National Indian Health Board

TRIBAL HEALTH DATA SYMPOSIUM 2025 REPORT

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EXECUTIVE SUMMARY

The National Indian Health Board (NIHB) hosted the 2025 Tribal Health Data Symposium (THDS) in Washington, D.C. on March 4 and 5, 2025. More than 750 attendees participated in the Symposium in-person or online.

Major Topics

The major topic areas of the Tribal Health Data Symposium were:

- **Advancing Tribal Data Sovereignty:** Discussions focused on barriers to accessing federal and state data, Tribal governance over health data, and ensuring Indigenous communities control their own narratives.
- **Reforming Tribal Health Data Infrastructure:** Panelists examined systemic challenges in federal data-sharing policies, racial misclassification, and the lack of AI/AN-specific dashboards for real-time public health insights.
- **Empowering Communities Through Indigenous Evaluation:** Sessions highlighted culturally grounded approaches to data collection and research, ensuring that AI/AN communities define success on their own terms.
- **Using Data to Identify Gaps and Solutions:** Experts explored disparities in AI/AN health, from chronic disease to maternal health, emphasizing the need for stronger data-driven policies and funding.
- **Building Tribal Data Workforce Capacity:** Presenters emphasized the importance of investing in Tribal Colleges and Universities (TCUs), training epidemiologists, and creating sustainable career pathways in health data.

Recommendations to CMS

Throughout the two days of the Data Symposium, a number of consistent themes emerged as priorities from Indian Country that can help Centers for Medicare and Medicaid Services (CMS) and other policymakers develop more effective, relevant, and ethical data policies, data systems, and data products. Based on these themes, NIHB makes the following recommendations.

Implement Training & Guidance for CMS Operational Divisions

This training or guidance should be co-created with Tribes and include the following elements:

- Tribal Sovereignty & Legal Underpinnings of Tribal Data Issues
- Culturally Respectful Approach to Data
- Tribal Engagement throughout the Data Cycle
- Improving Race and Ethnicity Data

Strengthen Tribal Protections in Governance of CMS Data

CMS should hold Tribal Consultation on CMS policies related to CMS data governance and access to Tribal data.

Expand Tribal Access to CMS Data

CMS should adhere to HHS policy and respect for Tribal rights and sovereignty.

Design Tribally-Informed Quality Metrics and Evaluation

CMS should strive for improved quality metrics, programs, and evaluation with increased Tribal engagement and incorporating Tribal priorities.

Develop Tribally-Informed Dashboards and Data Products

CMS should make certain Tribes have significant input into the creation of data products.

Create a Tribal Data Fellowship Program

CMS should explore creating a Tribal data fellowship program to expand the data workforce.

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INTRODUCTION

The National Indian Health Board (NIHB) hosted the 2025 Tribal Health Data Symposium (THDS) in Washington, D.C. on March 4 and 5, 2025. This biannual gathering brought together Tribal leaders, policy experts, public health professionals, and government agencies to explore how data can strengthen the health and sovereignty of Tribal communities. The THDS fostered action-oriented discussions on how to reclaim ownership of Tribal health data, advocate for policy changes, and build collaborative solutions that reflect the unique needs of AI/AN communities. More than 750 attendees participated in the Symposium in-person or online. See the Appendix for the demographics of attendees.

This Symposium has grown dramatically over the past several years, reflecting the increasing importance of and attention to data issues in Indian Country. Response to the Data Symposium has been overwhelmingly positive, and evaluations from participants emphasize the unique and critical role it plays as a national forum with a Tribally led, culturally driven agenda focused on timely and relevant data topics. Participants described the event as thought-provoking, valuable, enlightening, authentic, empowering, informative, and inspiring.

Below are some quotes from participants regarding the Data Symposium:

> "The data symposium was an incredible opportunity to learn from groups and organizations about what's happening in real time and the areas for partnership and community building."

> "Data is sacred and it's part of our relatives. Their stories are important and the need to care for the data set is paramount. We've always been researchers, scientists, & data analysts."

> "[The data symposium] brought together passionate and amazing professionals committed to tribal health at such a critical time."

“Enlightening. We are our own data repositories and have been researchers for generations.”

“Culturally relevant. Tribal Sovereignty. Brilliant. Educational.”

Over the two days, there were formal presentations, panel discussions, poster presentations, and interactive sessions. This report contains a summary of these presentations and discussions, highlighting the concerns and suggestions from each presenter and session. Then, NIHB provides recommendations for Centers for Medicare and Medicaid Services (CMS) to help address the issues and concerns highlighted over the two days. The Symposium agenda is included in the Appendix. All materials for the event including the presentations, session recordings, posters, and all other resources can be found at **nihb.org**. NIHB extends our heartfelt gratitude to all participants, presenters, and partners who contributed to the success of the 2025 Tribal Health Data Symposium. Your dedication and insights are invaluable as we work together to enhance the health and well-being of our communities.

Acknowledgements

NIHB would like to thank the CMS Tribal Technical Advisory Group (TTAG) Data Subcommittee for input on the agenda for the Symposium. We also acknowledge both the TTAG Data Subcommittee and TTAG members for providing a forum for NIHB to present and discuss the issues of concern raised in the Symposium.

DAY ONE PRESENTATIONS

NIHB's CEO **A.C. Locklear** opened the Symposium by explaining how "data, at its heart, is storytelling." To share data is to tell the story of people. These stories can uplift the realities that people experience, but they can also be used to mislead by excluding people and falsifying narratives. Locklear challenged Symposium participants to continually think about what stories are told when data is shared. "How are we using our data to tell the stories of our peoples' strengths? How do we tell the story of not only where we've been or where we are, but the future we intend to create?"

Circles Within Circles Presentation

Dr. Donald Warne and Brinda Sivaramakrishnan from Johns Hopkins University Center for Indigenous Health presented on their Tribally-driven research agenda from seven Great Plains behavioral health programs, including Tribes, not-for-profit programs, and Indian Health Service health centers. They used a Tribal Community Based Participatory Research (CBPR) approach to understand areas requiring further research; and a data dissemination process that generated practical actions and ideas towards improving outcomes in participating communities.

The process reflects Tribal Data Sovereignty by generating data collaboratively sourced from Tribal communities and returning it in a way that is useful, respectful, and generative of further collaboration and support from the research entity. The goal is to ensure that research impacts are long-term, sourced and supported by community, and endorsed by Tribal health leaders.

As part of the dissemination process, they heard from several of the Tribal Health Directors. The presentation included audio quotes from many of the Behavioral Directors who were involved in the study about the definition of data sovereignty. Donald Warne summarized the statements of the Tribal Health Directors by saying, "These files are the spirit of these people. It's not just numbers but these are community members."

