. Denise Dillard explained that SCF began its efforts by discussing with community members what they wanted. As a result, the foundation developed a vision to ensure that the Native community enjoys physical, mental, emotional, and spiritual wellness. The mission is to work with the Native community to achieve wellness through health and related services. SCF established its research department in 2004. An important principle at SCF is customer ownership, and more than 50% of employees are AI/ANs. All research proposals are reviewed by a committee that includes tribal leaders, clinical leaders, and customer-owners. The research then is vetted by the Alaska Area IRB and SCF's executive committee; all committee members are AN people. More than 30 people review every potential research project. When reviewing a research project, the SCF considers how AN people are involved in the research, whether AN people are treated with respect, how AN people will benefit from the research, whether it aligns with community priorities, and how areas of sensitivity (e.g., genetics, children/elders, behavioral health issues) are handled. Researchers are required to sign a research agreement that states that the SCF maintains ownership of the data and any future use of the data.

The Alaska Tribal Health System (ATHS) is a voluntary affiliation of more than 30 Alaskan tribes and tribal organizations providing health services to AI/AN people. Each tribe or tribal health organization serves a specific geographical area, and the entire ATHS serves approximately 130,000 AI/AN people, providing comprehensive services across the entire continuum of care. Tribes and tribal organizations manage hospitals, health centers, village clinics, substance abuse treatment centers, and a biobank repository that the ATHS assumed shared ownership of in 2004.

Dr. Vanessa Hiratsuka described the biobank and its history. Biological samples have been used for research studies in Alaska for more than 60 years, and the samples have been stored in the Alaska Area Specimen Bank since 1948. Many tribal leaders began to have questions about the samples (e.g., origin, whether the donor was still living) and decided to learn more about what community members thought about the biobank and its samples. A widespread mistrust of academic and clinical research exists within the AHTS service area as a result of historical and contemporary trauma inflicted in the name of “knowledge for the greater good.” Because of the critical need to understand the concerns and priorities of AI/AN people regarding the use of pharmacogenetics in the AHTS, a study was undertaken to determine AN leaders’ and community members’ views on biobanking; the findings were published in two peer-reviewed journals.

The AHTS approached tribal health organizations to partner and guide the study in their regions, and community liaisons were hired to lead recruitment for the study. The study included 82 community members and 81 tribal leaders who participated in 29 focus group interviews in 14 locations. Data were analyzed with ATLAS.ti software using a grounded theory approach. The AN people’s views on biobanking were influenced by their past experience with research and medical care. Individuals were concerned about stigmatizations, the relevance of the samples and how they would be used, the effects of governmental and cultural change, and the unknown capability of future technologies. A common hope was that the samples would be used to benefit future generations. The study participants had clear expectations about the use of biological specimens, including extensive disclosure of results, information about the motivation and intent of researchers, details about specimen storage and destruction, and a clear and extensive process of informed consent. The AHTS also determined AN people’s views about the use of pharmacogenomics within Alaska’s tribal health care system. This research, which involved 32 community members within four focus groups, also was published in a peer-reviewed journal. Pharmacogenomics generally was endorsed for its potential benefits but also was viewed as a “double-edged sword” with the potential to both harm and heal.

Discussion

A participant asked about the policies and protections in place about genetic research using the biobank samples. Dr. Dillard responded that the SCF research does not use the stored biobank samples. Research participants provide informed consent, and potential future uses of their genetic material are discussed prior to this consent. The overarching SCF policies in place for the conduct of all research apply to genetics research; separate policies have not been developed. Dr. Dillard reiterated some of the factors that the review committees consider when reviewing potential research projects funded by SCF. Another participant asked for a copy of SCF’s policies and procedures to use as a model.

