

Summary of Genetic Research Summit 2025



Voices of the Diné:

Bridging Science, Culture, and Community in Genetic Research Summit

May 29-30, 2025—Northern Arizona University, Flagstaff AZ

Disclosures

The Summit was educational and does not represent the political and any other views of the presenters, attendees, or any delegation of the Navajo Nation or other tribal entities.

The content and discussions at this event were solely the responsibility of the organizers and attendees and does not necessarily represent the official views of the National Institutes of Health or National Science Foundation.

This event was not sponsored by the Navajo Nation or the Navajo Nation Genetics Policy Development Working Group.

For this Summit Summary, authors tried to accurately and appropriately summarize the presentations, and we invited Speakers to review, provide feedback, and provide edits on their session summaries. Any errors are ultimately the responsibility of this Summary's authors. To note any questions or concerns, please email katrina.claw@cuanschutz.edu.

Our Sponsors

We thank our funders and sponsors for making this event possible!

T'áá íiyisí Ahéhee' (thank you very much).



National Institute of General Medical Sciences and National Human Genome Research
Institute

S06GM142121 (Co-PIs: Katrina Claw and Nanibaa' Garrison)

Title: Navajo Genetic Toolkit: A Culturally Tailored Guide for Engagement and Oversight
of Genetic Research



Navajo Native American Research Centers for Health (NARCH)



National Human Genome Research Institute

R13HG014112 (PI: Katrina Claw)

Title: Informing the Navajo Public about Genetic Research and Policy



National Science Foundation
Alan T. Waterman Award (PI: Katrina Claw)



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Jani Ingram, PhD
Partnership for Native American Cancer Prevention (NACP)

Summit Overview

The Voices of the Diné: Bridging Science, Culture, and Community in Genetic Research Summit was held on May 29 and May 30, 2025 in Flagstaff AZ at Northern Arizona University (NAU).

The Summit's goal was to increase understanding and awareness around genetics and genomics, focusing on future possibilities for Diné and Indigenous peoples across the nation to engage in discussions about genetics. The Summit was educational, and was open to a mixed audience of academics, scientists, policymakers, Tribal leaders, trainees, and the Navajo and Indigenous community more broadly. Summit presentations were tailored for a general audience to keep everyone engaged in learning and joining the conversations, regardless of pre-existing genetics knowledge.

The Summit featured both main presentation sessions and concurrent platform sessions on both days. The concurrent platform sessions featured presentations running in four separate rooms simultaneously, selected from a group of submitted presentations and invited speakers. These presentations were on a range of topics but were united by the common theme of genetics and education, with all presentations expected to speak to culturally-informed and/or community-involved research.

An estimated total of 142 people attended the Summit in-person, out of 189 registrations. Virtual attendance fluctuated throughout the event, with a low of 15 and a high of 40. On average, an estimate of 35 people attended virtually. To increase reach and accessibility for in-person attendance, organizers provided travel scholarships for community members and trainees. In addition, travel support and honoraria were offered to all invited speakers. The organizing committee supported travel and lodging for:

- 17 community members (16 Navajo, 1 from a different Tribal Nation)
- 12 trainees (11 Navajo, 1 from a different Tribal Nation; 4 Undergraduate, 6 Graduate, and 2 early-career professionals)
- 46 speakers

There were a total of 50 speakers during the event; 40 of the speakers were Navajo and 10 were non-Navajo (including 1 from a different Tribal Nation).

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Summit Presentation Summaries

Wednesday May 28, 2025

Pre-Summit Trainee Workshop

Speakers:

Katrina Claw, Ph.D., University of Colorado Anschutz

Carmenlita Chief, MPH, Kauffman and Associates, Inc.

Darold Joseph, Ph.D., Northern Arizona University

Tanya Riggs, Director of Oncology Services, Tuba City Regional Health Care Corporation

Jani Ingram, Ph.D., Northern Arizona University

Naomi Lee, Ph.D., Northern Arizona University

Moderator: Ursula Knoki-Wilson, MPH, Community Relations Liaison Officer at Chinle Service Unit, Navajo Area Indian Health Service

As part of the Summit's commitment to education and enhancing the experience of early career scientists, there was a pre-Summit Trainee Workshop on May 28, 2025. The Workshop included 12 students and early career professionals that applied and were approved for the Summit's Trainee/Student Travel Scholarships, which covered the cost of travel and lodging for the full Summit as well as for the Trainee Workshop. Rather than speaking on topics that would be covered during the Summit itself, the Workshop was an opportunity for professional development and networking. The event was opened with a prayer and welcome from moderator Ms. Ursula Knoki-Wilson. Dr. Katrina Claw then welcomed the trainees. The first session was *Learning Conversations with Students*, led by Dr. Darold Joseph and Tanya Riggs. After this, Carmenlita Chief led *Conference 101: How to Enjoy and Thrive at a Professional Conference*. Finally, there was a *Speed Networking* session led by Drs. Jani Ingram and Naomi Lee, where trainees met with invited scholars to broaden their professional networks.

Thursday May 29, 2025

Invocation

Perry Charley, Emeritus Professor, Diné College

Mr. Charley greeted the audience and gave a brief introduction in Navajo and English. He is a retired science professor from Diné College and an ordained minister. Mr. Charley asked the audience to join him in paying homage to the Lord in Navajo and English. The prayer began in Navajo, then transitioned to English. In English, he began by saying that today is a day for coming together as one mind, one body, one spirit and is a day for rejoicing. He continued by emphasizing that the day will be focused on attempting to bridge the gap between Navajo and Western cultures to come together as a community on policies and regulations related to science and research on the Navajo Reservation. He asked the Lord to share with us His understanding and wisdom. He gave a reminder that we are all humans. We all start as infants and develop through life guided by our parents, become adolescents, then adults, we age, and eventually go to the city of God. Elders share their knowledge and intellect with the young charges. He asked God for guidance, 'so we may continue to travel the lifeway of our journey as Navajos'. He concluded by thanking Jesus and ending the prayer.

Welcome Remarks

Jason Wilder, Ph.D., Vice President of Research, Northern Arizona University

Ann Marie Chischilly, J.D., Vice President of Native Initiatives, Northern Arizona University

Hon. Helena Begay, Navajo Nation Council Delegate

Dr. Ingram thanked Mr. Charley for leading the invocation and introduced Dr. Jason Wilder, the Vice President for Research at Northern Arizona University (NAU). Dr. Wilder expressed that it was a tremendous honor to host the Summit and thanked the audience, Dr. Claw, and Dr. Ingram. He finished by reflecting on the Native American Cancer Partnership with Dr. Ingram, which has enabled NAU to forge strong connections with Native communities in the Southwest and has aided them in training many students that are now heavily involved in research.

Dr. Ingram introduced Ann Marie Chischilly, the Vice President of the Office of Native American and Indigenous Advancement at NAU. Ms. Chischilly introduced herself in Navajo and English and welcomed everyone on behalf of NAU President Cruz Rivera. She then read NAU's Land

Acknowledgement. She reflected on her time with NAU and how she has been working collaboratively with campus leadership to decolonize NAU, doing so carefully and with the help of many advisors. She explained that they train students, researchers, and staff on the importance of Tribal consultation and following Tribal policies. She then addressed the students in the audience and told them that this work is important in making space for them to represent themselves as Indigenous individuals in academic spaces going forward.

Dr. Claw introduced Honorable Delegate Helena Begay. Delegate Begay expressed that she was fond of the idea of the Summit, stating that the focus on bringing culture back into community is needed both in the Navajo Nation and in other Tribal Nations. Her focus was primarily on Navajo youth in her remarks, explaining that it is important to teach Navajo traditions to the younger generations and involve them in the conversations being had around genetics and research. She invited the Summit team to report to the Health, Education & Human Services (HEHS) Committee. She introduced herself and her clans in Navajo and English.

Charge for the Summit

Katrina Claw, Ph.D., University of Colorado Anschutz

Jani Ingram, Ph.D., Northern Arizona University

Dr. Ingram thanked Delegate Begay and then began with a short summary of the history of the Genetics Policy Working Group. The group first convened in 2017 with the aim of discussing the genetic research moratorium, guided by a desire to rethink the moratorium as community members, scientists, and even students. Dr. Ingram then provided the charge of the Summit, which is to learn more about genetics and about the potential genetic research policy, not to simply declare that the moratorium should be lifted. She encouraged attendees to listen attentively and to ask questions of the presenters so that they can enjoy this educational opportunity to the fullest.

Dr. Claw then provided a history of how this event came to be. She described the research that she and Dr. Garrison had done, a key finding of which was that community members wanted more education on genetics. She thanked the Navajo Native American Research Centers for Health (NARCH) program for inviting them to submit a pilot research grant, with which the research team developed a number of educational products. These products included the

Summit itself, the Glossary of Genomic Terminology in the Navajo Language, digital story videos, and a cultural framework that was still in development. She thanked the National Human Genome Research Institute for funding both the NARCH pilot grant and an additional conference grant that was used for the Summit. She described the 17 community travel scholarships, which supported community members that wanted to attend the conference, as well as the 13 scholarships that supported trainees and students who attended. She then thanked the Organizing Committee members, the logistics team, her lab members, and the individuals at NAU that helped make the event happen. She also thanked the artists that created the Summit program, the lanyards provided at registration, the art for the Summit, and the tote bags that attendees received.

Keynote Address

Nanibaa' Garrison, Ph.D., University of California, Los Angeles

“Insights and Perspectives on Genetic Research with Navajo Nation and Indigenous Communities”

Dr. Garrison began her address with a Navajo introduction and acknowledged the Gabrielino/Tongva people of Tovaangar, where most of her work was conducted at UCLA. She described what it means to think about genetics, and how it relates to where we come from and our relations to each other. She provided this in the context of Navajo social and cultural customs of clanship introductions, starting with matrilineal connections. The genetic history of corn was used as an example due to its ancestral connection to the teosinte plant and the genetic selection for desired traits that are used by Navajo people today. In addition, she identified the Navajo Churro Sheep as another example of genetic traits that are selected for weaving and tapestry making—examples that are genetics, but we may not think of as genetics.

Dr. Garrison shared her early motivation to investigate genetic research questions that looked at human pigmentation and variations of skin, hair, and eye color features from around the world. Her work later considered the impact to Indigenous people and concerns about representation, following the Havasupai lawsuit (2004) on the misuse of genetic samples. This led to questions and considerations about the hesitancy for participation in genetic studies from Indigenous tribes: how many outside researchers approached research questions in problematic and stigmatizing ways. Dr. Garrison explained how indigenous participation and representation in genetics research is very small and has been staying small over time, due to the research

abuses in the past, a variety of other concerns about how data is used, and how communities may have other health, social, or economic research priorities.