The presentation highlighted the importance of community driven solutions. Research agendas that have been determined by the community establish respectful engagement for the future. The research described by Dr. Warne and Ms. Sivaramakrishnan represents an Indigenous-led response to the crisis of addiction that has impacted entire communities, families, and individuals across generations in the Great Plains.

CMS Tribal Data Learning Community (TDLC) Presentation

Tribal Epidemiology Center (TEC) staff members **Dr. Cheng Wang** (from the Great Plains Tribal Leaders Health Board) and **Dr. Ming Gong** (from the Albuquerque Area Indian Health Board) presented on their experiences with the CMS Tribal Data Learning Community (TDLC) program for TECs. Their presentations highlighted the importance of this one-year pilot program, as CMS data is crucial for learning about the health of American Indian/Alaska Native communities.

However, they also brought up several challenges they faced, including: (a) the lack of a designated pathway for Tribes and TECs to access CMS data despite their status as public health authorities, requiring TDLC participants to apply through the Research pathway and undergo IRB approval; (b) the significant time and resources needed to access and analyze the data effectively, which may not be feasible outside of the TDLC program (for example, the cost to access the data, hiring and training staff to perform the analyses); and (c) several procedural barriers resulting in delays and denial of access to CMS data. Given these challenges, the presenters emphasized the need for a streamlined application process for Tribes and TECs, ongoing training and resources from CMS given the complexity of the data, and continued support for a learning collective for members to share their experiences and their code. Currently, the TDLC program only includes Tribal Epidemiology Centers.

Reforming Tribal Health Data Infrastructure Panel

The first panel of Day One featured a variety of speakers who came together to discuss how Tribal health data systems, practices, and infrastructure can be reformed to improve the health of American Indians/Alaska Natives. **Isabel Algrant** and **Saundra Mitrovich** explored how the design of data systems can be biased, leading to underrepresentation of certain populations (for example, racial misclassification of AI/ANs) and contributing to health disparities. **Jessica Perfette** presented on how fatality review efforts that center Tribal voices can build Tribal capacity and reinforce Tribal sovereignty. Lastly, **Kaitlyn Guild** and **Elisa Garnenez** discussed how mobile health programs help improve access to care for hard-to-reach populations and the impact of evaluation metrics on advocacy and sustainability for these programs.

Across all three presentations, panelists agreed on several practices to improve AI/AN health outcomes and reinforce Tribal data sovereignty. Panelists emphasized the need to incorporate those individuals represented in the data in the process of reforming data governance, which can also help build trust. Communities and coalitions also need to be consulted with as early on as possible and at each stage of the data lifecycle. This may look like engaging Tribal and community leaders in data collection, analysis, and dissemination, and asking them what their interpretation of results may be, allowing for conclusions that are more aligned with Indigenous ways of thinking. Lastly, the role of qualitative data in highlighting lived experience was uplifted, with suggestions to lean on existing community relationships, such as the trust between a patient and their provider.

Tribal Data Modernization Implementation Center Fireside Chat

Amanda Franklin from National Network of Public Health Institutes (NNPHI) and **Sarah Price** from NIHB discussed the CDC-funded Tribal data modernization implementation center. At the time of the presentation, NNPHI was finalizing the contract with Chickasaw Health Consulting to be the agency to support Tribes and Tribal serving organizations for the data modernization program. NNPHI wants to collect information from the Tribes to get a sense of where Tribes are in the process. The two priorities of the program are electronic case reporting (eCR) and health information exchange. NNPHI hopes to recreate collaboration opportunities to respect Tribal Sovereignty. They plan to engage with Tribes during the summer of 2025. The project runs through the fall of 2027.

Census Data Roundtable

During this session, **Jessica Imotichey**, Chickasaw Nation Department of Health, discussed the role of the 2030 Census Advisory Committee (CAC). (Since this presentation, as of March 4, 2025, at 5 p.m., the 2030 CAC has been dissolved.) They had been partnering with the U.S. Department of Housing and Urban Development (HUD) and their Tribal Affairs office to get updated housing responses and early participation for the 2030 Census. Ms. Imotichey also discussed the new Office of Management and Budget (OMB) request to review race and ethnicity coding, particularly for developing guidance in how Tribal affiliation data is recorded and interpreted. The comment period has closed, but they will accept corrections to their coding, as the data is only as good as what is collected and coded properly.

In this same session, **Saundra Mitrovich**, Native American Rights Fund (NARF) Consultant, discussed the role of the Native Counts Census group. Native Counts was formed from a concern about the undercount of AI/ANs during the 2020 Census. They have learned about strategies used by communities who were undercounted to help increase representation for the 2030 Census. Ms. Mitrovich also discussed The Opportunity Project (TOP) spring in the Spring of 2024 which helped to build stronger pathways to grants and funding for Indigenous communities.[1]

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[1] See: https://opportunity.census.gov/sprints/.

Indigenous Evaluation Framework Interactive Session

After a poster session[2], Ms. Lannesse Baker and Ms. Banita McCarn led an interactive discussion on learning how to apply the **Urban Indian Health Institute (UIHI)'s Indigenous Evaluation framework** to Tribal projects, programs, and initiatives. They opened the session with a presentation on UIHI's Indigenous Evaluation framework and its four values: (1) community is created wherever Native people are; (2) resilient and strengths-based; (3) decolonize data; and (4) community-centered. Ms. Baker asserted that, "research and evaluation are Indigenous values" and that Native people must be included in research to "tell their own stories." Ms. McCarn shared examples of Indigenous Evaluation methods, including talk story, photo narrative, and using culturally attuned imagery and art. Both speakers challenged the idea of what is considered "data," stating that "stories are data, art is data, [and] winter counts are data."

Following the presentation, the speakers asked Symposium participants to discuss challenges they face in implementing Indigenous Evaluation and to brainstorm potential solutions. According to an evaluation of the session from UIHI, the top four challenges as identified by 87 participants were as follows: (1) Indigenous voices, representation, and methods not being centered in evaluation; (2) lack of organizational capacity; (3) challenges balancing priorities between funder and community; and (4) challenges with buy in. Potential solutions to these common challenges include involving Indigenous people and culture throughout the evaluation process, utilizing partnerships and trainings to build capacity, and incorporating relevant staff and advisory groups in program development and implementation.

To view the evaluation summary prepared by UIHI, see the Appendix.

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[2] All posters are on the symposium website: https://www.nihb.org/tribal-health-equity-data-symposium/.

