ADVANCING HEALTH EQUITY WITH TRIBAL PERSPECTIVES ON DATA

EXECUTIVE SUMMARY

The National Indian Health Board (NIHB) held the Tribal Health Equity Data Symposium on Monday, September 25 and Tuesday, September 26 at American University in Washington, DC. Throughout the two days, we heard the following four themes detailed below. For each theme, NIHB provides several recommendations of actions the Centers for Medicare and Medicaid Services (CMS) can take to improve the situation.

The detailed report provides a summary of each presentation and session from the Symposium. Within the report, context and details are given as to how the recommendations may be successfully implemented. This executive summary provides a brief snapshot of the major themes and specific recommendations.

Honor Tribal Sovereignty and Reinforce Tribal Self-Determination

Presenters and participants shared the importance of meaningful Tribal consultation when federal agencies are making any decisions regarding the collection and dissemination of Tribal data. To make progress on addressing all cross-cutting data issues for American Indians/Alaska Natives (AI/ANs), data collectors from any organization (local, state, federal, university) must recognize and respect Tribal data sovereignty. In addition, Tribal Advisory Committees, CMS Tribal Technical Advisory Group (TTAG), public listening sessions, and other methods of Tribal engagement all play a role in ensuring Tribal perspectives and Indigenous ways of knowing are included and listened to.

Recommendations

- NIHB recommends CMS receive full Tribal review of the CMS Office of Minority Health (OMH) data white paper[1] before implementing actions.
- CMS leadership, through robust training, must ensure that CMS staff understand what Tribal data sovereignty is, including how to uphold and honor data sovereignty to ensure Tribes take ownership of, access, and control their data.
- CMS must make sure that ongoing Tribal consultation and the principles of data sovereignty guide all work that CMS undertakes involving data.

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[1] See: https://www.cms.gov/files/document/path-forwardhe-data-paper.pdf.

- NIHB recommends that CMS encourage CMS presenters on data information to the CMS TTAG to answer questions in a timely manner and provide progress updates to the TTAG on a regular basis as appropriate.
- The research performed by anyone at CMS, including the CMS Innovation Center, must include the Tribal voice.

Respect Indigenous Cultures, Values, and Ways of Knowing

Participants uniformly expressed the importance of honoring Tribal culture. It is important to include Tribal language, culture, and ceremonies within the protocol of any research studies. Data, research, and reports about AI/AN people should be grounded in Tribal cultural perspectives and priorities.

Recommendation

- CMS must adopt a policy that Tribal cultural considerations, ways, and methods are considered, included, and encouraged in 1115 Waivers.

Build Trust through Authentic Relationships and Trustworthy Data Stewardship

Collectors of data must work with the community to gain permission and ensure they are adhering to Tribal nation rules, requirements, and protocols to gain cultural understanding, build respect and foster reciprocity. For AI/ANs to be more comfortable trusting institutions with health data, data collectors and users need to focus on building relationships and institutionalizing transparent practices that keep data secure.

Enable Equitable Access to Quality Data

Presenters and participants discussed their concerns over the accessibility, accuracy, and quality of data for AI/ANs. AI/ANs are often invisible in the data and the political status of many AI/ANs is not considered when collecting race data. Many data concerns stem from potential racial misclassification and missing data. Several participants also spoke of their mistrust in providing their race and Tribal affiliation data due to experiences of discrimination in the health care setting.

The lack of access to data for Tribes and Tribal and Tribal Epidemiology Centers (TECs) was discussed at length. While the U.S. Department of Health and Human Services (HHS) recently called for Tribal consultation on a data sharing policy for

Tribes and TECs,[2] data access challenges occur at both the federal and state levels.