The NIH and Health Research in Tribal Nations

David R. Wilson (Diné), Ph.D., Director, Tribal Health Research Office (THRO), Division of Program Coordination, Planning, and Strategic Initiatives, Office of the Director, NIH

Dr. Wilson emphasized the need to encourage Native youth to engage in science, technology, engineering, and mathematics education. The 567 federally recognized tribes in the United States are dynamic and unique, each with its own history, traditions, language, government structure, and so forth. The NIH has a strong commitment to funding biomedical research in AI/AN communities, providing \$130 million in 2015 to more than 200 projects that support AI/AN research. The U.S. Department of Health and Human Services (HHS) Tribal Consultation Policy guides all HHS operating and staff divisions; the NIH honors this policy through the THRO, which was established in 2015. The establishment of this

office allows the NIH to create uniform approaches to engaging tribal nations around areas of research. The office works with other NIH Offices, Institutes, and Centers to support AI/AN research and is developing an AI/AN research portfolio.

The THRO supports the Tribal Advisory Committee (TAC), which provides recommendations on NIH activities in tribal communities, and the Tribal Health Research Coordinating Committee, a trans-NIH working group that includes representatives from all NIH Institutes, Centers, and Offices. The TAC soon will meet on the NIH campus to discuss data sharing and ownership. Dr. Wilson encouraged tribal members from New Mexico and Arizona to apply to serve on the committee, as these regions are underrepresented. In addition to data sharing and ownership, the TAC also is discussing genetics research, social and behavioral health factors, and outreach to Native scholars. Additional information is available on the [TAC website](#).

The THRO's strategic plan includes five pillars. The cultural competency and community engagement pillar is the core that is included in the other four pillars: enhance communication and coordination, build research capacity in tribal nations, evaluate progress, and expand research. Dr. Wilson invited the participants to provide ideas about the strategic plan by emailing their thoughts to THRO at NIHTribalCommittee@od.nih.gov. The goals of the THRO are to increase communications with tribes, develop a unified NIH approach to engaging tribal communities, and coordinate intramural AI/AN activities (e.g., recruiting and retaining AI/AN scientists). The NIH Office of Science Policy is in regular contact with the THRO on issues that affect research with tribes. The THRO engages with many stakeholders on multiple levels to ensure tribal engagement in NIH research activities.

Discussion

A participant asked how the NIH engages urban Indians and works with scholarship recipients and interns. Dr. Wilson responded that the NIH recognizes the importance of urban Indians as migration from the reservation to urban settings increases. Urban Indians are a priority of the THRO and are included in the strategic plan. When the plan is released publicly, he will be able to discuss more specifically how the office will engage the urban Indian population. The THRO works with other NIH entities to ensure that outreach to students increases awareness of opportunities for NIH support. The NIH Office of Intramural Training & Education manages these opportunities, and the THRO works with this office to align opportunities more closely with the needs of tribal communities.

A participant asked whether NIH funding is provided to universities or to tribal communities. Dr. Wilson replied that the THRO works with other NIH Offices, Institutes, and Centers to ensure that funding opportunities address tribal community needs; the ability of a community to obtain funding also is considered. The THRO also is focusing on encouraging AI/AN students to pursue biomedical careers to ultimately be able to help their communities.

A participant commented that a major concern involves data sharing and ownership, which has been an ongoing concern with the ECHO program. Even when they own the data, tribes are concerned about data storage, the process to access the data, and similar issues. She asked how the NIH plans to be respectful of tribal needs. Dr. Wilson explained that the THRO has been brainstorming extensively about the potential options for creating a data-sharing system that will be acceptable to tribal nations. Dr. Blome added that ECHO has been working on this issue, and she wondered whether the NIH is working on the data privacy issue that can be globally applied to all of its programs. Dr. Wilson replied that ECHO is serving as a model throughout the NIH, but this also presents a challenge because each

program is structured differently. The effort currently is examining what is translatable among programs and incorporating these factors into data-sharing plans that then will be shared with tribes for their input on whether they are appropriate for their needs. Dr. Blome explained that ECHO is working closely with Dr. Wilson and his office on these issues. This is the first time that the NIH is thinking about data sharing in a way that is different from the Western science paradigm. The ECHO program is trying to be flexible in accommodating tribal data-sharing needs so that it can serve as a model for other NIH programs.