DAY TWO PRESENTATIONS

Updates on Federal Data Policies & NIHB Resources

Dr. Rochelle Ruffer, **Carrie Field**, and **Jeannie Le** from the National Indian Health Board shared updates on changes in data-related federal policies, current NIHB data projects, and new data resources. A highlight of the presentation was a discussion of the new policies from U.S. Department of Health and Humans Services on data access for Tribes and TECs[3]. These policies, effective as of December 2024, establish a department-wide policy for how HHS will provide Tribes and Tribal Epidemiology Centers with federally-held data, including the scope of data available, the process to obtain data, and the expected timelines for processing Tribal requests for data. These policies are intended to "ensure the Department is sharing data with Tribes to the maximum extent permissible" – a longtime Tribal priority. Crucially, each division under HHS is instructed to "develop operating protocols and guidance for responding to data requests from Tribes that are specific to each Division's internal operations, data systems, and legal authorities" by December 2025. Presenters emphasized the importance of these policies in upholding the federal trust responsibility and honoring Tribal sovereignty, as well as for long-term improvement of health outcomes for Tribal communities.

Other new resources highlighted in the presentation included a new **Electronic Case Reporting Roadmap for Tribes and TECs**, the **2024 Public Health in Indian Country Capacity Scan**, **AI/AN Behavioral Health Infographics**, **NIHB's annual State Health Insurance Status Report**, and a **peer-reviewed journal article** on law and equity issues related to Tribal access to public health data and Tribal public health authority.

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[3] See: https://cdo.hhs.gov/s/tribal-data.

NIHB also provided updates on two data projects. The **IHS Full-Funding project** is funded by Robert Wood Johnson Foundation. The goal of the project is to estimate the cost of providing comprehensive healthcare services. The analysis will provide detailed information on existing disparities in health risks and service use. NIHB has partnered with Mathematica to develop a model and perform the analysis. The Medicaid analysis has been completed and presented to the Tribal Advisory group and at the "Using Data to Identify Gaps and Solutions" panel at the Tribal Health Data Symposium. The IHS/CMS Data match is making progress. NIHB has completed the paperwork for the match for 2021 and 2022 can occur. Once the match has been performed, we will know how many IHS users were enrolled in Medicaid for 2019, 2020, 2021, 2022 and 2023. This information will help to compare to the existing data on Medicaid enrollment, specifically American Community Survey. NIHB will present the results to the TTAG Data Subcommittee and TTAG.

Biology of Tears: MMIP Data Presentation

Abigail Echo-Hawk provided a keynote address on the second day of the Symposium illuminating the role of data in responding to the ongoing crisis of Missing and Murdered Indigenous People (MMIP). Indigenous people not only go missing on- and off-reservations, but they also are being excluded in data systems. Ms. Echo-Hawk described a **2018 UIHI report**, which for the first time provided data on the MMIP crisis occurring in urban areas across the country. The report, alongside advocacy efforts, contributed to the passage of federal MMIP legislation such as Savanna's Act and the Not Invisible Act. However, challenges remain in federal implementation of these acts, as a **2021 Government Accountability Office (GAO) report** found that the Department of Justice (DOJ) had unfulfilled obligations under these acts past their statutory deadlines. Ms. Echo-Hawk's presentation emphasized how racial misclassification, underreporting (due to distrust of law enforcement and its lack of response to MMIP cases), and misclassification of cause of death (for example, as suicide) all contribute to the erasure of MMIP data.

Despite these barriers to improving MMIP data, Ms. Echo-Hawk asserted in her presentation that Native people are not a problem to solve, “we are every single one of the answers.” In 2024, UIHI released a report to assist law enforcement officers in their collection, analysis, and reporting of MMIP data. One of the key recommendations from this report is to collect race and ethnicity data for everyone, regardless of their appearance. Additionally, Ms. Echo-Hawk emphasized the importance of upholding Tribal data sovereignty by conducting Tribal Consultation and Urban Confer. Ms. Echo-Hawk brought up as an example the recent establishment by CMS of a diagnosis code for Missing and Murdered Indigenous People. She questioned the intent of gathering this data, how it will be used, and whether it would further stigmatize Indigenous people, urging CMS to conduct Tribal Consultation and seek feedback from Tribes on appropriate utilization of this code.

Using Data to Identify Gaps and Solutions Panel

This panel highlighted recent, diverse efforts to use data to identify Tribal health needs, disparities, and opportunities, with an emphasis on improving data quality. **Dr. Collette Adamsen** and **Elaina Seep** shared how there is currently a silent crisis in Indian Country in terms of lack of support networks for aging and disability. **Joel Earlywine** outlined a project aimed at estimating the cost of fully funding the Indian Health Service (IHS) to provide accessible, high-quality healthcare for all American Indians/Alaska Natives. **Karuna Tirumala** described the Northwest Tribal Epidemiology Center (NWTEC)’s approach to providing data, stating that, “High-quality data are not useful unless they are in the right hands, or in the format that is most useful.” Finally, **Dr. Janelle Palacios** explored how differing definitions of “AI/AN” and biased collecting and reporting of racial and ethnic data can lead to inaccurate data on AI/AN health disparities, particularly for infant deaths.

Panelists discussed several key points in their presentations about using data effectively to advance Tribal health priorities. First, data must be accurate, inclusive, and timely. This includes correcting for racial misclassification, using definitions of "AI/AN" that reflect multiple races and ethnicities, and prioritizing recent data while incorporating community feedback in a way that does not compromise the timeliness of data sharing. Secondly, it is important to "fit the process to the community" when working with Tribes to collect data. Examples of this may include tailoring program surveys to include questions that the community is specifically interested in, or having the community become the researcher and supporting them in collecting their own data. This process can build trust, sustain relationships and uphold Tribal sovereignty. Lastly, educational efforts need to be directed at both Tribal members on the importance of reporting racial and ethnic data to ensure they are counted accurately, and at entities who report information for specific populations. Erasure of American Indians/Alaska Natives in data can lead to consequences where they are left out of important conversations. One Symposium participant described how AI/ANs have not been included in recent conversations at the Congressional level around Medicaid cuts and maternal health. The participant emphasized how AI/ANs are not a special interest group but rather hold a political status in addition to their racial and ethnic identities.