Dr. Garrison talked more specifically about her research with indigenous community members and how people consistently brought up the importance of building relationships and improving transparency in research. Other major priorities from community members included understanding each community and Tribe as unique, so their specific needs are considered. Bringing in research from other countries and other Tribes, she has also explored how different Nations and Tribes develop their own genetic research policies.

Focusing on the Navajo Nation, Dr. Garrison talked about the Perspectives on Genetics in the Navajo Nation project and its research questions: How did the moratorium come to be? Why is now the time to reexamine the moratorium and genetic research? What are some Navajo perspectives on genetics? As part of this project, Dr. Garrison and colleagues used surveys, interviews, and deliberation discussions to learn more about Navajo people's perspectives, gather recommendations, and are using this data to help inform Navajo leaders, policy development makers, and the general community about genetics and genetic research. The Summit event is an important part of this project and Dr. Garrison prefaced some of the related research that would be presented during the Summit, such as the Genetics Glossary, the Digital Stories, and other educational sessions on genetics research.

What is the Navajo Nation's Research Review Process?

Sonya Shin, M.D., Chair of the Navajo Nation Human Research Review Board

Del Yazzie, MPH, Member of the Navajo Nation Human Research Review Board

Dr. Sonya Shin opened the presentation with a series of chemistry puns that were well-received by the audience. After warming up the crowd, she then introduced the purpose of the Navajo Nation Human Research Review Board (NNHRRB), which is to support Indigenous people and researchers and build collaborative partnerships to ensure that research is transparent and benefits the Navajo community. Dr. Shin walked through the full mission statement of the NNHRRB, as well as a timeline of its formation. Dr. Shin asked the NNHRRB members present in the audience to rise and be recognized, giving special recognition to Mr. Mike Winney for his work as IRB Administrator.

Dr. Shin explained and outlined the strengths of the NNHRRB. She described how the NNHRRB is recognized as a leader of tribal IRBs both nationally and internationally with its dedicated volunteer board members, established relationship with academic institutions, data sovereignty practices, and the bi-annual NNHRRB Research Conference in Window Rock, AZ. She went on to describe the requirements and best practices for submitting research to the NNHRRB. For new studies, the “big three” requirements for approval are evidence of community partnerships, support letters, and permissions/resolutions relating to the proposed research. She reminded researchers in the audience that they will need to go through the IRB at their academic institution as well as the NNHRRB, so it’s vitally important to understand what each IRB requires and how to fit that into the timing of their research activities. She closed her portion of the presentation by reminding researchers that Navajo co-investigators should have opportunities to present at conferences and be included as co-authors to ensure they are getting proper credit for their work.

Dr. Sin introduced Mr. Del Yazzie. Mr. Yazzie went over his own personal background with uranium mining within his community and how that influenced his role as a NNHRRB member. He reviewed the demographics of who is conducting research supervised by the NNHRRB and said that there has been an increase in Navajo students submitting their own research proposals. Mr. Yazzie finished the presentation by providing an overview of what the NNHRRB would like to do going forward. He promoted an open Research Director job, described efforts to update the NNHRRB Research Code, discussed potential Expedited/Exempt categories for studies that have lower risk and require less oversight, and linked the presentation back to the Summit’s larger goal of prompting discussion around a potential Navajo Nation Genetic Research Policy.

Audience comments included concerns about the strain on NNHRRB members that may arise with the sudden influx of proposals if the moratorium is lifted, questions about what training might be needed for NNHRRB members to review proposals related to genetics, and worries about any potential fees that the NNHRRB might charge could be detrimental to early-career Indigenous scientists. Additionally, an audience member expressed frustration that Indigenous groups are forced to pay for interventions that are developed from work done within their own communities.

The panel members responded to these concerns with information on how the NNHRRB prioritizes research. The panelists commented that the NNHRRB prioritizes the importance of ensuring that results of the research are shared equitably in the community.

Navajo Nation Policy and Genomic Research

Hon. Carl Slater, Navajo Nation Council Delegate

Delegate Carl Slater addressed the Navajo Nation's ongoing work on a genetics research policy, stressing sovereignty, cultural integrity, and protection from exploitation. He traced the history of the 2002 moratorium on genetic research; how it was a response to community concerns, lack of safeguards, and ethical risks. While the moratorium protected Navajo people and set a leadership example for other tribes, most community members remain unaware of it. In 2018, a Genetics Policy Working Group was created to begin developing a comprehensive policy, and in 2024 legislation reestablished and clarified the group's mandate. Its work now includes multidisciplinary members—health experts, researchers, legal scholars, traditional knowledge holders, and community representatives—tasked with drafting code, setting culturally grounded standards, and ensuring data sovereignty.

Delegate Slater emphasized that genetics governance extends beyond human DNA. It also includes plants, animals, and ecosystems, where issues like biopiracy of traditional medicines pose urgent threats. He framed the policy effort as both local and global: the Navajo Nation must protect its people while engaging in international debates on intellectual property and Indigenous rights. Enforcement, compliance, and alignment with federal grants will be key. Slater suggested a tiered, cautious approach, starting with human protection while recognizing the parallel need to guard non-human relatives. He also highlighted the importance of educating future leaders, maintaining traditional consultation, and ensuring policies evolve as technology advances.

Community voices highlighted the need for inclusion, transparency, and inclusion of rural members, stressing that policy must not only protect DNA but also honor prayers, ceremonies, and obligations to future generations. Overall, the session affirmed that genetics policy is not merely technical but an exercise of sovereignty—shaping research to serve Navajo values, protect sacred knowledge, and benefit coming generations.

Moratorium on Genetic Research HSSCAP-20-02

RESOLUTION OF THE HEALTH AND SOCIAL SERVICES COMMITTEE OF THE NAVAJO NATION COUNCIL

Approving 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 by the Navajo Nation Council

WHEREAS:

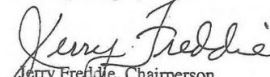
1. Pursuant to 2 N.N.C. §§451 and 454(B)(8), the Health and Social Services Committee of the Navajo Nation Council is established with oversight authority over the Division of Health and the Division of Social Services; and
2. Pursuant to 2 N.N.C. §454(B)(6), the Health and Social Services Committee of the Navajo Nation Council is authorized to recommend legislation relating to health, environmental health and social services; and
3. On October 10, 1995, the Health and Social Services Committee of the Navajo Nation Council by Resolution HSSCO-108-95 and on October 25, 1995, the Navajo Nation Council by Resolution CO-106-95, approved the Navajo Nation Health Research Code. Resolutions HSSCO-108-95 and CO-106-95 are attached hereto as Exhibit "A"; and
4. In August 2001, the Health and Social Services Committee of the Navajo Nation Council and the Navajo Nation Health Research Review Board held a joint work session in which the Committee directed the Review Board not to consider any investigations, research or studies regarding genetics; and
5. The Health and Social Services Committee of the Navajo Nation Council further directed the Navajo Nation Health Research Review Board to develop educational materials to inform the Navajo public through media and public forums prior to developing the Navajo Nation policy on genetic studies; and
6. The Navajo Nation Health Research Review Board agrees with and supports the Health and Social Services Committee of the Navajo Nation Council to impose a moratorium to genetic research and study. The Navajo Nation Health Research Review Board is coordinating with the Navajo Division of Health Office of Planning, research and Evaluation, the amendment of the Navajo Nation Health Research Code, including genetic research related protocols.

NOW THEREFORE BE IT RESOLVED THAT:

The Health and Social Services Committee of the Navajo Nation Council hereby approves a moratorium on genetic investigations, research or studies that are conducted within the Navajo Nation until such time that a Navajo Nation Health Research Code has been amended and approved by the Navajo Nation Council.

CERTIFICATION

I hereby certify that the foregoing resolution was duly considered by the Health and Social Services Committee of the Navajo Nation Council at a duly called meeting at Montezuma Creek, Navajo Nation (Utah), at which a quorum was present and that same was passed by a vote of 6 in favor, 0 opposed and 0 abstained, this 2nd day of April, 2002.


Jerry Freddie, Chairperson
Health and Social Services Committee

Motion: Annie Descheny
Second: Harry Hubbard



Lunch Session: Preview of Digital Stories

Tonesha Yazzie, BS, Northern Arizona University

Luke Nez, BS, University of California, Los Angeles

Tonesha Yazzie, one of the creators and developers of the Digital Story videos, introduced and shared more about the Digital Stories project. The Digital Stories are available online here and were created by Dr. Jiun-Yi Tsai and Tonesha Yazzie:

<https://www.voicesofdinesummit.com/digitalstories>. Surveys were also conducted by Luke Nez, to gather feedback about the Digital Stories.

Panel: Rare Genetic Diseases Affecting the Navajo People

Panel Members:

Anna Joe, Navajo community member

Lacy Tsingine, Navajo community member

Diana Hu, M.D., FAAP, Tuba City Regional Health Care Corporation

Jennifer Puck, M.D., Professor of Pediatrics, University of California San Francisco

Moderator: Mae-Gilene Begay, MSW, Member of Navajo Nation Human Research Review Board

Anna Joe shared her experience raising two children with retinitis pigmentosa who became progressively blind—moving from “why?” to “how?” as she navigated school services, bullying, mobility training, and independence, underscoring the need for plain-language education and support even when no cure exists. She also discussed the ways in which her children’s diagnoses were seen as a result of her breaking a taboo, which was an isolating experience as she raised her children. She discussed a mix of traditional ceremonies and Western physicians, none of which succeeded in halting the progression of the disease. She expressed that she is supportive of genetic research because it may one day result in treatments or cures for individuals like her children, and those treatments may help future individuals avoid the barriers and discrimination that she and her family have faced.

Lacy Tsingine honored her daughter Gracie Skai, who lived 51 months with Navajo neuro-hepatopathy (MPV17), describing intentional, love-first caregiving, close partnership with clinicians, and her advocacy to raise awareness for other Navajo families who may face the diagnosis alone.

Pediatrician Dr. Diana Hu outlined why modern clinical genetics changes care: several rare conditions are more frequent in Navajo communities (e.g., severe combined immunodeficiency (SCID), microvillus inclusion disease, Navajo neurohepatopathy, Athabascan Brain Stem dysgenesis, metachromatic leukodystrophy), and timely diagnosis improves outcomes. She reviewed autosomal-recessive inheritance, explained non-determinism (same genotype, but different clinical course), and discussed the ethics around data ownership, and stigma.

Dr. Jennifer Puck traced advances in SCID from population-wide newborn screening of dried blood spots, adopted early by the Navajo Nation after participation in a Navajo IRB-approved research study to improved and cutting-edge new therapies. Early detection of SCID saves lives; Artemis-SCID, which is common in Navajo people, can be treated with low-dose conditioning plus autologous gene therapy, with all children achieving T-cell immunity and most discontinuing antibody infusions.