A participant wondered what happens to the genetic material that remains after all research has been performed. Another participant noted that advancements in statistical analysis have not moved at the same pace as technology development. She wondered whether anyone had considered training tribal youth about how to use and analyze data.

A participant asked how the NIH as a whole is examining how to review grants to ensure that they are more inclusive of indigenous research methodologies. The NIH, as a Western science entity, does not have a clear understanding of indigenous knowledge systems. To allow innovation and positive effects in tribal communities, a balance between Western and indigenous understandings must be achieved. A global indigenous data sovereignty movement has begun, and more tribes will be calling for data sovereignty. The NIH must be ready to understand this movement and the role of federal agencies in supporting tribal data sovereignty. Dr. Wilson responded that the THRO has been discussing the grants issue with NIH's Center for Scientific Review, which reviews all grants submitted to the NIH, to develop a process that enhances reviewers' competencies regarding cultural aspects. THRO is in the strategic phase of determining how to approach these competencies. Dr. Dillard added that the SCF is proactive in the area of data sovereignty. The research agreement that researchers are required to sign stipulates data ownership, storage, and use.

Report-Out of Breakout Sessions

Each of the breakout groups summarized its discussions from the previous day.

Cancer Diagnosis, Prevention, and Treatment Needs

The group made the following recommendations regarding any potential genetic study projects carried out on the Navajo Nation:

Researchers must clearly define for study participants what tests they will use and the limitations of each test; participants must be fully aware of what they are being tested for.

Study participants must have the option to either choose the cancers for which they want to be tested or receive full genomic screening.

Study participants must be able to decide how their samples will be treated at the conclusion of the study (e.g., storage, destruction, return to participant).

Researchers and clinicians working on the study must be required to complete cultural competency training.

Study participants must have access to genetic counselors.

The study must provide local follow-up support and the opportunity to join survival groups.

The privacy of each study participant must be protected at the individual level.

Researchers must obtain tribal IRB approval for any future studies using samples.

Researchers must inform participants of available treatment options and provide any relevant animal study data.

Researchers must report back to the local communities from which they recruited.

Policy Development Needs

The group provided the following preliminary recommendations regarding policy development:

Consider how the funding sources for a research project influence the authorities or stakeholders involved with the project.

Invest more in tribal research facilities and structure.

Determine how funding stipulations affect the depositing of genomic information.

Require cultural competency training.

Determine whether penalties for individuals or groups that violate research requirements or codes will be administered.

Define noninvasive research so that an expedited process can be developed.

Learn from other tribal communities that have instituted research policies.

Cultural Perspectives to Address

The group consensus was that genetic research is important, but it is necessary to listen to the Navajo narratives. What does performing genetic research mean from the Navajo viewpoint? Knowledge is changing, and a paradigm shift is occurring. When a transformation occurs, it is important to include the traditional Navajo songs, prayers, and so forth. Another question is how to obtain the support of the general Navajo population to lift the moratorium, as well as obtain their cultural input. The Navajo people will continue to embrace their cultural values whether or not genetic research returns to the Navajo Nation. The group expressed concern about the sacredness of the human body and animals, which must be honored in the changing environment. Discussions need to be held that include Navajo spiritual concerns and the Western science perspective; the development of a glossary could facilitate the success of these discussions. The Navajo Nation Council has a fundamental law that defines cultural terms; how can this fundamental law be used in genetic research? The tribe must uphold this fundamental law within any future policies that are developed. Genetic knowledge is not a foreign concept to the Navajo people, who have had a knowledge of science for time immemorial. The Navajo people have a fundamental, cultural knowledge of genetics. A plan for implementing these Navajo philosophies must be included in all future policies.

Biomedical Ethics Needs

This group discussed informed consent and data sharing, the types of samples that would be stored, the parameters around future uses of data, and how the community will benefit from research. The group acknowledged the need to have an understanding of genetics at all levels and ensure that good governance is in place. Principal investigators must be held accountable. Research conducted on the Navajo Nation should be owned by the Navajo Nation, and the Navajo people should benefit from the research. Scientific and medical jargon and information should be translated and presented in a way that the community can understand (i.e., at a sixth-grade level). The group also discussed data ownership, access, and use and sample storage. The group thought that the Alaska example of specimen storage and informed consent could be used as a model. Individuals who can serve as a bridge between non-Native researchers and the Native community should be included in each research project.