Data Workforce Roundtable

In the afternoon of Day Two, NIHB hosted a roundtable discussion focused on the current state of the Tribal health data workforce, gaps that exist, and strategies for how Tribes can expand their capacity for data roles like epidemiology, statistics, and informatics. **Dr. Jessica Dean** opened the roundtable by presenting data collected from the Public Health in Indian Country Capacity Scan (PHICCS), which showed that while staffing and funding are top priorities for many Tribal Health Organizations, the top unfunded positions were data-related (Epidemiologist, Biostatistician, and Data Analyst). **Ahniwake Rose** discussed how Tribal Colleges and Universities (TCUs) can help to fill gaps in the Tribal health data workforce, sharing health programs like NARCH-BIRCH (Native American Research Centers for Health – Building Indigenous Research Capacity in Health) that are currently offered at TCUs. **Pam Thunder** closed the presentation portion of the roundtable with a deep dive into the Ho-Chunk Nation Department of Health's journey through accreditation and building public health capacity.

Following the initial presentations, attendees had an open discussion with presenters on experiences related to efforts to improve Tribal health data workforce capacity. One participant shared their difficulties with finding external funding and staffing opportunities for Tribes. They mentioned how culturally tailored, Tribal-specific programs are consistently underfunded, while programs that are broader have more funding available, but also tend to be more competitive. TCUs can help address barriers around cultural competency through building a health research and education pipeline for AI/ANs. They serve as an excellent bridge by providing exposure to Tribal health data careers and the academic paths to reach those careers in Indian Country. However, TCUs often struggle to recruit and retain faculty, particularly for those with a PhD and who teach math and science. Another participant shared that while many state health departments may have more staff trained to work with data and who can provide technical assistance to Tribes, they often lack the knowledge of how to work with Tribes. Once these partnerships with health departments and other external organizations are established, however, they can support Tribes and Tribal health departments seeking to strengthen their data workforce. This can be seen through the Ho-Chunk Nation Department of Health's partnerships with external organizations to assist with initial efforts to develop public health capacity and achieve public health accreditation.

Electronic Case Reporting (eCR) Presentation

Sophie Sembajwe (NIHB), **Myca Grant Hunthrop** (National Council of Urban Indian Health, or NCUIH) and **River Carroll** (NCUIH) presented together on the process of eCR implementation from Tribal and Urban Indian Organization (UIO) perspectives. eCR is a crucial system for Tribes, TECs, and UIOs to exercise their rights as public health authorities to receive timely data for health decision-making. eCR strengthens Tribal data sovereignty by ensuring Tribes have access to their own data.

NIHB and NCUIH have supported Tribes, TECs, and UIOs in implementing eCR systems, which has been met with both successes and challenges. Full implementation of eCR has taken place at three Tribes and one TEC, while soft implementations have occurred at six UIOs. Through these implementation processes, NIHB and NCUIH have gathered knowledge to support future capacity building around eCR in Indian Country. Challenges around implementing eCR include technical delays, communication challenges with electronic health record (EHR) software developers, technology upgrades, receiving buy-in from healthcare or health department leadership (and Tribal leadership for Tribes), and insufficient staffing due to turnover. Tribes specifically face jurisdictional challenges with reservations that do not align with zip codes.

To view a roadmap created by NIHB on how Tribes and TECs can use eCR to improve data access, click [here].

A New Legal Framework for Tribal Health Data Sharing Fireside Chat

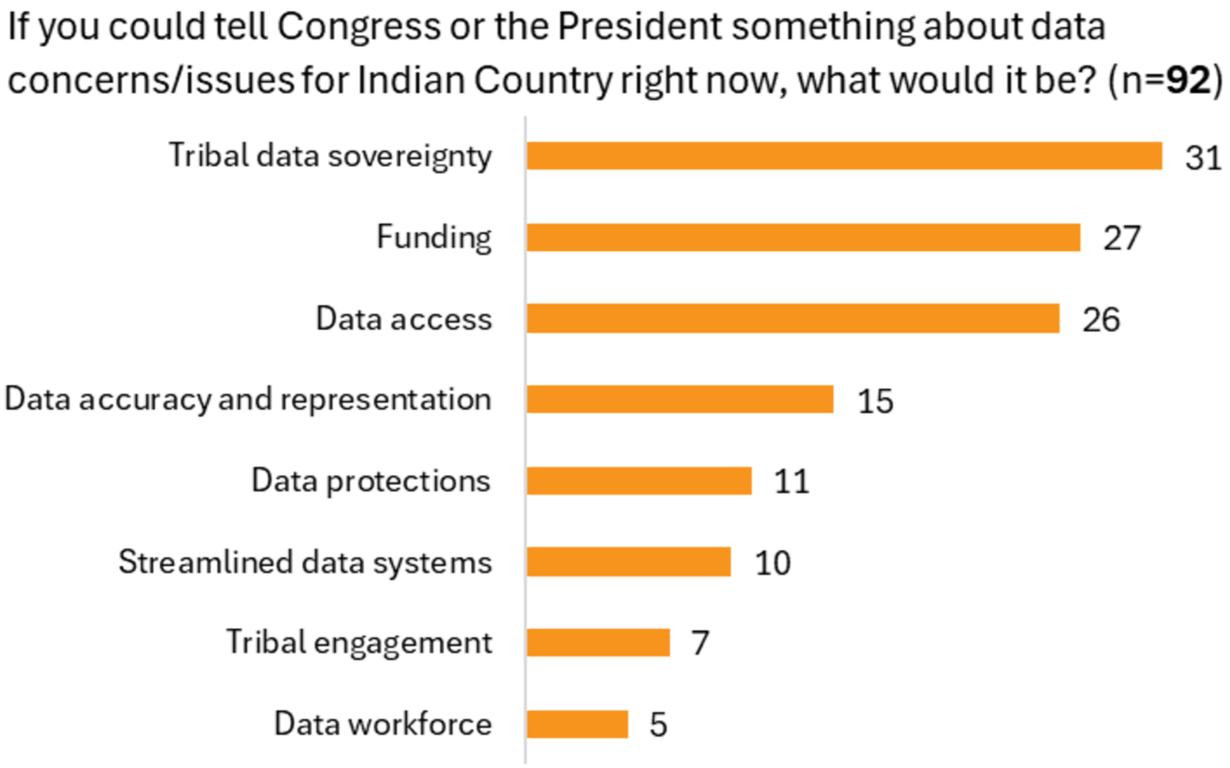
The Symposium concluded with a fireside chat featuring Ms. Chris Alibrandi O'Connor. Ms. Alibrandi O'Connor, in her role as a legal consultant, helped facilitate the creation of a standard data sharing framework between the state of Alaska and the Alaska Native Tribal Health Consortium (ANTHC). During the fireside chat, she answered questions and provided insights about this process. She explained that state governments, especially those with limited legal resources, usually do not have a complete understanding of Tribal and TEC public health authority. While Tribes have inherent public health authority due to their status as sovereign nations, TECs are granted public health authority through federal statute for the purposes of data access. In addition, there was no policy of standardized data sharing between the state of Alaska and ANTHC, and both sides lacked legal resources. Therefore, data requests from ANTHC to the state of Alaska ran into the same issues again, which had to be renegotiated with each data request.