Across talks, themes were consistent: pair culturally respectful, community-guided policy with access to screening, counseling, and a full range of treatments; keep the family voice at the center; and ensure sovereignty, transparency, and benefits that improve Navajo children's health.

Audience feedback included expressions of appreciation for the stories that were told, individuals sharing their own experience with childhood illness and a mix of traditional treatment and Western science, and comments about a mother's actions during pregnancy impacting the baby's development. Remote attendees asked additional questions regarding whether or not the testing that was discussed is standard and at what age it should be done, to which Dr. Hu explained that screening for certain conditions is done at birth, while diagnosis of other conditions is based off of symptoms rather than applied to all. A discussion was also had regarding traditional herbs being included in treatments, to which Dr. Puck responded that there is still a lot to learn about the application of herbs. A final commentator was surprised by the moratorium on genetic research in the Navajo Nation and believes that more discussion must be held regarding the balance of traditional medicine and Western science.

Concurrent Platform Sessions 1

Panel: Advancing Cancer Health Equity Through Research

Panel Members:

Dornell Pete, Ph.D., MPH, Assistant Professor, Epidemiology Program, Fred Hutchinson Cancer Center

Jani Ingram, Ph.D., Regents' Professor of Chemistry & Biochemistry, Northern Arizona University

Monica Yellowhair, Ph.D., Assistant Director of Community Outreach and Engagement, University of Arizona Cancer Center

Moderator: Jalissa Ingram, MA, Program Coordinator, Alaska Native Tribal Health Consortium

“Slaying the Monster: Addressing Uranium Impacts on Health” — Dr. Monica Yellowhair

Dr. Yellowhair began her presentation by discussing the Oppenheimer movie, which provides a historical context for the race to build the atomic bomb. However, she noted that the film fails to address the untold story of the bomb's aftermath and its ongoing effects on people today. The construction of the atomic bomb generated significant waste, much of which remains at the sites where uranium was extracted. Many of these locations are ancestral homelands for tribes in the Southwest and New Mexico.

She provided background information on uranium and its legacy in the Southwest. This region has a substantial natural uranium deposit. In the past, uranium miners lacked the necessary personal protective equipment (PPE), leading to a high incidence of lung cancer and dangerous exposure to radon among the workers. After the Cold War, the United States no longer required the uranium mines, leaving them abandoned. As a result, these abandoned sites have contaminated several water sources. Additionally, local residents have been known to use mine materials for constructing their hogans. There are areas where mine waste remains, with people and livestock living in close proximity.

The Navajo Nation Epidemiology Center reported that between 2014 and 2018, individuals on the Navajo Nation experienced higher rates of certain cancers—including uterine, kidney, stomach, and liver cancers—compared to non-Hispanic whites living in the same area. Dr. Yellowhair raised the question of why Navajos are experiencing these types of cancer at higher rates than non-Hispanic whites in the same region. Her research focuses on the genotoxic

effects of uranium. Depending on the level of exposure, uranium has been shown to cause chromosomal aberrations, micronuclei formation, sister chromatid exchanges, and DNA damage. The body has sensors that continuously detect DNA damage, which is a natural response. Overall, her talk highlighted the impacts on the Navajo Nation and the greater Southwest region.

“The Partnership for Native American Cancer Prevention” — Dr. Jani Ingram

Dr. Ingram began by acknowledging the passing of her counterpart at the University of Arizona, Dr. Francine Gachupin. She then explained that the Partnership for Native American Cancer Prevention, or NACP, is a partnership funded by the National Cancer Institute. They began their partnership in 2002. Their goals are to reduce the cancer burden in Native American populations through research and community engagement, and to increase the number of Native American investigators working in cancer research. They are strategically placed at NAU to serve northern tribes and at the University of Arizona to serve the southern tribes. There are specific cancers related to concerns from different communities, and NACP partners with those communities to build research that can really address those concerns. They try to advocate for culturally appropriate interactions and provide education about cancer.

They also aim to help early-stage investigators become successful in Cancer Research. Their research education is really focused on students. They have worked with many students over the 20+ years of NACP. Many students go on to get degrees at higher levels: physicians, clinical settings, biomedical industries, science education, and tribal leadership roles. They also have a community advisory board. The community engagement that the partnership has become one of the strengths. As a result, research projects focused on *H.pylori* found that stomach cancer is much higher in Navajo people. For outreach, they have done many tabling events, which were restructured because of COVID-19, as well as podcasts and Indigenous cancer webinars. One example webinar was on the Navajo Nation Breast and Cervical Cancer Program, and the webinars were widely watched from all over the United States. The program lost funding (August 2025) but hopes to continue through other funding opportunities.

“Path for Microbiome Research in the Navajo Nation: Helicobacter pylori, Gut Microbiota, and Stomach Cancer” — Dr. Dornell Pete

Dr. Pete’s lived experiences motivated her to make a positive impact on the health of tribal people in cancer research. Previously, she worked as an epidemiologist in the Southwest and on the Navajo Nation, where access to cancer data was important, and tried to align cancer data with cancer experiences and patterns in the community. Stomach cancer rates are much higher among the Navajo Nation, but also across the American Indian and Alaska Native population. There is a low survival rate for stomach cancer (15-30%) in Native populations and it’s usually in the late stage and among the younger population. Stomach cancer is the 6th most common cancer in Navajo Nation and it’s the fourth leading cause of cancer death in Navajo Nation (over 4 times the rate compared to other AZ and NM white populations).

Cancer is a multifactorial disease. Infection with the bacteria *Helicobacter pylori* (*H. pylori*) is the leading risk factor for stomach cancer. Infection with *H. pylori* most often occurs in childhood, and they will have this infection as they go into adulthood. 75% of Alaska Native people and 55% of Plains Natives have this infection, but there isn’t good prevalence data for other areas. This led to her initiation of the Navajo ABID (Navajo word for stomach) study, started during her Ph.D., and using community engaged research. This is a cross-sectional study where she asked tribal adult community members to submit stool samples and do a food frequency questionnaire and a health questionnaire. Among the 104 people who were included, 57% of our study participants had *H. pylori* infection. Of those, 80% had more virulent strains of *H. pylori*. This led to the question of what is going on with our gut microbial community? The gut microbial community is the microbes in the gut system, including the stomach, intestines and colon. The Navajo ABID II study goal was to characterize the gut microbiota in *H. pylori*-infected and non-infected individuals. Dr. Pete’s team found differences in the organisms in infected and non-infected individuals, with *H. pylori*-infected individuals having an abundance of *Faecalibacterium*, *Prevotella*, and *Bacteroides* compared to *Blautia* and *Subdoligranulum* found in non-infected individuals. Guiding values of this project include tribal sovereignty, self-determination, equity, traditional knowledge, best practices, and data stewardship.

Audience questions prompted Dr. Pete is to share about a new intervention (being designed to hopefully use in the next five years) to focus on families and education and there was a discussion of provider education as another opportunity, given a high prevalence of *H. pylori*.

Physician and Health System Perspectives

Panel Members:

Jonathan Credo, M.D., Ph.D., Internal Medicine & Psychiatry Resident and Research Affiliate,
UC Davis Health System Department of Internal Medicine, & Northern Arizona University
Department of Chemistry and Biochemistry

Amanda Burrage, M.D., MPH, Tuba City Regional Health Care Corporation

Laura Schepens, FNP, Public Health Clinic, Tuba City Regional Health Care Corporation

Abbie Willeto, MA, Alaska Native Tribal Health Consortium

Moderator: Ursula Knoki-Wilson, MPH, Community Relations, Indian Health Services

“The Road Taken - Perspective Care Barriers for Tribal Patients from Contrasting Research and Clinical Experiences” — Dr. Jonathan Credo

Dr. Credo introduced himself and his research, including an overview of how he has worked with Dr. Jani Ingram for around 15 years, including working with Indigenous, rural people in the Southwest and then in the Western and Midwestern United States as well. Along with research, he is interested in the clinical side of healthcare and helping remove barriers to care. Credo, which is how he identified himself (as opposed to “Dr. Credo”) talked about the inconsistencies in how the specific needs of tribes and Indigenous people are not well understood, and how this can lead to confusion in health research and in clinics. He used an example of how it is detrimental to identify yourself as a Native American in some urban health clinics in California, because that limits the services that would be available to a patient. Credo emphasized the importance of informed consent in clinical settings when patients are experiencing a lot of stress, and how important it is for communities to have full control over their health data.

“Public Health Approach to Familial Hypercholesterolemia on Navajo Nation” — Dr. Amanda Burrage

The presentation focused on explaining low-density lipoprotein (LDL) cholesterol, talking about Familial hypercholesterolemia (FH) and going into detail about the Tuba City public health approach to dealing with FH. Laura Schepens provided an overview of the Navajo Nation healthcare system and how Tuba City Regional Health Care Corporation is a Tribal Hospital seeing patients from all over, including Hopi and Kayenta. Laura also explained how LDL is the focus for the presentation and, as the “bad” type of cholesterol, LDL can create a plaque (or a

sludge) inside arteries that can cause injury, stroke, or heart attack. FH is a genetic disorder causing dangerously high levels of LDL. With FH, the body has a hard time clearing out LDL because of a gene mutation and will need to be on medication to help manage LDL levels, even with good diet and exercise. If untreated, men with FH have a 50% chance of heart attack before age 50 and women with FH have a 30% chance of heart attack before age 60.

Dr. Burrage shared how FH can get passed down in families, and how a more intense version of FH (homozygous) may impact their patients at a rate 2-4 times greater than United States averages. Barriers to FH treatment include providers not making the diagnosis as well as the amount of patient follow up needed to treat FH. In the last 15 months, they started new public health approach for reaching out to and focusing support on patients who had a high LDL level. Of 242 patients with an LDL over 200, 49 patients have opted in to genetic testing; 36 tested positive for FH gene so far. The public health approach is purely a clinical approach and is not research. Samples were obtained for clinical purposes for individual patients, with their informed consent around any optional genetic testing. The goal of this public health approach is to understand the prevalence of FH and to increase adherence to medication to prevent the negative health outcomes. They also suggest coming to see them if you're near Tuba City clinic to get your cholesterol checked at the Public Health Clinic (walk-ins available).