Recommendations

- CMS can help with communication and relationship building with states to encourage and/or require states to share data with Tribes and TECs.
- CMS must respond to the HHS policy on sharing data with Tribes and TECs[3] in a timely manner.
- CMS must include Tribes and TECs in the rollout of new data sources and data sets to ensure Tribes are being accurately represented in the data and that the indicators collected are relevant and meaningful.
- CMS must create a public health access track for Tribes and provide the data for free to Tribes and TECs.
- CMS must explore including Tribes in the Tribal Data Learning Center (TDLC) and making the TDLC permanent as an ongoing way to have meaningful relationships and discussions with Tribes and TECs around data.
- To improve the collection of accurate AI/AN race data, CMS must provide guidance and tools to states including Best Practices for AI/AN Data Collection, [4] encourage states to collect and submit Medicaid race data and train providers on personal bias to avoid racial misclassification.
- CMS must waive fees for Tribal data requests.

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[2]See:https://image.connect.hhs.gov/lib/fe4515707564047b741472/m/1/1f0d3948-d9c0-40bf-8f95-e7ad86bec5eb.pdf.

[3]See:https://image.connect.hhs.gov/lib/fe4515707564047b741472/m/1/1f0d3948-d9c0-40bf-8f95-e7ad86bec5eb.pdf.

[4]See:https://www.uihi.org/download/best-practices-for-american-indian-and-alaska-native-data-collection/.

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CMS Funding Disclaimer

INTRODUCTION

The National Indian Health Board (NIHB) held the Tribal Health Equity Data Symposium on Monday, September 25 and Tuesday, September 26 at American University in Washington, DC. The goal of the Symposium was to reimagine the ways in which we use data to advance health equity for American Indians and Alaska Natives (AI/ANs). The Symposium presented an opportunity to hear diverse perspectives for the 175 attendees and participate in robust discussions about what it can look like to have a Tribally driven, culturally grounded approach to data collection, analysis, governance, and communications.

The three major topic areas of the Symposium were:

- Measuring health equity: Considering Tribal sovereignty, strengths, and Indigenous identities.
- Promising practices in improving how we collect data about race and ethnicity.
- Challenges and opportunities in Tribal access to data held by federal and state agencies.

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 next recommendations for CMS to help address the issues and concerns highlighted over the two days. The Symposium agenda is included in Appendix A. A summary of the facilitated discussion on what it means to be a good steward of sensitive data and those policies to ensure comfort in sharing data is in Appendix B. All materials for the event including the agenda, presentations and biographies of each speaker, posters, and all other resources can be found at **nihb.org/health-equity**. We thank all participants for their contributions to this report and look forward to continuing the conversation.

"What is your song? What will you sing? What data is meaningful to you in your community? How will you protect it? How will you govern it? How will you share it, and how will you hold that sacred responsibility to it for these children?" - Abigail Echo-Hawk, Seattle Indian Health Board and Urban Indian Health Institute

DAY ONE PRESENTATIONS [5]

NIHB Chairman, **Chief William Smith**, opened the Symposium with his remarks about the importance of accurate data that is "relevant to and reflective of our own Indigenous communities, our cultures, and our priorities." He remarked that "**improving data is one of the first steps toward health equity**."

Health Equity Update from CMS

Next, **Ms. Meagan Khau** provided updates that the Data Analytics and Research Group within the Office of Minority Health (OMH) is working on. She highlighted OMH's White paper on data[6] and its current state of sociodemographic data across CMS programs (see Table 2 of the report). In terms of race data collection, she mentioned the Office of Management and Budget (OMB) proposal to review the standards on maintaining, collecting, and presenting federal data on race and ethnicity, called Statistical Policy Directive Number (SPD) 15.[7] Ms. Khau expressed CMS's commitment to collecting race and ethnicity data in healthcare settings, such as home-health agencies, long-term care in patient rehab facilities, and skilled nursing facilities. They are working on ways to present the many data sets that CMS has to the public in the "most user-friendly, understandable fashion." She highlighted the Mapping Medicare Disparities Tool,[8] which they hope to be able to release data at the county level long term.