Given this, the state of Alaska and ANTHC developed a standard legal framework that could be used for every data request, which reduced the amount of time and legal resources consumed during each renegotiation. This framework consisted of an Umbrella Agreement (including recognition of sovereignty and legal authority to receive data for ANTHC), Data Disclosure

Appendices, and Data Request Forms. This type of legal framework can be applied for States who are open to wanting to share more data with TECs and Tribes and have limited legal resources.

PARTICIPANT RECOMMENDATIONS

Participants shared their highest priority recommendations for policymakers in the evaluation at the end of the event. The following themes were identified amongst responses to the question, “If you could tell Congress or the President something about data concerns/issues for Indian Country right now, what would it be?” This question was answered by 92 participants.



- **Tribal data sovereignty:** Honoring trust and treaty obligations by granting Tribes access to and ownership of their data.
- **Funding:** Sustainable funding for Tribal public health priorities and health care services, as well as investing in Tribal data systems and infrastructure.
- **Data access:** Providing Tribes and TECs with timely access to accurate, Tribal-specific health data.

- **Data accuracy and representation:** Ensuring data that is collected and reported about Tribes and AI/AN people are corrected for racial misclassification, are included as a separate category from “Other,” and that AI/ANs with more than one race are represented.
- **Data protections:** Taking steps to prevent the misuse and exploitation of AI/AN data. For example, developing data use agreements that outline what can and cannot be done with Tribal data.
- **Streamlined data systems:** Building Tribal data capacity and incorporating Tribes into the design and modernization of data systems to simplify data access.
- **Tribal engagement:** Increased engagement with Tribes from policymakers and ensuring Tribal participation in decisions impacting their health.
- **Data workforce:** Funding Tribal health data roles and investing in programs to engage and support youth interested in Tribal public health

RECOMMENDATIONS FOR CMS

Throughout the two days of the Data Symposium, a number of consistent themes emerged as priorities from Indian Country that can help CMS and other policymakers develop more effective, relevant, and ethical data policies, data systems, and data products. Based on these themes, NIHB makes the following recommendations.

Implement Training & Guidance for CMS Operational Divisions

As CMS expands training on working with Tribes, the findings from the Data Symposium can inform the creation of guidance to operating divisions within CMS that interact with Tribal data (including, for example, Medicare and Medicaid data from Tribal citizens) to ensure such data is handled appropriately, Tribal rights are respected, and Tribal needs are met to improve health outcomes and reduce disparities. **This training or guidance should be co-created with Tribes and include the following elements:**

Tribal Sovereignty & Legal Underpinnings of Tribal Data Issues

Learning objectives for the training would include an understanding of the federal trust responsibility to Tribes, Tribal sovereignty, Tribal data sovereignty, public health authority and its implications in Indian Country, and the political status that American Indians/Alaska Natives have.

Training on Tribal sovereignty for data professionals should include additional particular emphasis on the fact that Tribes and Tribal Epidemiology Centers have public health authority and should be given the same access to the data as other health entities.

Culturally Respectful Approach to Data

CMS data staff should be aware of the cultural significance of data for Tribes and what this means for how data should be handled and used. All CMS Operational Divisions should enable and support a culturally respectful approach to data. As presenter Donald Warne reminded us, “These files are the spirit of these people. It's not just numbers but these are community members." CMS should work with CMS TTAG and Tribes to develop guidance for culturally respectful treatment of data and provide training, co-created with Tribes, for CMS staff who engage with data. This training and guidance should discuss Tribal views of what data is and its meanings for Tribal communities, and how this may be a more expansive worldview than Western scientists commonly understand. Relatedly, trainings should also cover the importance of cultural humility in treating data respectfully and interpreting results meaningfully.

Tribal Engagement throughout the Data Cycle

CMS trainings and guidance should clarify that one implication of Tribal sovereignty is that Tribes must have a say in every state of the data lifecycle, including: 1) what and how data is collected; 2) how data is analyzed and interpreted; 3) what and how data is published publicly; and 4) how Tribes can access and use CMS data about their citizens. CMS operating divisions should seek input from the CMS TTAG and through Tribal Consultation. Tribes have an ownership interest in the collection and use of data about their citizens. Tribes should also be involved in the development of new data variables, like Healthcare Common Procedure Coding System (HCPCS) codes, to ensure they will be useful and avoid any negative impact for Tribes. Research-oriented divisions of CMS have a particular responsibility to include Tribes at every stage of the research process.

Improving Race and Ethnicity Data

Several Symposium speakers discussed the importance of accurate race and ethnicity data for Tribes to be able to separate out data relevant for their communities. Speakers also addressed the longstanding issues in widespread inaccuracy of race and ethnicity data that contributes to lack of available data for Tribal public health purposes. CMS should work with Tribes to put together guidance for Medicaid programs, healthcare facilities, and CMS operating divisions in best practices for collecting race and ethnicity data, in a way that is both respectful and will lead to improved data quality.

Strengthen Tribal Protections in Governance of CMS Data

Tribal data sovereignty means that Tribes should have a say in how their data is used, by whom, and for what purpose. **CMS should hold Tribal Consultation on CMS policies related to CMS data governance and who has access to Tribal data**, especially related to research. CMS policies should include special protections for Tribal data to prevent the unauthorized use or misuse of data about Tribal citizens.

Expand Tribal Access to CMS Data

As sovereign nations and inherent public health authorities, Tribes have a right to access data about their own citizens, as is clarified in the HHS Tribal Data Access Policy. **To ensure CMS adherence to HHS policy and respect for Tribal rights and sovereignty, NIHB provides the following recommendations to improve Tribal access to CMS data:**

- CMS should provide adequate training to staff on the HHS Tribal Data Access Policy and Tribal Epidemiology Center (TEC) Data Access Policy and how they apply to CMS's data work.
- In compliance with the Data Access Policies, CMS must "develop operating protocols and guidance for responding to data requests from Tribes that are specific to each Division's internal operations, data systems, and legal authorities." The policies also emphasize that "such protocols and guidance shall ensure data is secure and sufficiently available" to Tribes and TECs. CMS should engage the CMS TTAG and Tribes in the development of implementation guidance to ensure Tribal needs and concerns will be fully addressed. The HHS policies state that this guidance should be complete by December 2025.
- As part of the Data Access Policies implementation guidance and protocols, CMS should create a streamlined process for Tribes and TECs to request and access the data they need. CMS must create a track for Tribes and TECs to access CMS data that recognizes the use of the data for public health reasons and not research. Currently, the only track available requires a research project and potentially IRB approval for many Tribes and TECs.