“Co-Management of a Biorepository” — Abbie Willetto

Abbie Willetto manages the Alaska Native Tribal Health Consortium (ANTHC) Pathology Specimen Archive and the ANTHC research review process. She shared her family background and educational experiences, including studying at NAU for her bachelor's and master's degrees. She explained the history of the Alaska Area Specimen Bank, and how it was created as a Tribal-Federal partnership for health research. Ms. Willetto shared about how samples were collected in the past (1958-1973) under direction of the Arctic Health Research Center. When this Center was defunded in 1973, specimens were moved to Anchorage, Alaska and housed at what is now the Center for Disease Control and Prevention, Arctic Investigations Program. In 1998, 229 tribes came together to form the Alaska Native Tribal Health Consortium. ANTHC provides and manages healthcare for the Alaska Native people across the state. The formation of ANTHC and the Alaska Native Medical Center provided the setting for a unique opportunity of a Tribal-Federal partnership. The CDC-AIP moved to ANMC health campus and manages the biorepository. The focus of the AASB is to conduct research approved by Alaskan

Native Tribal Health Organizations (THO) accessing the biospecimens. The focus is on research approved by the THO's. As genetics research has expanded in recent years, their procedures continue to be updated to ensure that biospecimen research serves to support the health of Alaska Native and American Indian peoples. She also noted that all biospecimens remain the property of the individuals who consented to have their specimens stored for future research. A new draft of policy is currently being written, guided by community-based discussions and updated best practices. This Tribal-Federal partnership illustrates how collaboration and commitment to partnership can have a positive impact on relevant health research for AN peoples.

Audience comments included how the LDL and FH issues impact different parts of the Navajo Nation, how important it is to bring people together on issues such as this, and how there is more connecting and collaboration to be done. Questions about Alaska Area Specimen Bank highlighted the importance of consistent funding when trying to respond to rapid scientific discoveries and changes.

Creation of the Navajo Genetic Glossary

Panel Members:

Perry Charley, Ph.D., Emeritus of Diné College

Martha Austin-Garrison, MAed, Emerita of Diné College

Susie John, M.D., retired Pediatrician

Rene Begay, MS, MPH, University of Colorado Anschutz

Mallery Quetawki, Artist

Moderator: Nanibaa' Garrison, Ph.D., University of California, Los Angeles

Dr. Nanibaa' Garrison opened the session by introducing the Navajo Genetic Glossary team, except Frank Morgan who was not present:

- *Perry Charley*, an environmental scientist with over 50 years of experience, shared his background in uranium cleanup and previous glossary work for the weather service and with geological terminology. He helped initiate the project around 2018–2019, recruiting linguists and medical experts who understood Navajo concepts of harmony, healing, and “walking in beauty.”
- *Martha Austin-Garrison*, a linguist and educator at Diné College. She teaches medical terminology in Navajo. She described the translation process as challenging, requiring

deep contextual understanding and iterative revisions—especially for complex scientific terms.

- *Dr. Susie John*, a pediatrician and former CEO of Tuba City Indian Health Services (IHS), was recruited for her medical expertise. She shared her personal journey—from attending Berkeley to raising children—and expressed joy in contributing to the glossary.
- *Mallery Quetawki*, a Zuni artist and biologist, blended her scientific training with her culture. She described Zuni artists as record keepers and shared how the cover art—her most challenging piece—symbolizes growth and continuity.
- *Rene Begay*, a geneticist and public health researcher. She helped identify all genomic terms and simplified terms using online, National Human Genome Research Institute (NHGRI), and personal knowledge as resources for the authors to define the terminology in Diné, ensuring translations were accessible and respectful of Diné linguistic structure. She spoke about learning from Elders and the sacred nature of the work, which included frequent prayer and consistently showing up and engaging in deep collaboration with the authors.

The session consisted mainly of audience questions and panelist responses. During the Q&A, panelists reflected on the glossary's origins, translation challenges, and cultural sensitivities. Austin-Garrison noted that Navajo's descriptive nature made scientific terms difficult to translate without visual aids and context. Begay emphasized the importance of mentorship and listening to Elders. Dr. John reiterated that all terms were difficult, especially DNA, which required careful conceptual framing.

Charley highlighted the importance of consulting Hataałii (medicine people) and respecting sacred boundaries, especially when dealing with concepts related to the “essence of life.” Quetawki discussed the complexity of illustrating language and the importance of revisions, noting that the unfinished design on the cover represents the glossary's ongoing evolution. Begay added that choices about color and symbolism were intentional.

Looking ahead, panelists envisioned the glossary as a living resource. Charley noted the need to develop terms like “gamma radiation” and emphasized its potential to inspire Navajo youth. Austin-Garrison plans to use it in her classes to help students learn. John sees it as a reference for healthcare workers. Quetawki believes it will help Navajo students overcome imposter syndrome and communicate scientific concepts more confidently. Begay suggested including

disclaimers to reflect how the Diné worldview may shape certain interpretations, positioning the glossary as a tool for fluent speakers.

The session ended with a book signing.

Community Perspectives and Education on Genetics

Panel Members:

Vanessa Hiratsuka, Ph.D., Southcentral Foundation

Carissa Sherman, Ph.D. Candidate, University of Colorado Anschutz

Luke Nez, BS, University of California, Los Angeles

Shazia Tabassum Hakim, Ph.D., Diné College

Moderator: Gilbert John, Ph.D., Colorado State University

“Southcentral Foundation’s Ethical, Legal, and Social Implications of Genetic Research” — Dr. Vanessa Hiratsuka

Dr. Hiratsuka began by introducing herself and the Southcentral Foundation (SCF), explaining that it is a Tribally owned and managed organization that seeks to understand what community members really want in their healthcare services. She explained that the research approaches employed by herself and other researchers at SCF use elements from both Western research methods and from pan-Indigenous research frameworks. Dr. Hiratsuka then explained the timeline of her research, starting in the early 2000’s as ownership and management of the Tribal health system in Alaska moved from federal to Tribal hands.

Many questions arose during this transfer of management, including the matter of how to continue managing the existing biobank that was in the Alaska Tribal Health System. To address the matter of how health research and resources can best be deployed to help communities, Dr. Hiratsuka conducted focus groups beginning in 2006 with community members and Tribal leaders. She explained that the research further investigated questions around pharmacogenomics and ways in which scientific knowledge can be used to help people live good lives. A key case study identified through community research for pharmacogenomics implementation was tobacco cessation.

Following the summary of her research, Dr. Hiratsuka also outlined recommendations for researchers based on her experience doing community-engaged research. She recommended that researchers gain awareness of past research, engage in dialogue with community members and community leaders about the research, work with the community on how to handle data, and communicate clearly about informed consent and the return or destruction of biological samples. She stressed that it is crucial to be thoughtful about what you're doing, even if the work takes a bit longer due to that care. Her closing thoughts emphasized that research should be purposeful and have a clear benefit to communities.

Audience comments and questions included reflections on the fact that community benefit (as opposed to humanity benefit) is crucial for historically marginalized communities, whether Alaska Native groups have their own research policies in place, and if the Alaska Native model is a good way of doing things. Dr. Hiratsuka explained briefly about the existing research policies in the group that she works with and that the model has been working well for them. It is a dialogue on how to move forward with research and maintain equitable research relationships.

“Deliberations about genetic research and policy considerations on the Navajo Nation” —
Carissa Sherman and Luke Nez

Sherman and Nez began by introducing themselves and provided an overview of the presentation. They began by defining the deliberative method and explained how the approach relates to the larger research question regarding considerations for a potential genetic research policy on the Navajo Nation. They walked through the process of conducting the three deliberations as well as the ways in which the results from the deliberations were analyzed using both quantitative and qualitative methods. They then walked through the general demographics of the deliberation participants, including answers to questions about general genetics knowledge and their familiarity with both the moratorium and Navajo culture more broadly.

Sherman and Nez then explained the preliminary results from the three deliberations, including both considerations and recommendations from participants. Two key recommendations were related to researcher training and Indigenous data sovereignty. It is important to both train Navajo individuals to conduct this type of research, but also train non-Navajo researchers in conducting respectful research in Navajo communities. Sherman and Nez then compared

results from all three deliberations related to benefits, risks, and priorities for genetic research. Though the details differed between the three deliberations, Sherman and Nez explained that across all the deliberations, they saw an emphasis on the need for a robust genetic research policy that prioritizes Diné culture, community interests, and the sovereignty of the Navajo Nation. They closed with the next steps for the project, which included continuing analysis on the deliberations and sharing the results with the Navajo community.

Audience questions included the best ways to educate non-Native researchers and the best ways to consider community needs, as well as questions about tracking demographics in the deliberations and whether or not the team has considered conducting deliberations with Native trainees. In addition, there were questions on geographic influence on participant views and whether or not the team uses artificial intelligence (AI) in the review process.

Sherman and Nez outlined the need to emphasize Tribal sovereignty for non-Native researchers and discussed the Summer Internship for INdigenous peoples in Genomics (SING) program in response to the desire for trainee focus groups. Panel participant, Dr. Vanessa Hiratsuka, also chimed in about SING. Sherman and Nez clarified that AI has no place in their research process.

“Genetic Education and Ethical Review Process: An Understanding” — Dr. Shazia Tabassum Hakim

Dr. Tabassum Hakim began with an introduction and an explanation of her positionality as a non-Diné researcher who is currently with Diné College. Dr. Tabassum explained that back in 2018, when she first came to work with the Diné community, she wanted to pursue work around clinical microbiology, which is her background, but she was met with resistance on the topic of human samples. She detailed her multiple attempts to receive Chapter approval for wastewater research and her eventual success. Through this process of seeking research approval, she learned several important lessons about bringing research proposals to the community. The first lesson was that it’s crucial to build community trust and ensure that everything is both coming from and benefiting the larger community. The second lesson was that there is a specific process to approve research within the Navajo Nation that must be followed. The third lesson was that the gathering and analysis of data must be carefully planned and considered with respect to Indigenous data sovereignty. Giving local students the opportunity to aid with data

collection and analysis is an excellent way to support young scientists and ensure data stays within the community.

Dr. Tabassum elaborated on the last point by stating that many health fields could be tapped into and supported for young Navajo individuals who are interested in health careers, especially on the Reservation. She explained that Diné College is pushing to support students in these areas, especially following COVID. She detailed an NIH-funded program, “CONVOY,” that is targeted at youth in middle and high school and provides them with training in biomedical research methods and other science areas. This program allows students to remain close to home and also receive excellent training to inspire them in the future. This focus on training and inspiring youth will result in capacity building and local workforce development for Navajo scientists and will ultimately add to a strong foundation for research being done by Navajo scientists in their own communities.

Audience comments highlighted the importance of engaging Navajo professionals in the training process and ensuring that the training is respectful of Navajo values and traditions.

Dr. Tabassum clarified that at Diné College School of STEM, their preference is to bridge Diné knowledge with Western knowledge, and hence they involve as many Navajo professionals as possible who have traditional knowledge and expertise required to motivate and train the Navajo youth. She explained that the trainings provided at DC intend to combine Navajo teachings with Western science. She further elaborated that the students have conducted interviews with Elders and medicine men to ensure that the approach is keeping things harmonious.

Evening Reception and Poster Presentation Session

Over 20 students, trainees, and young professionals set up posters for the evening reception. Dinner was served, and participants were encouraged to explore the research projects represented.