Finally, Ms. Khau discussed the newly launched **Tribal Data Learning Community (TDLC)**, a one-year pilot program for the Tribal Epidemiology Centers (TECs) to have free access to the Chronic Condition Data Warehouse. Ms. Khau expressed OMH's hope for the TDLC to "promote developing a research analytic method in dissemination of practices relevant to the Tribal communities, including opportunities for folks to come together and learn the data and develop meaningful and sustainable connections, provide timely technical assistance as well as a forum for CMS to engage with the TECs for their research."

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[5] Appendix One includes the agenda with formal job titles for each of the speakers. In addition, the bios for each speaker can be found on: https://www.nihb.org/health-equity/data-symposium-speakers.php.
[6] See: https://www.cms.gov/files/document/path-forwardhe-data-paper.pdf.
[7] See: https://spd15revision.gov/.
[8] See: https://data.cms.gov/tools/mapping-medicare-disparities-by-population.

Keynote Addresses and Panel: Culturally Relevant Data Collection Methods

Ms. Abigail Echo-Hawk's keynote address titled "Decolonizing Data: Restoring Culture, Building Beauty" opened with what it means "to think about health equity and data access from the **stories of our people**."[9] Ms. Echo-Hawk talked about an Alaska Native tradition of a blanket toss where seal skins would be stitched together to make a big blanket. "And those who stitched the pieces back together held incredible responsibility because...they were going to put somebody in the middle of that blanket, and then they were going to throw them with that blanket so high in the air, they'd go 80 or 90 feet." To ensure that someone was going to be caught, everyone holding the blanket had to move together, but it also required "those who made the stitches to make the blanket strong." Ms. Echo-Hawk asked participants to **reframe the discussion of health equity** not as a problem to solve but rather to think of themselves as the makers of the blanket, as "one of those who holds the needle in their hand who's going to take those pieces and stitch them back together into a blanket ... that was sewn with strength." Ms. Echo-Hawk's keynote address highlighted a few concerns with data.

In Ms. Echo-Hawk's remarks, she reminded us of the concerns of **racial misclassification** for AI/AN people. These issues of being **invisible in the data due to misclassification and missing data** came to light during COVID-19. "[W]hen they eliminate us in the data, we're invisible, as our Tribal leaders spoke about. **When we don't have the data, then the treaty rights that we have are not given to us**. And so instead, we are literally seeing our relatives dying around us as a result of the invisibility and the lack of data that is both gathered and shared appropriately. And I mean that in how are our Tribes governing that data and ensuring that it is shared for our people, not to create some story, some made-up story about us, but one that allows us to fight for not only our treaty rights, but also for the healing of our relatives." This is counterintuitive to the culture values of Indigenous people, where sharing is respected. Ms. Echo-Hawk encouraged us all to "sing our own song." To bring her talk full circle back to the "blanket of **strength and resiliency** in the most beautiful, bright, bold colors of our stories, our songs, our knowledge systems, our great jewelry, our beautiful ribbon work, our prayers, and the strength of our relatives in every single stitch so we have a blanket that our Tribal leaders can stand on and be thrown in the air and be caught

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[9] To learn more about Ms. Echo-Hawk's work on using data as a tool for racial equity, see the recent December 12, 2023 New York Times article featuring her work: https://www.nytimes.com/2023/12/12/health/indigenous-data-abigail-echo-hawk.html.

by us [...] for all of your children and their children and their children."

Dr. Myra Parker's keynote address on "Indigenizing Data: Mapping a Path Toward Health Equity" spoke about the ways that Indigenous knowledge systems might be different. This includes the **importance of relationships** in Tribal nations and the transmission of knowledge across generations. She discussed the way that people learn: "[t]he Indigenous pedagogy, the value of witnessing something and experiencing it firsthand. The apprenticeship-style learning in our communities where we're actually sitting there with an elder, with a parent, with some other person who has the important information, and then transmitting it to us as they're understanding it and making sense of it." This leads to a need to "interrogate the data" to best support community members to understand and protect their own health.