- CMS should reinstitute the TDLC program permanently and include Tribes as well as Tribal Epidemiology Centers (TECs). The inclusion of Tribes was also recommended from the 2023 Tribal Health Equity Data Symposium. Since the Tribal Health Data Symposium, the TDLC program has been cancelled.
- CMS should create protocols for keeping CMS-related portions of the Tribal Data Homepage updated and accurate.

Design Tribally-Informed Quality Metrics and Evaluation

Development of quality metrics, programs, and evaluation can be improved with increased Tribal engagement, and should incorporate Tribal priorities. The CMS TTAG and Tribes can provide critical input on the usefulness of potential quality metrics to support quality improvement for health care in Indian Country.

Develop Tribally-Informed Dashboards and Data Products

As in every other part of the data lifecycle, **Tribes should have significant input into the creation of data products**, including reports, dashboards, and other publications. Tribal input is critical to honor Tribal sovereignty; to ensure data shared supports the improved health of Tribal communities and is not stigmatizing; to ensure appropriate and accurate interpretation of data results within the full context; and to ensure a culturally respectful approach to data. Tribes need a say in which data gets publicly reported and how the story is told and framed. For data dashboards and similar products, Tribes can also provide valuable input on which data will be the most meaningful for improving health outcomes in Tribal communities. Furthermore, because “American Indian/Alaska Native” is a political status and not a race, data publications should report outcomes for all AI/AN, of any race or ethnicity combination (and lumping AI/AN into a “Other” or “Multi-Race” category is inappropriate). CMS can get seek Tribal input regarding data products from the CMS TTAG and through Tribal consultation.

Strengthen Tribal Protections in Governance of CMS Data

Tribal data sovereignty means that Tribes should have a say in how their data is used, by whom, and for what purpose. **CMS should hold Tribal Consultation on CMS policies related to CMS data governance and who has access to Tribal data**, especially related to research. CMS policies should include special protections for Tribal data to prevent the unauthorized use or misuse of data about Tribal citizens.

Expand Tribal Access to CMS Data

As sovereign nations and inherent public health authorities, Tribes have a right to access data about their own citizens, as is clarified in the HHS Tribal Data Access Policy. **To ensure CMS adherence to HHS policy and respect for Tribal rights and sovereignty, NIHB provides the following recommendations to improve Tribal access to CMS data:**

- CMS should provide adequate training to staff on the HHS Tribal Data Access Policy and Tribal Epidemiology Center (TEC) Data Access Policy and how they apply to CMS's data work.
- In compliance with the Data Access Policies, CMS must "develop operating protocols and guidance for responding to data requests from Tribes that are specific to each Division's internal operations, data systems, and legal authorities." The policies also emphasize that "such protocols and guidance shall ensure data is secure and sufficiently available" to Tribes and TECs. CMS should engage the CMS TTAG and Tribes in the development of implementation guidance to ensure Tribal needs and concerns will be fully addressed. The HHS policies state that this guidance should be complete by December 2025.
- As part of the Data Access Policies implementation guidance and protocols, CMS should create a streamlined process for Tribes and TECs to request and access the data they need. CMS must create a track for Tribes and TECs to access CMS data that recognizes the use of the data for public health reasons and not research. Currently, the only track available requires a research project and potentially IRB approval for many Tribes and TECs.

Create a Tribal Data Fellowship Program

CMS should explore creating a Tribal data fellowship program to expand the data workforce. Given that many Tribes do not have epidemiologists or biostatisticians, a Tribal data fellowship program would help to build Tribal capacity to access and analyze CMS data and improve the health of American Indians/Alaska Natives.

CONCLUSION

The Tribal Health Data Symposium provided a valuable and timely opportunity for Tribal data experts from a variety of health-related disciplines to come together for discussion, collaboration, problem-solving, and community building around high-priority data topics. NIHB will present the outcomes from the Data Symposium to the CMS Tribal Technical Advisory Group (TTAG) and follow up with CMS on the recommendations in this report. NIHB hopes to have a webinar series on specific data topics to continue the conversation until the next Tribal Health Data Symposium planned for 2027.

APPENDIX

Symposium Agenda

Tuesday, March 4, 2025

8:30am | Breakfast and Check-In

9:00am | Welcome Prayer and Opening Remarks

- A.C. Locklear (Lumbee Tribe of North Carolina), CEO, National Indian Health Board (NIHB)
- Dr. Rochelle Ruffer, Tribal Health Data Project Director, NIHB

9:25am | Circles Within Circles: Co-Creating Tribally Driven Research & Practice Agendas

- Dr. Donald Warne (Oglala Lakota), Co-Director, Johns Hopkins University Center for Indigenous Health (JHU CIH)
- Loretta Grey Cloud (Kul Wicasa Lakota and Hunkpati Dakota), Administrative Coordinator, JHU CIH
- Brinda Sivaramakrishnan, Research Associate, JHU CIH

10:10am | CMS Tribal Data Learning Community (TDLC): Experiences from Two Tribal Epidemiology Centers (TECs)

- “Leveraging CMS Platform and TDLC Training & Support for AI/AN Population Analysis in Medicare and Medicaid”
    - Dr. Ming Gong, Biostatistician, Albuquerque Area Indian Health Board
- “Navigating the Data Landscape: GPTEC's Journey with CMS Data for AI/AN Population”
    - Dr. Cheng Wang, Biostatistician, Great Plains Tribal Leaders’ Health Board

10:45am | Morning Break

11:00am | Panel: Reforming Tribal Health Data Infrastructure

- “Centering Tribal Sovereignty Throughout Data Integration: Addressing Biases in Data Systems and Practices”
    - Isabel Algrant, Assistant Director of Training and Technical Assistance, Actionable Intelligence for Social Policy
    - Saundra Mitrovich (Tyme and Yahomee Maidu), Civic Engagement Consultant, Native American Rights Fund