Moderators: Kyle Coulon and Carmenlita Chief

Of the posters, three were selected for Summit awards:

- Tribal College Research Award went to Avery M Begay, for “Exploring the Biodiversity of Endophytic Fungi: A Possible Source of *Pinus edulis* Decline,” Navajo Technical University.

- Genomics Research Award went to Brooke Damon for “Identifying *Phragmites australis* subspecies using genetic markers,” Northern Arizona University.
- Community Engagement Award went to Kylie Butler for “Recommendations for Genetic Counseling Alaska Native/American Indian People Based on Results from a Public Deliberation,” South Central Foundation and Brandeis University.

Friday May 30, 2025

Welcome Remarks

Recap of Day One: Walter Phelps

Hon. Vince James, Navajo Nation Council Delegate and Health, Education & Human Services Committee Chair

Moderators: Katrina Claw and Walter Phelps

Dr. Claw and Mr. Phelps began with introductions. Dr. Claw provided information on the American Society of Human Genomics leaders, which was followed by Mr. Phelps playing a small trivia game with the audience to see what information they are recalling. Mr. Phelps then welcomed Honorable Delegate Vince James to provide the welcome for the day.

Delegate James opened by introducing himself and then moved into an appreciation for the artwork on the tote bag provided to conference attendees. He explained that the artwork inspired him to think back on his grandfather and the items he would use in ceremonies as a medicine man. He thanked the assembled group for taking the time and initiative to study and research these important topics to benefit Navajo Nation. He explained that his main concern is cancer, especially in elders. He had always wondered why cancer could not be caught earlier and why it impacts some individuals and not others. He finished by sharing a traditional song with the group to demonstrate his gratitude for the work that everyone is doing.



The Summit Artwork as displayed on the tote bags, given to in person attendees.

Artwork created by Mallery Quetawki

Keynote Address

Eric Green, M.D., Ph.D., Former Director, National Human Genome Research Institute, National Institutes of Health

“From the Human Genome Project to the Realization of Genomic Medicine: A Scientific, Medical, & Societal Journey”

Dr. Eric Green opened his talk by noting that it was a pleasure to attend the Summit and that he was learning a great deal. Speaking at the meeting’s halfway point, he reflected on how best to contribute. He noted the heterogeneity of the audience and shared his aim to clarify and contextualize key ideas being discussed and, as the Summit’s “halftime show,” provide a bit of entertainment as well.

Dr. Green opened by explaining why genomics matters, highlighting its connection to historic scientific achievements and its growing relevance to human health, medicine, and everyday life. He framed genomics as a field designed to contribute to gaining a comprehensive answer to the key question: what is the fundamental blueprint required to create and operate a human? He reviewed key milestones leading to the field’s establishment, including the founding of the field of genetics in 1907, the discovery of DNA’s double-helical structure in 1953, and the coining of the term *genomics* in 1987. He also highlighted the scientific advances that provided tools for the field of genomics and how a steady drumbeat of discussions helped formulate the launching of the Human Genome Project in 1990. Dr. Green remarked that he feels fortunate to have been involved in the project and emphasized its uniqueness and significance.

He then turned his attention to discussing the Human Genome Project and its sequencing of the human genome. To help illustrate the scale of the human genome sequence, Dr. Green offered several metaphors, including a video of a hallway outside his previous office at the National Institutes of Health (NIH) where 1/1,000th (0.1%) of the human genome sequence is displayed on a wall in very small font along an 83-foot stretch. He explained that displaying the entire human genome sequence in this manner would have required ~15.5 miles of hallway. Dr. Green then emphasized that completion of the Human Genome Project in 2003 represented both a finish line and a starting line, and he went on to describe the many subsequent applications of genomics and the important pivot of the National Human Genome Research Institute (NHGRI) in 2003 toward understanding how differences in individual DNA influence health, disease, and the practice of medicine.

Dr. Green defined genomic medicine as the use of genomic information about an individual as part of their clinical care, noting that related terms (e.g., personalized medicine, individualized medicine, and precision medicine) are overlapping but broader than genomic medicine, which just focuses on genomic information. He highlighted the progress made since completion of the Human Genome Project towards realizing genomic medicine, including a more than million-fold reduction in the cost of sequencing a human genome; the sequencing of millions of human genomes; major advances in understanding genome function; significant progress in uncovering the genomic basis of human disease; and the early integration of genomics into medical practice.

He provided examples of genomic medicine being implemented, including cancer genomics, rare disease diagnostics, noninvasive prenatal genomic testing, pharmacogenomics, and genomics-based prevention. He noted that this list will continue to grow and he identified newborn genome sequencing as a top item on his “watch list,” citing recent studies examining the ways that genome sequence information about newborns can be valuable. While celebrating that genomic medicine is becoming a reality, Dr. Green also acknowledged major challenges that remain, including the difficulty of interpreting the relevance of genomic variants in patients and the lack of adequate representation of non-European ancestral populations in genomic datasets.

Dr. Green then addressed what he described as “the elephant in the room.” He spoke candidly about not being reappointed as Director of NHGRI by the Trump Administration, noting that multiple additional NIH institute directors and thousands of NIH employees also lost their

positions. He reflected on being the first NIH institute director appointed under the Obama Administration and the first to be dismissed under the Trump Administration. He expressed his view that the cuts to NIH thus far did not increase government efficiency, enable radical transparency, or make America healthier, as had been claimed. Dr. Green concluded his keynote by sharing his motivation to help rebuild the NIH in the future and expressing optimism about the future of genomics.

During the audience discussion, participants shared experiences conducting genomics research in other Indigenous communities, describing studies that identified unique genomic variants in specific tribes, the knowledge of which was then used for genomic testing to prevent health complications. Questions focused on recommendations for developing appropriate genomic policy within the Navajo Nation that address challenges posed by the federal government. In closing, Dr. Green emphasized the importance of meaningful engagement with communities. He expressed his belief that common ground can be found in which community traditions and values are respected and preserved while still enabling everyone to benefit from genomic medicine, provided the effort is collaborative and driven jointly by scientists and Indigenous communities.

Concurrent Platform Sessions 2

Viruses and Microbes: Integrative Approaches to Culturally Inclusive Research

Panel Members:

Joslynn Lee, Ph.D., Assistant Professor of Chemistry, Fort Lewis College

Phillida Charley, Ph.D., Research Scientist I, Colorado State University

Dalaki Livingston, Ph.D., University of Utah

Justin Reedy, Ph.D., University of Oklahoma

Moderator: Gilbert John, Ph.D., Colorado State University

“Engaging Indigenous students in environmental microbiome research through a cultural framework” — Dr. Joslynn Lee

Dr. Lee shared about ‘engaging indigenous students in microbiome research’, and talked about the importance of finding a sense of belonging in science and academia, while maintaining and honoring cultural values. Dr. Lee completed her undergraduate degree in cellular and molecular biology, Choixsh—bugs/bacteria—as she described it to her grandmother. She took classes

involving plants and animals, and really enjoyed chemistry, at a molecular level. She approached her work with prayer and shifted away from academia into industry. She worked at a pharmaceutical company and was interested in the representation aspects of research (such as who benefits) as one of the only Native American folks there; at that job she got interested in computational chemistry. It was still new, and eventually worked with Dr. Mary Jo Ondrechen for her PhD, another Indigenous scientist. She found a focus that fit well with her community and cultural beliefs; she was very interested in exploring proteins and small molecules. She graduated in 2014 and showed some statistics about how limited Native representation in sciences was then and is now. Continuing to train as a post-doc, she decided genomics and the increase in data that was coming from genetic and epigenetic sciences was a trend that would continue. She shifted gears to become a data science educator, exploring ways to enhance technical curriculum and how to support students to persist in science programs. She realized that microbiomes seemed like an accessible area for students.

With the Gold King Mine spill, Dr. Lee had an opportunity, in 2017, to come up with a teaching mechanism to study microbes, exploring the cultural aspects of balance with the impacted rivers. On the molecular side, the 16S RNA gene was used to study bacterial communities. In a partnership with three schools, the technical aspects were framed and supported by elders. Students learn about science, data, and technical and presentation skills during the workshop. Over 100 people from 58 federally recognized tribes have attended since 2022. They recruit from schools that don't have access to this type of research, partnering with schools in Arizona, Montana, and Washington. Dr. Lee shared some of the data results, pre and post-tests: they saw increases in knowledge about microbial communities, computational knowledge, and knowledge about careers in genomics. Students reported feeling comfortable in the community and noted how shared cultural values were supportive of the workshop learning. Dr. Lee shared some success stories from former participants.

Audience Questions were about starting at the high school level instead of college level. Dr. Lee replied that they also help with the Four Corners Computing Club, which engages students at a pivotal point for early computing skills, in 3rd grade to 8th grade. Students do hands on coding and they have worked in Tuba City and Kayenta, as well as with the Southern Ute and Ute Mountain tribes. Dr. Lee noted the importance of teaching students these types of skills at all ages.

“Surveillance of SARS-CoV-2 on Navajo Nation Lands” — Dr. Phillida Charley

Dr. Charley studied virology and molecular biology and works with Dr. Gilbert John, the moderator for this session. Dr. Charley began with the idea that the environment, human and animal health is all connected, and the importance of community engagement. They discussed how Navajo communities live near uranium mines and the EPA comes in and gives talks—but the community doesn’t always understand the scientific language. The community reached out to Dr. John to help with understanding what the EPA was talking about. Dr. John assembled a team, and they have done a lot of community engagement. They talked to the community about scientific topics and working to better explain scientific terms by listening to community priorities and responding. They came up with several community engagement topics including social science and impact, wildlife drinking water, heavy metals, and the soil microbiome. The community was involved in the development of research questions and the research itself. To engage with the community, they often fed them as well. Projects such as the Livestock Well Project are ongoing, which explores how to filter water to better limit livestock exposure to pollutants like arsenic and uranium.

The COVID-19 pandemic affected many research projects and, therefore, many of the end results were gathered after the pandemic. They developed a new question related to rodents and livestock—how they were infected with coronavirus. The team took swabs of livestock on the Navajo Nation to test for the presence of SARS-CoV-2. They extracted RNA from the swabs and did testing for SARS-CoV-2 viral RNA, which if detected represents active infection. Serum from blood samples tested for antibodies which can detect previous infection. They had a high amount of positives but think this was due to different types of coronaviruses. To return results to community members, they had one-on-one sessions with people who owned livestock that were volunteered for the testing. There was no active infection that they could detect.

Audience questions initially concerned the specifics of hantavirus, such as how genetics play in and where the virus originates. Additional questions were about how the lifting of the moratorium might impact future viral epidemics on Navajo Nation and whether or not researchers are trying to conduct additional studies on long-term COVID.

Dr. Charley clarified that the severity of hantavirus varies based on a number of individual factors. The Navajo Nation has pamphlets available on how to clean up after rodents properly.