Dr. Michelle Kahn John also spoke of the importance of **respecting Indigenous cultures, values, and ways of knowing** in her talk "Being a Good Relative: Community and Indigenous Grounded Principles for Bridging Data Disparities and Implementing Culturally Safe Research Approaches to Address Youth Suicide." There are many places where it is relevant for Tribal culture to be honored, whether by implementing traditional medicine or ceremonies. It is important to **include the language, culture, and ceremonies within the protocol of any research studies**. This can best be done by asking the Tribal leaders and members what would make sense. Dr. Kahn John spoke about incorporating ceremony into research protocols. She advocates to "bring those elements of your teachings with you, especially the spiritual piece. I'm always advocating for the importance of spirit and culture. You have to take the cues from your community, tailoring your approaches to the voice of the community, to the priorities of your community."

The **panel discussion** focused on Indigenous, culturally based perspectives of data and health equity. Panel speakers commented on the **importance of strengths-based approaches, relationship building, community engagement, ceremony, and Indigenous values**. Dr. Parker concluded the panel discussion with a story exemplifying the role that gratitude plays in her work: "...whenever I think about my responsibility to doing research and data is it's a gift, and I have a responsibility in that gift to have nothing expected in return, just to be able to give it to the community."

We are More than Numbers Presentation

Ms. Rachel DeMarce and **Mr. Ben Han** from the Alaska Native Tribal Health Consortium (ANTHC) presented "We are More than Numbers: The Impacts of

Different Counts and Definitions of Alaska Native and American Indian People." They spoke on the legal context they have been using to identify AI/AN patients, some examples that they have seen in Alaska about how AI/AN people are identified, and their operational definition that they created for how they identify AI/AN people. They talked about ways in which they have tried to correct the **missing data and undercount of AI/ANs** by making sure the electronic health record had an accurate list of Tribe names (including name changes and new Tribes), that the data is accessible to all Tribal health organizations in the state, and that they include both AI/ANs who identify as either a single race or more than one race. Ms. DeMarce and Mr. Han demonstrated much thought in making sure that AI/ANs were represented in the data. They followed best practices to honor Tribal data sovereignty to work with Tribes.[10]

Roundtable: Promising Practices to Improve How Race and Ethnicity Data Are Used

Ms. Denise Scholfield and **Ms. Nancy Scherden** from the Blue Cross Blue Shield Association shared some results of research they have been conducting on improving the advocacy of self-reported race data collection. Their study found that the comfort level of people in sharing demographic and personal information to health-related organizations varied by age, political affiliation, and the intended use of the information. Their presentation prompted a robust discussion during the panel discussion about **Tribal sovereignty** and how to follow best practices, as outlined in the Urban Indian Health Institute publication. The focus is to make sure that **Tribes have a role in how their data is collected, reported, and presented**.

Dr. Rochelle Ruffer reported on the results from the National Tribal Health Conference Roundtable on Race and Ethnicity Standards. Dr. Ruffer reported that communication of the intent behind asking the question is very important. Many AI/ANs are hesitant to share their personal information, including race, due to **mistrust**, and concerns of potential data misuse. Since the Symposium, the Urban Institute has published a study that includes "lack of trust" as one of the major barriers to process in collecting individual race and ethnicity data.[11]

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[10] See "Best Practices for American Indian and Alaska Native Data Collection" from the Urban Indian Health Institute: https://www.uihi.org/download/best-practices-for-american-indian-and-alaska-native-data-collection/.
[11] See: https://www.urban.org/research/publication/using-race-and-ethnicity-data-advance-health-equity.