- “Equipping Tribes to Use Data Systems to Achieve Health Priorities and Uphold Sovereignty”
    - Jessica Perfette (Cherokee Tribe of Northeast Alabama), Tribal Liaison, National Center for Fatality Review and Prevention (NCFRP)
    - Gretchen Martin, Technical Assistance Manager for Child Death Review and Fetal and Infant Mortality Review, NCFRP
- “Measuring Impact, Sustaining Care: Data-Driven Strategies for Tribal Mobile Health Programs”
    - Kaitlyn Guild, Manager of Evaluation and Strategic Relationships, Mobile Health Map
    - Elisa Garnenez (Navajo/Diné), Patient Registration and Benefits Specialist, Fort Defiance Indian Hospital Board Mobile Health Program
- Moderator: Carrie Field, Senior Policy Analyst, NIHB

12:10pm | Lunch

1:10pm | Fireside Chat: Tribal Data Modernization Implementation Center

- Speaker: Amanda Franklin, Senior Partnerships Manager, National Network of Public Health Institutes
- Moderator: Sarah Price, Public Health Policy and Programs Associate Director, NIHB

1:30pm | Roundtable: Census Data

- Jessica Imotichey (Chickasaw), Health Policy and Legislative Analyst, Chickasaw Nation Department of Health
- Saundra Mitrovich (Tyme and Yahomee Maidu), Civic Engagement Consultant, Native American Rights Fund
- Moderator: A.C. Locklear (Lumbee Tribe of North Carolina), Interim CEO, NIHB

2:10pm | Poster Session and Afternoon Break

3:00pm | Interactive Session: Indigenous Evaluation Framework - Storytelling for Community, By Community

- Lannesse Baker (Turtle Mountain Band of Chippewa), Public Health Associate Officer, Urban Indian Health Institute (UIHI)
- Banita McCarn (Koyukon Athabascan), Evaluator II, UIHI

4:30pm | Adjourn

Wednesday, March 5, 2025

8:30am | Breakfast

9:00am | Opening Remarks and Updates from NIHB

- Dr. Rochelle Ruffer, Tribal Health Data Project Director, NIHB
- Carrie Field, Senior Policy Analyst, NIHB
- Jeannie Le, Tribal Health Data Project Analyst, NIHB

9:30am | Biology of Tears: MMIP Data

- Abigail Echo-Hawk (Pawnee), Director, Urban Indian Health Institute (UIHI)

10:35am | Morning Break

10:50am | Panel: Using Data to Identify Gaps and Solutions

- “Elder Data Collection in Our Communities and Urban Sites: Thirty Years of Best Practices”
    - Dr. Collette Adamsen (Turtle Mountain Chippewa), Director, National Resource Center on Native American Aging (NRCNAA)
    - Elaina Seep, Senior Policy Specialist, NRCNAA
- “Estimating the Cost of Providing Comprehensive Healthcare Services through the Indian Health Service”
    - Joel Earlywine, Health Researcher, Mathematica
- “Development and Delivery of AI/AN Health Data to Northwest Tribes through State-wide Community Health Profiles”
    - Karuna Tirumala, Chronic Disease and Cancer Epidemiologist, Northwest Tribal Epidemiology Center
- “Misreporting and Underreporting of AI/AN Data in Fatality Review”
    - Dr. Janelle Palacios (Salish and Kootenai from Montana’s Flathead Indian Reservation), Founder, Encoded 4 Story
- Moderator: Rochelle Ruffer, Tribal Health Data Project Director, NIHB

12:10pm | Lunch

1:10pm | Roundtable: Data Workforce

- “2024 Public Health in Indian Country Capacity Scan (PHICCS): A National Snapshot of the Capacity of Tribal Public Health Systems”
    - Dr. Jessica Dean, Public Health Policy and Programs Manager, NIHB
- “The Role of Tribal Colleges/Universities (TCUs) in Building the Tribal Health Data Workforce”
    - Ahniwake Rose (Cherokee and Muscogee - Creek), CEO, American Indian Higher Education Consortium

- “PHAB Accreditation and Our Data Journey”
    - Pam Thunder, Environmental Health Program Manager, Ho-Chunk Nation Department of Health
- Moderator: Carrie Field, Senior Policy Analyst, NIHB

3:00pm | Afternoon Break

3:15pm | Electronic Case Reporting (eCR) for Tribes, TECs, and Urban Indian Organizations (UIOs)

- Sophie Sembajwe, Public Health Policy and Programs Lead, NIHB
- Myca Grant Hunthrop, Public Health Project Coordinator, National Council of Urban Indian Health (NCUIH)
- River Carroll (Cheyenne-Arapaho), Policy and Communications Associate, NCUIH

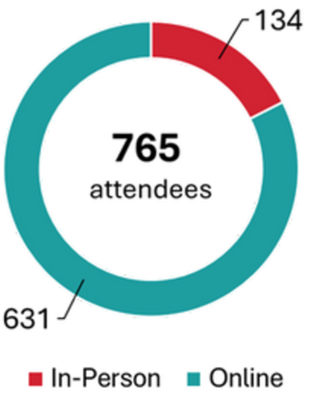
3:50pm | Fireside Chat: A New Legal Framework for Tribal Health Data Sharing: The Alaska Experience

- Christine Alibrandi O’Connor, Managing Director and Owner, CAOC Consulting
- Moderator: Carrie Field, Senior Policy Analyst, NIHB