She also explained that different policies impact research on viral diseases, with studies needing to comply with NIH and NSF guidelines. While Navajo Nation is not conducting research on long-COVID, other places are, but their results will not be available anytime soon due to the nature of the research (studies taking place over longer periods of time).

“Navajo Nation Virtual Deliberation – Quality Analysis” — Drs. Dalaki Livingston and Justin Reedy

Drs. Livingston and Reedy began by introducing themselves and their positionality as scholars of communication rather than geneticists. They described the topic of their presentation—a virtual deliberation that was held with healthcare workers who were either Navajo themselves or who worked closely with Navajo communities. The deliberation asked these healthcare workers to discuss issues related to genetics research on Navajo Nation and Drs. Livingston and Reedy were involved in assessing the quality of the deliberations.

They outlined the aims: there are concerns surrounding genetic research and how it relates to Tribal sovereignty and historical research abuses. They reiterated that policies like the moratorium exist to protect the community. There is an opportunity to incorporate Western practices in a respectful and effective manner to engage community members in conversation about genetic research. To determine the best way to incorporate these practices, community-based research like deliberations can be effective in understanding community views and using those in making policy decisions. They further explained that because of COVID-19, they had to conduct the initial deliberation online using Zoom.

They explained that the research team wanted to assess how well the deliberations went, which was determined based on a number of factors that were assessed during the event and while analyzing the transcripts following the event. The focus was on how well participants interacted with each other, shared time, expressed their values, and how engaged they were. Assessing quality in this way is essential to determine if the research framework has been adapted well and what changes might need to be made to use the format in the future. The goal is to form a good relationship between the participants and the research team for community-based research that is informed and respectful.

The panel ran out of time for audience questions.

The Art and Science of Storytelling

Panel Members:

Tonesha Yazzie, BS, Northern Arizona University

Mallery Quetawki, Artist

Eric Lockard, Publisher, Salina Bookshelf, Inc.

Moderator: Carissa Sherman, Ph.D. Candidate, University of Colorado Anschutz

“Indigenous Perspectives on Genetics Research: Digital Storytelling” — Tonesha Yazzie

Tonesha Yazzie graduated from NAU with a Creative Media and Film (BS) degree, focusing on the science of communication, and is a documentary filmmaker. Tonesha collaborated on the digital storytelling project with Dr. Jiun-Yi Tsai (NAU), which is part of the larger Navajo NARCH Partnership. She began by explaining how she was hesitant to join the project because of taboos that she grew up with around genetics. As she learned more about the research and the interest from the Navajo community in learning more about genetics, she recognized how important it would be to present the information in a useful and relevant way, as well as to encourage collaboration with people who watch the videos.

Yazzie described how the videos took complex topics in genetics and made it relatable, memorable, and engaging. She emphasized the importance of ethical storytelling: to be honest and sensitive to these cultural issues. Going through the process of each video’s editing and creation, she explained how genetics is best understood through family and way of life. There was a through-line for some of the videos about the interconnections between humans, animals, and the environment. As part of ethical storytelling, Yazzie talked about how each character in the videos is a real person, so she must keep them updated on the work as it progresses. Yazzie noted that life isn’t simple: it’s not always good and bad. What pushes a story forward is the complexities of it—leaving it open to interpretation and engagement, too.

“Communicating Health Science Information through Culturally Relatable Artwork” — Mallery Quetawki

From Zuni Pueblo, Mallery Quetawki is the conference artist featured on the Summit logo, Summit tote bags, and the Genetics Glossary books. Recruited by Dr. Johnnye Lewis at UNM,

who saw some of Quetawki's work at the Zuni IHS hospital, Quetawki consults on and creates art that informs the community and starts dialogues.

When creating art for this purpose, Quetawki explained that she thinks in her language and considers how the scientific info relates to language and culture. She considers how to explain to her grandparents and to her kids. Working with UNM for 8 years, she focuses on translating the science as accurately as possible, using the cultural and spiritual context of the Tribal Nation she's working with to be as relevant as possible. Transitioning to share artwork about genetics too, Quetawki noted how you can lose your audience when talking about negativity and how it impacts the body. She likes to insert the art first before talking about what can happen in order to emphasize how DNA can repair itself. She uses the example of a strand of beads: you can go back and fix a bead if it's broken, you wouldn't just throw it away. In a related idea about genome sequencing, she uses the example and image of a turquoise necklace. All human DNA is similar, but each necklace and each genome is unique to just you.

Publishing Navajo Language Resources — Eric Lockard

With his twin brother, Lockard started Salina Bookshelf because of their interest in publications. They started publishing Navajo language materials and were asked about a year ago to produce the Genetics Glossary book. After a lot of effort from the five authors, the cover artist (Mallery Quetawki), Corey Begay (graphic designer), and the printer, the book was completed and arrived just before the Summit.

One of their main goals in publishing is to inform and develop community around Navajo language. This includes work to provide language materials to youth. They are a few weeks away from releasing an audio version of *Diné Bizaad Bináhoo'aah*, a book by Evangeline Parsons Yazzie which was the first textbook to be adapted at the state level to teach native language. Eric shared from and discussed *Running with Changing Woman*, a young adult novel by Farmington-based 5th grade teacher Lorinda Martinez. In addition, Eric shared an excerpt from a poem (A Child's Laugh) by former Vice President of the Navajo Nation Rex Lee Jim. Lockard paraphrased one of the authors of the Glossary, Martha Austin, around the importance of language: giving young people access to their language and encouraging them to build language skills can validate who they are; so, as they become scientists, they maintain their traditional knowledge and connections to community.

Audience questions included how different works are created and then shared with communities. One obstacle mentioned was making scientific content relevant and digestible. The importance of translating stories accurately was mentioned, as well as efforts to explore the complexities present in stories. There was a discussion about bi-directional communication which highlighted the need for researchers to come to community to explore what data means to community and what can be done with data. Reporting back to community was also discussed, with the possibility of researchers presenting to tribal communities multiple times, noticing where people lose interest and finding new ways, including new infographics and images, to better explain scientific ideas.

Cultural Considerations in Genomic Research: A Framework with and for the Diné

Panel Members:

Michelle Kahn-John, Ph.D., PMHNP-BC, AGNP, Johns Hopkins University

Frank Sage, Ph.D., Navajo Technical University

Leah Nez, Ph.D. Student, Case Western Reserve University

Martha Austin-Garrison, MAed, Emerita of Diné College

Katrina Claw, Ph.D., University of Colorado Anschutz

Illustrators: Carissa Sherman and Luke Nez

Panelists introduced themselves, with Drs. Michelle Kahn-John and Katrina Claw sharing the community derived origins of this cultural framework project: how it was designed to increase understanding, guide genetic and genomic research through a Diné lens—with an emphasis on compiling knowledge and guidance for future generations. The audience engaged in an interactive poll, asking audience members to reflect on the words “cultural framework,” they thought of words like “knowledge,” “Navajo,” “philosophy,” and “resilience,” and they engaged with the presenters by sharing words like “life,” “lineage,” “cells,” and “family/k’é” for the word “genetics.” Results from the survey included: half of attendees grew up with Diné traditions, most of the attendees were between the ages of 31–45, and many came from the Northern and Western agencies of the Navajo Nation.

Speakers clarified the framework does not share sacred knowledge and is also informed by previously published works. Dr. Franklin Sage outlined a few of the previously published sources of Diné cultural teachings including foundational models: Navajo Nation Fundamental

Law, Cornstalk Philosophy, Hogan Philosophy, and Diné Education Philosophy. Each panelist has worked on developing sections of the framework that align with many aspects of Diné culture including the cardinal directions, stages of thinking and life stages. Dr. Sage briefly explained the sections of the framework, which include:

- Doorway: How research enters the world.
- Center: Honoring community as co-owners and fostering long-term connections.
- East: Thinking stage, approaching research with positive intent.
- South: Planning genetics research, involving advisory boards, and addressing data ownership.
- West: Community-approved methods and accessible language.
- North: Distribution of research findings, storytelling, and Elder wisdom.

The framework supports understanding genetics through a Diné worldview and was developed by Diné scholars, cultural experts, and artists. Next steps include continued community consultation and collaboration with spiritual groups and eventually distribution through publication.

Audience feedback included starting with East to reflect Diné perspectives, inclusion of LGBTQIA and non-binary gender representation, appreciation for this multi-worldview integration, and calls for more engagement with non-Indigenous educators, healthcare professionals and researchers. The team developing the framework welcomed ongoing review and input.

Trainee Research Session

Speakers:

Kendrick Freeland, National Institute of Diabetes and Digestive and Kidney Diseases

Tse'yi'nii II Begay, Fort Lewis College and Justin Billy, University of Wisconsin

Catrina Alberts, Northern Arizona University

Moderator: Lucas Rozell, MA, University of Colorado Anschutz

“Functional analysis of an eQTL in CELSR2/PSRC1/SORT1 gene cluster associated with energy expenditure in American Indians” — Kendrick Freeland

Kendrick Freeland opened his presentation with an explanation of the more complex terminology he would be using throughout. He explained that Genome-Wide Association

Studies (GWAS) are used as a hypothesis-free method to look at single nucleotide polymorphisms (SNPs), genetic differences, all along the genome and associate SNPs with disease. He also defined LDL-C as Low-Density Lipoprotein cholesterol and RMR as Resting Metabolic Rate (the amount of energy your body uses at rest). The mission of the study was originally to understand the causes of diabetes and obesity in American Indians, with a particular focus on what genes affect lipid levels in American Indians. The study resulted in a novel association of the SNP rs12740374 with energy metabolism.

The audience questions and comments were very engaged, as the Principal Investigators for the trainees were in attendance and provided larger context where the trainees could not. Kendrick Freeland was praised for his skill at presenting complicated and technical information in an understandable way and audience members clarified whether the SNP that was identified had been characterized as associated with human diseases—the answer was no, it had not been associated with human disease.

“Investigating the gut microbiota community structure of Helicobacter pylori infected Navajo adults” — Tse’yi’nii Il Begay and Justin Billy

Tse’yi’nii Begay and Justin Billy described their research into *Helicobacter pylori* and related the research to an extension of a Navajo ABID Study (“Abid’ is the Navajo word for stomach,” as noted on the study’s website: <https://www.theabidstudy.com/about>) that is assessing microbiota. Begay outlines parallels between traditional Navajo teachings and Western science, including the links between modern genetics and the Navajo clan system. They describe gut microbiota as an extension of a kin network and explain that the relationship between you and your gut microbiota is bi-directional. *H. pylori*, the gut microbe in focus within the study, is a strong risk factor for stomach cancer, which Navajo adults are 3.5 times as likely to develop. The study involved ribonucleic acid (RNA) analysis of genomic DNA extracted from stool samples, in order to identify the bacterial composition of Navajo adults with *H. pylori*.