Justice was another important concept discussed during the breakout session. If everyone benefits from research, precision medicine might not be immediately attainable. Certain technologies may not reach communities in a timely manner. The word “enrollment” should be used instead of the term “recruitment,” as it conveys a more voluntary situation. Communities with high risk may encounter situations that are unfair.

Ultimately, the group determined that to be a part of a study, study participants must understand the language of consent and the concept of the study, and their genetic information must benefit their family and community.

Tribal Nations’ Needs

This group discussed the importance of considering how addiction is affecting Navajo children. Facilities, in addition to funding, are needed to address violence and abuse. Native peoples have been conditioned to make decisions under oppressive circumstances, so it is important to include ancestral knowledge to move away from that decision-making paradigm.

Trained and educated professionals are interested in returning to their tribal communities. How can tribal nations work with the NIH to support Native thinkers to return and contribute to strengthening the sovereignty of the tribal nation? The NIH must continue to support the training of Native peoples who can return to and provide benefit for their reservations.

Tribes historically have not been asked to “sit at the table,” but they must be asked in the future. Tribes must consult community members who hold Native perspectives; Native and Western perspectives can be blended to address tribal needs.

The group also emphasized the need to respect indigenous rights. Some of the language that has been developed globally could be used to develop the Navajo Nation policy. A timeline and transparent process for lifting the moratorium must be established so that fruitful discussions about moving forward can occur. The Navajo Nation needs to develop an overarching perspective that explains why lifting the moratorium is important. The One Health Initiative, which emphasizes the interconnectedness of humans, animals, and the environment, can be used as a model.

Holding publicized public hearings, and ensuring that they are publicized, will be critical, and the Navajo Nation must determine how it can encourage Navajo citizens to attend these hearings and express their thoughts. The Navajo Nation has a cultural obligation to share, and the main question is how to share in a safe manner and incorporate this into any future policy and decision making. Ancestral knowledge must be included in the conversation to improve the health and well-being of the Navajo people.

Discussion

A participant noted that his tissue, blood, and DNA belongs to him and not to the tribe or a federal agency; he gives permission for them to be taken. The Navajo Nation has a fundamental law that honors traditional teachings and culture, and cultural perspectives must be incorporated into any future policies. A clear data-sharing policy that incorporates the traditional perspective is needed. The Navajo Nation Code, Title 1, Chapter 2 makes it clear that the fundamental law is the law of preference and supersedes all other Navajo Nation codes. A paradigm shift is occurring now, and the Navajo people must view it through the lens of traditional thinking.

Regarding the previous questions and discussion about the treatment of samples after research is completed, Ms. Becenti-Pigman explained that the Navajo Nation HRRB requires the researcher to include in the research plan how the samples will be stored or disposed of, including the option of returning samples to the study participants at their request. Any equipment bought for a study with federal funds is given to Navajo Nation chapters when the study is completed. Tribal nations have their own tribal laws because they are sovereign. For example, the Navajo Nation has its own privacy act beyond the federal Health Insurance Portability and Accountability Act of 1996 that researchers must follow.

A participant noted that this workshop is about developing a set of ideas that will help the Navajo Nation participate in genetic research. These ideas must be put in action within the Navajo Nation and not merely discussed. The participants can bring to the Navajo Nation a unified vision of how research should be performed on the reservation.

The participants were asked to consider what a reasonable timeline would be for lifting the moratorium.

President Begaye explained that public hearings are being scheduled throughout the reservation about lifting the moratorium and defining a policy. Following these hearings, a policy will be developed based on the information received at the hearings, and then the legislation will be written. The Navajo Nation HRRB current policy may be amended, and other existing policies will be used as models. Four council sessions occur each year, in January, April, July, and October. The goal is to lift the moratorium during the October session.