Ms. Sujata Joshi spoke on "Moving Beyond Race and Ethnicity Data Collection to Define AI/AN Communities." She spoke of the efforts at the Northwest Tribal Epidemiology Center to address Tribes' priorities for data, including efforts to increase the visibility of their communities and data. She mentioned that often state and federal surveillance systems don't collect data in a way that is meaningful for Tribes. The way that race data is collected does not adequately capture that many AI/ANs have a political status as members of Sovereign Nations. She spoke about the issues of **misclassification and accuracy of race data for American Indians/Alaska Natives** stating that:

> "*Misclassification happens when American Indian People are recorded as being another race, usually white, in a data set. We have looked at misclassification over a whole range of data sets in the Northwest and have found really significant levels of misclassification. We see it highest in data such as communicable disease, hospital discharge, and cancer data, but it's also significant in things like births, deaths, and HIV data. That missing-ness and misclassification really further erodes the quality of state and Federal data for Tribal and Urban Indian communities and further erases Native People in data.*"

She also highlighted how it is important to pay attention to the definition of AI/AN and how data is reported for multi-race categories. Northwest Portland Area Indian Health Board (NPAIHB) uses an **inclusive definition of AI/AN** that includes single, multiple races, and people of Hispanic or non-Hispanic ethnicities. This is quite different from how state and federal agencies often report data on American Indian people and can result in significant differences in morbidity and mortality estimates.

Finally, Ms. Joshi spoke on the importance of **Tribal consultation**.[12] For example, during the discussions around the proposed changes to the race and ethnicity definitions from OMB's SPD 15, there was only one formal Tribal consultation. Many Tribal organizations responded to the request for comment, but there have not been any additional Tribal consultations since. The NPAIHB specifically requested additional Tribal consultations to discuss developing policies for allowing appropriate access to disaggregated data on individual Tribal nations if there is movement toward collecting Tribal affiliation and community attachment data. Neglecting Tribal consultation during policymaking disregards Tribal sovereignty, reinforces federal paternalism, and leads to policy decisions that are more likely to harm the health and wellbeing of AI/AN people.

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[12] For guidance on Tribal consultation, see: Sec 2: Consultation Principles in: https://www.whitehouse.gov/briefing-room/presidential-actions/2022/11/30/memorandum-on-uniform-standards-for-tribal-consultation.

Ms. Delight Satter spoke on "Current Strategies for Improvement through an Intergenerational Lens." She spoke most about many concerns of data including the **misclassification and accuracy of data** and stated that "the American Indian health data capacity is impeded by the quality of information that is collected, released, and reported in population-based surveys." She highlighted the importance of how race data is reported, like the discussions by Ms. Joshi and Ms. DeMarce above.

Facilitated Discussion: Identifying the AI/AN Population

After a poster presentation,[13] **Ms. Carrie Field** facilitated a discussion on "Identifying the AI/AN Population." We heard many stories from Symposium attendees of situations where disclosing their race prompted a negative response from a health care provider. Interpersonal and systemic discrimination leads to mistrust by patients towards providers and the health care system overall. Many AI/ANs worry about the care they will receive given the preconceived misconceptions of care providers about AI/ANs. **Participant stories of experiencing discrimination ranged from health care providers' assumptions and beliefs** that AI/ANs should have bad teeth, no allergies, or no knowledge of prenatal care. **Many participants expressed concern over the kind of care they would receive if they disclosed that they are AI/AN**. In such cases, disclosing racial identity can be a detriment.

After discussion, all participants worked in groups to provide input to two questions to help identify key characteristics for an organization or government agency to consider and implement when conducting data research to ensure they will be good stewards of that data. The two questions are: (A) What does it mean to you for an organization to be a "**good steward**" of sensitive data? And (B) What kinds of **policies or protections** would need to be in place for you (or an elder relative) to feel comfortable and safe entrusting an organization with personal data? There were five characteristics recognized by audience participants to be a good steward of data: **Tribal sovereignty, reciprocity, transparency, confidentiality, and trust. See Appendix B** for more clarification and a visual summary of the results from the facilitated discussion.