Billy goes on to discuss the analysis methods. QIIME 2 was used to process the sequence and then matched sequences were used to identify a bacterial composition. The analysis confirms that Navajo adults with *H. pylori* infections do have a different bacterial composition in the gut. Identifying this and explaining the results with familiar Navajo kinship terms will enable

researchers to design more Navajo-focused research and communicate findings to a more responsive audience.

Tse'yi'nii Begay and Justin Billy received questions related to study design, which were answered by the two presenters and their Principal Investigator. They also answered questions regarding the difficulties included in swapping away from infected water sources within Navajo Nation, acknowledging that it's a large-scale issue that would need to be addressed with policy changes and education.

“Culturally responsive wildlife monitoring methods” — Catrina Alberts

Catrina Alberts' project is focused on re-introducing the Northern Leopard Frog to its natural range. She included disclaimers in her slides that frog imagery will be present, in order to honor those that would prefer not to look at the sacred species and then told the story of how the frogs bring rain. Her study was conducted with the help of the Navajo Nation Department of Fish & Wildlife and involves assessing the viability of several lakes to see if the Northern Leopard Frog is present or could be re-introduced. These lakes are Big Lake, Walker's Lake, Wheatfields Creek, Long Lake, Berland Lake, and Todacheene Lake. Monitoring and testing must be done in a low-impact way, and Alberts described a mix of environmental DNA testing, encounter surveys, audio loggers, and camera traps. These are all used to test for both the presence of frogs and the presence of invasive species that would prove dangerous to a frog population. With the success of this study, the next step is to start the re-introduction process with approval from the Navajo Nation Human Research Review Board and local Chapters.

Catrina Alberts explained to the audience that their methods were in-depth enough to confidently detect the presence of a species, but could not account for the abundance of any one species, which is why the genetic research is paired with audio logs and encounter logs. Finally, an audience member expressed surprise that the gut microbiome and frog sequencing was allowed to happen, given the moratorium, to which Catrina Alberts went in depth on her approval process from Navajo Nation.

Lunch Session: Preview of Digital Stories

Tonesha Yazzie, BS, Northern Arizona University

Luke Nez, BS, University of California, Los Angeles

Tonesha Yazzie, one of the creators and developers of the Digital Story videos, introduced and shared more about the Digital Stories project. The Digital Stories are available online here:

<https://www.voicesofdinesummit.com/digitalstories>.

Recap of Summit

Nanibaa' Garrison, Ph.D, University of California, Los Angeles

Dr. Garrison started the recap of the Summit by thanking the opening presenters and NAU for hosting the event. Dr. Garrison explained that it's a special moment for her to be part of the discussions about genetics research at this location. She went on to list some of the different topics and discussions that happened over the past several days: the history of genetics and genomics; research involving Navajo people; how the Navajo Nation Human Research Review Board operates and evaluates research protocols. Dr. Garrison expanded more on the Navajo Institutional Review Board process before continuing to list other topics discussed, such as the moratorium on genetic research that has been in place since 2002. She commented that while the moratorium did slow down genetic research involving Navajo people, it also protected them and has enabled them to decide how genetics research should be done in the future. Next, she mentioned the session on the impact of rare genetic diseases on families, highlighting how moving it was to hear stories from family members about their loved ones and the benefit of newborn genetic screening. She also highlighted the digital stories that were played during the lunch break.

Thursday's concurrent sessions featured cancer and health in/equities, perspectives from physicians and healthcare professionals working with patients and communities and the challenges they face, how the genetics glossary was created, and presentations from researchers on their work engaging communities to understand their perspectives on genetics research. Thursday evening, there was a poster session for students, trainees and young faculty to share their research. Dr. Garrison took a moment to congratulate the poster award winners again. She then thanked Dr. Jani Ingram, a professor at NAU, for her personal efforts in making sure the conference ran smoothly.

Friday's breakout sessions featured topics including considerations of incorporating cultural frameworks in genetics research moving forward, a trainee session featuring Diné and Indigenous scholars learning and conducting important and impactful research, and a session discussing the development of genetics policy and supporting documents for proposed legislation. Dr. Garrison gave special thanks to Dr. Eric Green, the keynote speaker for Friday, who shared his journey working in the field of genetics and genomics as well as the current state of the federal government and ended his presentation with words of motivation to keep moving forward.

Dr. Garrison stated that both Diné and non-Diné perspectives were shared, which was one of the main priorities of the conference in addition to providing an opportunity for people to learn about the work being done. She gave a reminder that policy development is still ongoing and there is still opportunity to provide feedback and perspectives.

Moving Forward: Navajo Nation Policy and Genomic Landscape

Hon. Carl Slater, Navajo Nation Council Delegate

Rene Begay, Chair of the Navajo Nation Genetics Policy Development Working Group (NNGPDWG)

Walter Phelps, former Chair of the NNGPDWG and former Navajo Nation Council Delegate
Nanibaa' Garrison, Ph.D., University of California, Los Angeles

Moderator: Mae-Gilene Begay, MSW, Member of Navajo Nation Human Research Review Board

The panelists began by introducing themselves and briefly outlining their backgrounds and how those relate to the Navajo Nation Genetics Policy Development Working Group (NNGPDWG).

Ms. Begay described her educational and work background and how she was led to the topic of the genetic research moratorium while trying to bring her research back to her people.

Delegate Slater discussed his tenure as a delegate and how he had been personally interested in genetics before engaging with the NNGPDWG.

Mr. Phelps told the story of how he returned to Navajo Nation after living in Washington State for many years and became involved in the local community. He worked with Dr. Joe Engelken, a hospital CEO from Tuba City, as both a grants administrator and liaison to Window Rock, AZ. They accomplished many things in Tuba City, AZ, including the building of a new facility that became the cancer treatment center. Following the reduction of the Navajo Nation council from 88 to 24 members, Phelps decided to try to get involved and was elected as a delegate. He served on the first HEHS (Navajo Nation Health, Education, and Human Service) Committee and said that anything related to healthcare was directed to him, given his prior experience. He was appointed to the NIH Tribal Advisory Committee through which he met many other Tribal leaders who became friends and colleagues. He was passionate about directing resources to cancer research, especially given the presence of uranium on the Navajo Nation, and was eventually directed to speak with Nanibaa' Garrison and Katrina Claw. Then Mr. Phelps relayed a history of how the NNGPDWG first came to be.

Dr. Garrison then spoke about her path to the NNGPDWG and the current research she is conducting. She had been interested in doing research around the moratorium and genetic research since she was a postdoc but had received a lot of push-back from the Navajo Nation leadership and community. Mr. Phelps reached out to her to request her help with thinking through a policy to lift the moratorium, specifically so that the Navajo Birth Cohort's Environmental Child Health Outcomes (ECHO) program could conduct the genetic testing that they needed for their research aims. Dr. Garrison initially refused because of her previous experience with the pushback in this area, as well as her concerns about feeling out-of-touch with the Navajo community, but then agreed to help with a data-driven policy that takes into account what community members think about genetics and what their specific concerns are. She, Dr. Claw, and Dr. Clarita Lefthand-Begay (who were all at the University of Washington) drafted research proposals, received initial funding from the University of Washington, and received Navajo Nation Human Research Review Board (NNHRRB) approval for initial community surveys and interviews. Eventually, a full genetics research policy group arose out of a Tribal Data Sharing and Genetic Policy Development Workshop held at University of New Mexico in 2017 where Dr. Garrison asked those who wanted to help develop a policy to make their interest known.

Ms. Begay, the current Chair of the NNGPD, spoke about how the NNGPD has developed over time and its official recognition within Navajo Nation legislation developed in 2018 and formed

the official NNGPDWG. She explained that the charge of the group was to draft the policy and provide educational materials to the community, the latter being a stipulation of the initial moratorium. The group had mainly phone meetings (prior to Zoom becoming more common) and also in person meetings in Window Rock, AZ, during which they discussed the educational materials, which include the Summit itself, other conferences, and the glossary books that were given out to Summit attendees. She walked the audience through some sections of Navajo Nation legislation that were being projected on the screen, explaining that this new legislation around the NNGPD gave the group a bit more teeth and support to continue moving forward. She closed by discussing how the group needs input from a variety of sources to move forward with the policy, as well as needing infrastructure, funding, and insight on how regulations are going to be enforced.

Delegate Slater explained that he was initially asked to support the NNGPD because the project might not be able to move forward in any meaningful way. He has no formal training in genetics, so he has been doing his own research and reading his own textbooks to make sure he is knowledgeable about what is being discussed. He spoke about a need to balance the immense potential benefits of lifting the moratorium against the need to perpetuate the Diné way of life. He also spoke about the legislative language around the NNGPD, pointing out that the incorporated support from other agencies and the requirement for all NNGPD members to be bound by Navajo Nation law establishes that the group is seeking balance and harmony in a way that honors Navajo Nation law and tradition.

Ms. Begay asked audience members to submit feedback on the policy via either the QR code on the projector or via slips of paper.

Moderator Mae-Gilene Begay then moved the session to collect audience questions and comments. Audience questions and comments included:

- What decisions and steps need to be made to remove the moratorium?
- How the Working Group intends to incorporate recommendations from the Summit
- How Native Colleges can contribute to genetic research
- Who will oversee guidelines and policy, and how data will be stored on the Navajo Nation?
- One audience member commented that, as a clinician, they want the moratorium to be lifted as soon as possible so that they can implement new kinds of care for their patients.

Mr. Phelps expressed gratitude for the working group's time and effort and reiterated that it is just a recommending body that will be giving recommendations to the decision-making body (Navajo Nation Council) and that the NNHRRB carries a very critical role. How it will happen is a matter of political will.

Dr. Garrison mentioned the immediate things to be done include revisions to NNHRRB research code. They would love to continue partnering with faculty members from Diné College and Navajo Technical University or at neighboring universities. The glossary was highlighted as an opportunity to share more and to help people to understand the impacts/benefits/risks of this work and what it's all about.

Ms. Begay noted how the working group has been incorporating comments and questions for years. A big concern is what the government (Navajo Nation/United States) is going to do with my DNA? Lots of people said 'don't do it, we are sacred beings' and they have built out a spirituality section in the policy: what should you be doing traditionally/spiritually before any research gets started, during your research, after your research.

Delegate Slater described this type of work as the most elemental level of Nation-building and essential for balancing what people want and need. If you want to live very traditionally, you can do that, and if you want to go to the hospital, you also need infrastructure and money to make that happen. This process will help the Navajo government learn how to move forward, including the community in conversations about legislation and policy.

Discussion and Closing

Moderators: Gilbert John and Jani Ingram

The final session of the Summit was a chance for group reflection and public comments from Summit attendees. The moderators passed around a portable microphone to ensure that audience comments could be heard by all.