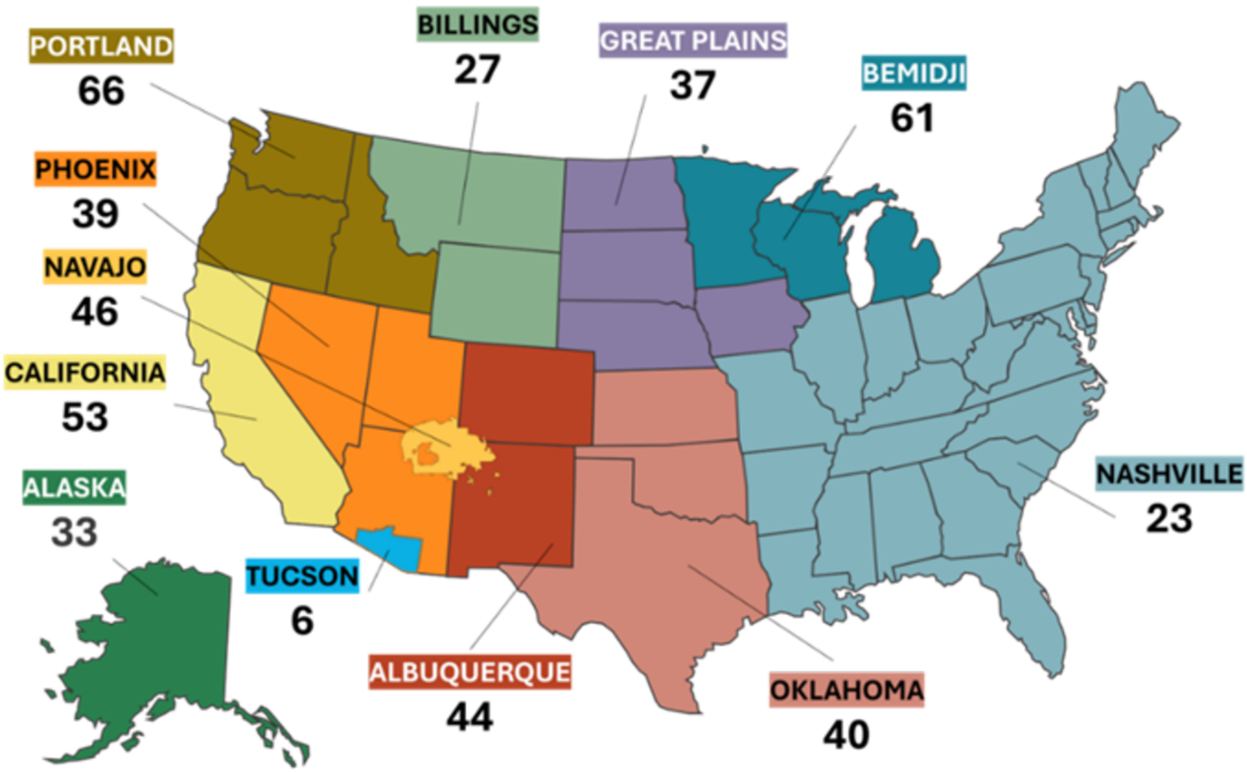
4:15pm | Closing Remarks and Adjourn

- Dr. Rochelle Ruffer, Tribal Health Data Project Director, NIHB

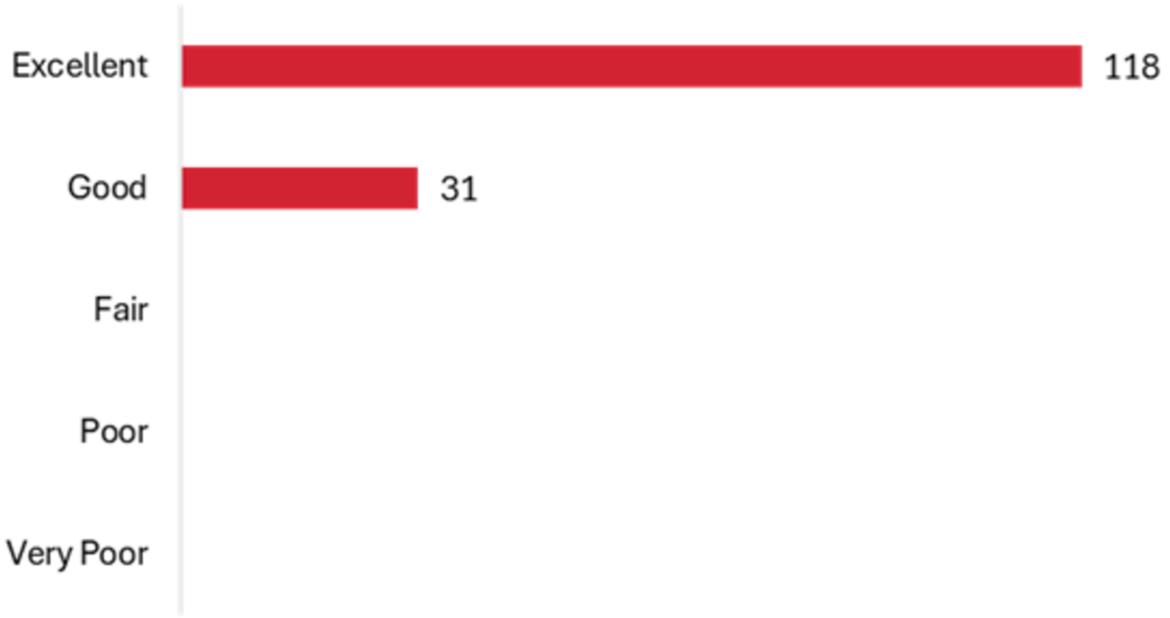
Participant Demographics & Evaluation Summary




Of **566** participants who reported their **employment setting**...



Please rate the overall quality of the data symposium. (n=**149**)



UIHI Indigenous Evaluation

INDIGENOUS EVALUATION PRESENTATION

Authors: Lannesse Baker(Anishinaabe), MPH, PhD Candidate, Banita McCarn(Koyukon Athabascan), MEd

Difficult Evaluation Issue Summary

For the “Indigenous Evaluation: For Community, By Community” presentation and activity hosted by UIHI at the Tribal Health Data Symposium on March 4th, 2025, hosted by the National Indian Health Board, 87 participants provided responses, comments, and votes to the following questions:

1. “What is a barrier or challenge to implementing Indigenous Evaluation at your organization?”
2. “What is a difficult evaluation issue your organization is grappling with?”

Through content[1] and thematic[2] analysis, challenges with implementing UIHI’s Indigenous Evaluation framework[3] were identified and voted on by participants. The four challenges with the most participant votes included Indigenous voices, representation, and methods not being centered in evaluation (votes=99); lack of organizational capacity (votes = 45); challenges balancing priorities between funder and community (votes = 29); and challenges with buy in (votes = 21). See Table 1 below.

Table 1: Counts of participant votes for each response theme

Response Theme	Votes
Indigenous voices, representation, and methods not being centered in evaluation	99
Lack of organizational capacity	45
Challenges balancing priorities between funder and community	29
Challenges with buy in	21

Participants identified solutions to common challenges to implementing Indigenous Evaluation which include the following:

- Include Indigenous people, values, and language in every step of the process, from the application of the grant to the evaluation deliverables
- Build capacity for Indigenous Evaluation through utilizing partnerships and providing training to Indigenous people on evaluation
- Include relevant program and evaluation staff and advisory groups are in the development and implementation of the program

References:

1. Krippendorff, K. (2004). Content Analysis: An Introduction to Its Methodology (2nd ed.) Thousand Oaks, CA: Sage Publications.
2. Braun, V., & Clarke, V. (2021). Thematic analysis: A practical guide. Sage.
3. Locklear S, Hesketh M, Begay N, Brixey J, Echo-Hawk A, James R. Reclaiming Our Narratives: An Indigenous Evaluation Framework for Urban American Indian/Alaska Native Communities. Canadian Journal of Program Evaluation. 2023;38(1):8-26. doi: https://doi.org/10.3138/cjpe.75518

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