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[13] All posters can be found here: https://www.nihb.org/health-equity/data-symposium-presentations.php.

DAY TWO PRESENTATIONS

Keynote Address

Dr. Donald Warne presented "Measuring Health Equity with a Tribal Lens: Leaning on Strengths, Sovereignty, and Indigenous Identity." He discussed how research in Tribal communities must begin with a bidirectional relationship andthe communities must be equal partners in research. Dr. Warne encourages determining research priorities through a community driven process. For **any community-based participatory research**, resources need to be committed to the community and the expectations must be clear. Tribal consultation must be part of any process where the funds distributed impact Tribes and/or their partner organizations. A **key tenet of Tribal data sovereignty is to get permission from the Tribes from whom you wish to gather research**. Dr. Warne noted that "historically, we've been treated as the laboratory, the laboratory from which data are gathered. And that's not good enough for our people, and we need the communities to be equal partners."

Dr. Warne also spoke of the success in connecting to "culture, ceremony, and language" to have better health outcomes. He encouraged the lens of health care to include **Indigenous determinants of health.**[14] Even without overtly discriminating against AI/AN patients, many health care providers do not understand the importance of Native beliefs and practices around traditional medicine and healing. Despite studies that show that using traditional medicine, ceremony, and culture can help improve health outcomes for Indigenous people, many health care providers still lack the cultural humility to respect and value these practices and values. But to incorporate Native cultures and traditional medicine into the current healthcare setting, there is a need for a "**bigger Indigenous health research workforce**." He also spoke of the need to "decolonize and Indigenize curricula." He also spoke of some of the changes needed in the medical school education system to make sure that traditional medicine is incorporated into the curriculum.

Panel: Getting to Yes: Data Sharing between States and Tribes

Ms. Pharah Morgan spoke of "Collaborating with State partners to promote Tribal Health Data Equity." The Rocky Mountain Tribal Leaders Council Tribal Epidemiology Center (RMTLC-TEC) successfully **strengthened partnerships** with each state in their service area. They set up regular quarterly or monthly meetings

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[14] See: https://www.nihb.org/idh/.

with state representatives and Tribal health directors to converse openly about data. As a result of the conversations, the Tribal health directors learned about existing public health data and gained access to data which they previously had not been able to use. She stated that "bringing these Tribal subject matter experts to the table improved engagement because they also saw the challenges that we were having with regard to data."

Ms. Jessica Imotichey spoke on "Data Sharing to Support Tribes through Medicaid Unwinding." She spoke about the importance of collaboration involving **Tribal consultation** in the State of Oklahoma and the sharing of state Medicaid data with Oklahoma Tribes. The Oklahoma Medicaid agency has conducted bimonthly consultations which have allowed for **ongoing communication and relationship building** with Tribes. As a result, data on Medicaid unwinding for AI/ANs has been made available without the need for a data sharing agreement. The access to this data has benefited all Tribes in Oklahoma.

Ms. Krystal Schramm emphasized that the **timely sharing of patient data** across providers is necessary to ensure that patients receive the care they need when they need it. However, many Tribal health care organizations lack the **technology and infrastructure required to support seamless, comprehensive care**. As a result, patients often receive delayed care or are unable to access essential health care services altogether.

Note, several participants brought up the challenges of receiving continuous care at Tribal health care organizations due to issues with different providers not receiving patient data and referrals. One attendee described the difficulties in data sharing between providers: "A lot of us have labs inside Tribal health care, but they can't even get the results from the lab itself down the hall from where your primary care provider is. Even that system can be broken." Ms. Schramm also mentioned how a referral to specialty care for her father-in-law was lost between their Tribal health care clinic and the hospital.