Attendees largely praised the organization of the Summit and gave their thanks to all the presenters and the organizing committee. Several expressed a desire to see this event repeated in the future, to which the organizing committee members explained that it is going to

be a matter of funding. In giving thanks, audience members also related their own lived experiences to what they had learned at the Summit and several stated that they will be praying for researchers to receive more grants in a period of federal funding issues.

The opportunities provided for trainees at the Summit were also praised by several audience members. Gratitude was expressed for the Navajo Genetic Glossary, with an audience member stating that they can finally explain their work to their family in terms that everyone will understand.

A main point raised by multiple attendees was that it is going to take time to produce a new genetic research policy and it is important to continue working diligently with community members and with Navajo Nation delegates that support the idea of developing and implementing the policy. At the same time, attendees stressed that it will be impossible to craft a policy that is perfect, so it's important to focus on keeping it flexible enough to continue supporting community needs as time passes. One suggestion was to follow the FDA's structure and save capacity by simply approving or denying study design rather than explaining exactly how a study protocol ought to be developed. It is also crucial to ensure that the NNHRRB receives support as the policy is developed and implemented.

Additional Resources

Summit Feedback Report	49
Summit Video	50
What is Genetics?	51
Perspectives on Genetics in the Navajo Nation Project (brochure, 6 pages)	52-57

The Voices of the Diné: Bridging Science, Culture, and Community in Genetic Research Summit, Report from Feedback Surveys (**Summit Feedback Report**) is available here:

<https://www.voicesofdinesummit.com/summitfeedbackreport>



Voices of the Diné: Bridging Science, Culture, and Community in
Genetic Research Summit

May 29-30, 2025

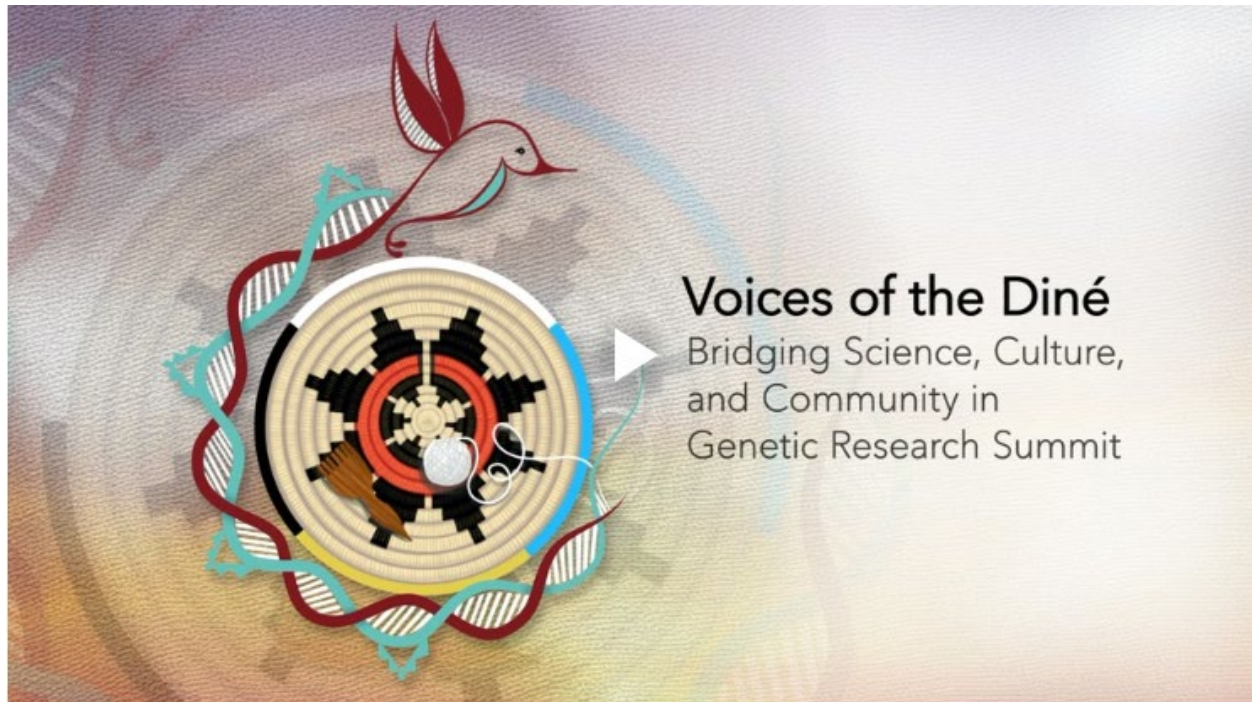
Report from Feedback Surveys

Introduction

The Voices of the Diné: Bridging Science, Culture, and Community in Genetic Research Summit was held from May 29 – May 30, 2025 in Flagstaff, AZ at Northern Arizona University (NAU). The Summit's goal was to increase understanding and awareness around genetics and genomics, focusing on future possibilities for Diné and Indigenous peoples across the nation to engage in discussions about genetics. The Summit was educational, and was open to a mixed audience of academics, scientists, policymakers, tribal leaders, trainees, and the Navajo and Indigenous community more broadly. Because of this, Summit presentations were tailored for a general audience to keep everyone engaged in learning and joining the conversations, regardless of pre-existing genetics knowledge.

We worked with PlainDEPTH Consulting for audio/visual support during the Summit
and to create a **Summit Video**:

<https://www.clawlab.org/post/voices-of-the-diné-summit-2025-video>



At the heart of a hogan, a fire often burns—offering warmth, light, and life to those within. In many ways, the hogan resembles a cell: its center, like a nucleus, holds the essence of life.



Just as the fire is central to the hogan, the nucleus houses our DNA, the blueprint of who we are.



**GLOSSARY OF GENOMIC
TERMINOLOGY IN THE
NAVAJO LANGUAGE**

Dahinamití B'e'íini Bít'ool' Yee
Hadít'ígíí: T'áá, Áí'á
Dinejí Saad Álk'é' Noodah

Marika A. Austin-Garrison
Joni B. BMD
Nore H. Charly
Nancy A. John
Frank Vernon

SALINA BOOKSHELF
INC.

- 🧬 Diagnosing Diseases
- 💊 Personalizing Medicine
- 👶 Newborn & Carrier Screening
- 🎯 Targeting Cancer Treatments
- 🔍 Understanding How Genes Work
- 🌍 Studying Ancestry & Heritage
- 👮 Solving Crimes (Forensics)
- 🌱 Improving Crops & Food
- 🐄 Breeding Healthier Animals
- 🐼 Protecting Endangered Species

PERSPECTIVES ON GENETICS IN THE NAVAJO NATION (NNR-17.281)



OVERVIEW

- The “Perspectives on Genetic Research in the Navajo Nation” project gathers community input to shape a future genetic policy, provide genetics education, and highlight Diné community voices.
- The research project includes surveys, interviews, and deliberative discussions.

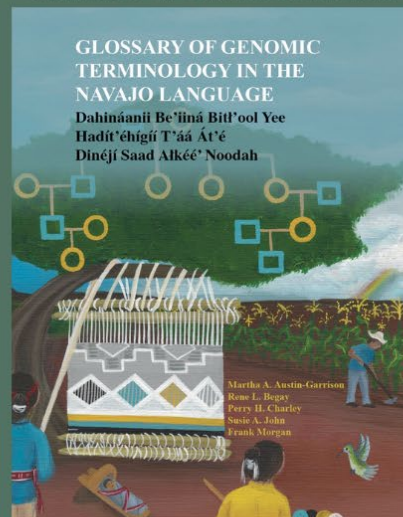
VOICES OF THE DINÉ SUMMIT

Educational event hosted in Flagstaff, AZ in May 2025 with 140 attendees and featured 40 Diné presenters



GENETICS GLOSSARY

Translation of genetics terms into the Navajo language.
Available at Salina Bookshelf.



PROJECT TIMELINE

2002

A moratorium on genetic research conducted within the Navajo Nation was approved by the Navajo Nation Council.

2017

The “Perspectives” study was approved by the Navajo Nation Human research Review Board (NNHRRB).

2017-2018

Interviews were held with 47 Navajo people to understand their views on genetic research.

2018-2019

A survey of 690 Navajo people about their opinions and perspectives on genetic research was conducted.

2021

A survey was conducted with 29 researchers with NNHRRB approved projects.

2022

A virtual deliberation with Diné research & healthcare professionals was held.

2024

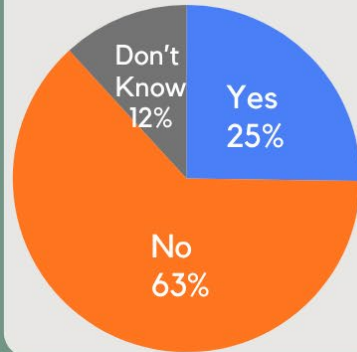
Two in-person deliberations with Diné community members and cultural leaders were held.

2025

The Glossary of Genomic Terminology in the Navajo Language was published and the Voices of the Diné Summit was held in Flagstaff, AZ.

COMMUNITY SURVEY

Knowledge of the Moratorium



690 Diné participants shared their views on genetic research.

75% had no knowledge of the moratorium before taking the survey.

Themes from survey responses

1. Need for more information and education on genetics and the moratorium
2. Conflicted about how they feel about moratorium and genetic research
3. Stressed the importance of health research to Navajo people

RESEARCHER SURVEY

Researchers with NNHRRB approved projects with a biomedical focus were invited to take the survey about these topics:

29 Participants:

59% White
31% Diné
4% Indigenous (non-Diné)
3% Asian
3% Hispanic or Latino

Learn about Approved NNHRRB Projects

Genetic Technologies and Analyses

Benefits and Risks of Genetic Research

Ethical Concerns about Genetic Research

Questions, Concerns, or Comments

Demographics of Researchers

- Researchers described potential health benefits to Navajo people like improved disease prevention and treatment
- Researchers considered building trust and engaging the community to be important when conducting research

OVERVIEW OF DELIBERATIONS



POTENTIAL BENEFITS & HARMS OF GENETIC RESEARCH

POTENTIAL BENEFITS

1. Valuable information from research for healthcare
2. Supporting Indigenous researchers
3. Including cultural values for respectful research that supports sovereignty

POTENTIAL HARMS

1. Disregard of cultural norms
2. Lack of oversight and accountability
3. Westernizing health and healing

PRIORITIES FOR RESEARCH

- Being transparent about the research
- Ensuring truly informed consent
- Building trust with the community
- Ensuring no research participants are harmed
- Supporting Diné researchers to lead future genetic studies
- Publishing accurate and appropriate information
- Giving presentations to the community

Ahéhee'!



Publications

History of Genetic Research
Involving Navajo People



Community Survey



Virtual Deliberation



Researcher Survey



PERSPECTIVES CONTACT

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