In terms of building capacity and encouraging Native scientists, scholarships are in place at various universities. A Navajo funding source recently has been established to build additional health care facilities and hire additional medical professionals. The paradigm has changed so that the Navajo Nation is beginning to develop its own health care system instead of relying on outside support. President Begaye encouraged anyone interested to become a tribal advisor to the NIH, as an opening currently exists.

Ms. Yazzie emphasized the need to hold public hearings in more locations on the reservation to ensure that all citizens who want to participate are able to without having to travel long distances.

Discussion and Next Steps

Moderator: Walter Phelps (Diné), Delegate, 23rd Navajo Nation Council

Delegate Phelps explained that a roadmap toward lifting the moratorium was developed, and this workshop is part of that roadmap. Cultural and spiritual considerations also were included in the roadmap.

Dr. Garrison reported that the Navajo Nation HRRB had approved a proposal to interview Navajo citizens about their thoughts on genetics. The interviews will be 1 hour in length and include the following questions: What do you understand about genetics? What are your concerns about genetics? If the moratorium is lifted, what would you like to see in the new policy? What cultural considerations need to be addressed? Drs. Lefthand-Begay and Claw will be assisting with the interviews, which will include a diverse population of Navajo citizens. Those interested in the research project can contact Dr. Garrison at nanibaa@uw.edu.

A participant has been working with Native researchers at the Mayo Clinic to improve data about AI/AN populations. The Canadian equivalent of the NIH has an institute devoted to aboriginal health research (Canadian Institutes of Health Research Institute of Aboriginal Peoples' Health), which has established an "OCAP" policy around data that addresses ownership, control, access, and possession. This could be another source for the Navajo Nation when developing policy. The AI/AN Initiative on Cancer sponsors an annual meeting to discuss various aspects of cancer in Native communities, including research, policy, and working with Native populations. The next meeting is being held September 21–24, in Niagara Falls, New York.

A participant explained that the Arizona Board of Regents established a tribal consultation policy (Policy 1-118). The policy is a working document, and changes can be made as necessary. The policy took 8 years to develop to ensure that sufficient tribal input was included. It has been a guiding document for university researchers at Arizona's public universities engaging in research with tribal communities. The government-to-government relationship with tribes is presented at the beginning of the document. Several universities in Arizona provide annual training about engaging in research with tribal communities.

A participant reiterated that existing policies could be used as models for the Navajo Nation's policy.

Delegate Phelps asked the participants if they would like another workshop like this one; they did. He explained that the Navajo Nation HRRB is traveling to Bethesda, Maryland, to present at the NIH on September 14–15; participants were invited to attend in person or watch the proceedings that will be webcast. The Navajo Nation HRRB is holding its annual Navajo Research Conference October 18–19, at the Navajo Nation Museum in Window Rock, Arizona. The Navajo Nation HRRB meets monthly in addition to holding the annual conference.

Ms. Becenti-Pigman expressed her pride in Navajo scientists and researchers. She also thanked the NIH personnel for attending the workshop. A participant added that the passion of the Navajo Nation Health, Education, and Human Services Committee members is apparent in that they all were in attendance at the workshop along with supporting staff members.

A participant reminded the Navajo Nation that any policy that it implements will affect other tribes. She asked the delegates to remember this as they move forward; they have an opportunity to make a significant, positive change.

A participant from the NIH reiterated that the NIH is eager to work with the Navajo Nation to assist in lifting the moratorium and building research capacity.

Dr. John commented that the investment that the Navajo Nation is making in medical school and scholarships provides a great opportunity, but it is important to think about training Native veterinarians in addition to medical doctors. Many veterinarians are interested in performing research and will partner with medical doctors under the One Health Initiative. The Navajo Nation must think progressively and provide opportunities for veterinary scholarships.

Delegate Phelps led the closing blessing and adjourned the meeting.

Tribal Data Sharing and Genetics Policy Development Workshop
University of New Mexico Comprehensive Cancer Center
Albuquerque, NM

August 31 – September 1, 2017

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