Learning From Covid: Communicating Data

Ms. Darby Gallagher and **Ms. Jeannie Le** provided some input on best practices for data visualization and sharing on social media. One of the lessons learned they shared was to "**use a positive tone**" when appropriate, and to "avoid messaging that elicits negativity, fear, and guilt...overpromising or claims that are unproven." Using positive messaging, validating concerns, and bringing in community members were discussed as methods of **building trust**. This also resonates with what we have heard throughout the data Symposium to make sure to **tell our story with strength and resiliency**.

Tribal Environmental Health Priorities: From Data to Action

Mr. Brett Weber and **Ms. Aliza Bolling** presented the work of NIHB's Environmental Health Summits. Their next steps to "facilitate **meaningful engagement with Tribal environmental health programs**, Tribal leaders" is a good reminder of the importance of meaningful engagement with Tribes.

Panel: Data Flow Between Tribes and Federal Agencies: Challenges and Opportunities

Mr. Mitch Thornbrugh spoke on "Data Modernization at the Indian Health Service: Opportunities to Improve Interoperability and Data Sharing." He emphasized how important it is to engage people across the country when making changes. He spoke about how the health information technology (HIT) project is truly going to change how clinical professionals interact with one another and will hopefully help with the issues of **data interoperability**. He highlighted increased access to care as a benefit of data modernization. Finally, he emphasized the importance of **data privacy and security**–two themes in the interactive session on day one.

Ms. Aila Hoss spoke on "Federal Sharing Obligations." She spoke frankly about **legal reasons given by federal agencies for denying Tribes' access to data. She stated, "[i]t's not a legal reasoning. It's racism and anti-Tribal Sovereignty."** She focused on the legal aspects of data sharing and that since there are Tribal-specific requirements regarding data sharing, it can be complicated. However, **Tribal access to data is part of the Trust responsibility**. She stated, "[i]t is a moral obligation of the highest responsibility in trust. It is an obligation per the federal government to execute the mandates of the federal Indian law, which includes protecting Tribal sovereignty from the feds …". She mentioned that one of the problems is the lack of an enforcement mechanism for breach of trust claims.

Ms. Chris Alibrandi O'Connor presented Dr. Meghan O'Connell's presentation on "Current Issues in Federal Data Sharing with TECs and Tribes." She discussed a 2022 Government Accountability Office (GAO) report[15] that found that federal agencies have failed to comply with federal law by **withholding health data from TECs**. Little progress has resulted since. Two of the GAO report's recommendations concerned IHS, which holds critical health data needed by

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[15] See: https://www.gao.gov/products/gao-22-104698.

Tribal public health authorities. As of the most recent update from the GAO, these recommendations remain unfulfilled. With no mechanism to enforce the law, Tribes are left with little recourse. Thus, many health-related data sets are not shared with Tribes and TECs. Without access to vital health data, it is difficult for Tribes and TECs to advance public health in Indian Country.[16]

Mr. A.C. Locklear joined the panel discussion and discussed how important it is to **seek Tribal input** at the beginning of a project. He spoke of the CDC's modernization of the electronic case reporting system as an example of when Tribes were brought into the process early on. By involving Tribes early in the process, CDC showed that they were interested in making sure that Tribal entities could have equitable access to data.

Case Study: Lessons from COVID

Dr. Amanda Lam and **Mr. Tyler Baccam** exemplified **trustworthy data stewardship** in their "Case Study: Lessons from Covid: How Partnerships and GIS Can Facilitate Data Sharing and Improve Health Equity." They developed a solution to a Tribe's incomplete health data by **collaborating with the Tribe**. They walked through the process to create the **data sharing agreement** and then their use of geocoding to help identify missing data. Their new methodology identified 1.9 times as many COVID-19 case records on the reservation. Overall, this presentation emphasizes **the impact of missing data on public health statistics**.

Interactive Session: Putting it into Practice: Story as Data and Data as Story

Ms. Anamalia Su'esu'e and **Ms. Dawn Hunter** facilitated the interactive session on the importance of stories. Stories can help to share experiences, build relationships, create meaningful change, cause awareness, uplift voices, provide support, and generate a shared understanding. Most of these characteristics are ones that were highlighted by our speakers and participants throughout the two days of the Data Symposium. In an interactive session, participants had time to discuss in groups questions about data including: "What is the important thing you think others should know about health data and your Tribe, and why?" and "What is one action that government entities can take to improve Tribal data access?" Audience members then shared their responses to the group. In addition,

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[16] Since the Symposium, Dr. O'Connell was featured in an article on the syphilis crisis and how the lack of data is impacting the response to the public health crisis. See: https://www.vox.com/health/2024/1/3/24010263/pregnancy-maternity-prenatal-care-deserts-rural-syphilis-indigenous-women-babies-south-dakota.

in previously recorded videos, the answers to these questions were also explored. Some of the responses are recorded below.

One participant shared that **Indigenous health data is important because it is used to make policies and drive change in initiatives in Tribal communities**.

Olivia Trujillo from National Network of Public Health institutes shared that "**Data gives us a chance as Indigenous people to be seen. It gives us a seat at that table, so that we can not only share the concerns we have within our community but also share stories of resiliency**."

Speaker Rachael DeMarce stated that while there are certainly many actions that government entities could take, one of the most fundamental ones might be providing **free access to health data**.

Chris Tall Bear from National Network of Public Health Institutes stated: "**Data, in my opinion, represents truth, and ways that the government can improve that process is to continue to hold government-to-government consultations with Tribes and Tribal leaders. The federal government can also respect, continue to respect Tribal sovereignty.**" He continued: "let's not be afraid to admit what we don't know. A lot of times, we get so caught up that we think that we have to be an authority, that we're not willing to be vulnerable to admit that we have to learn. So don't be afraid to admit what you don't know and agree that we all need to sit down together and find a solution to move forward."

RECOMMENDATIONS FOR CMS TO IMPROVE DATA PRACTICES TO ADVANCE HEALTH EQUITY

NIHB's previous work in AI/AN health equity[17] has emphasized the foundational importance of five key elements of health equity for Tribes: resilience through culture; Tribal sovereignty; strong Tribal institutions; Tribal empowerment in state and federal governance; and the federal trust responsibility. Our findings from the Symposium further support these concepts as central to advancing AI/AN health equity when considering how to improve data practices. The recommendations below are based on the discussions throughout the two days of

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[17]See:https://www.nihb.org/docs/03212023/2023_CMS%20Health%20Equity%20Report_FINAL_508.pdf

the Symposium. They incorporate the speaker presentations, comments by participants, and input from NIHB.

Honor Tribal Sovereignty and Reinforce Tribal Self-Determination

Prioritize Meaningful Tribal Consultation

In their data white paper, the CMS OMH discuss the link between health equity and data on social determinants of health.[18] Through the process of collecting social determinants of health data, CMS should strive to be more intentional about gathering data that specifically addresses Indigenous determinants of health. To address Indigenous determinants of health, **Tribal consultation is recommended per the CMS Tribal Consultation Policy**.[19]

We appreciate CMS's effort to include Tribal sovereignty in their data white paper, but the way it is incorporated shows a lack of understanding within CMS as to what "Tribal sovereignty" means. In particular, the report says that through their programs, "CMS strives to identify and remedy systemic barriers to health equity so that every person served by its programs has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, **tribal sovereignty**...or other factors that affect access to care and health outcomes." The phrase "Tribal sovereignty" does not belong here. It is not a demographic or risk factor; rather, "Tribal affiliation" better suits this statement. **NIHB recommends CMS receive full Tribal review of the CMS Office of Minority Health (OMH) data white paper before implementing actions**. CMS should work with Tribes to make sure that their policies are inclusive and understanding of Tribes.

Understand and Honor Tribal Data Sovereignty

Before data that involves Tribes is reported publicly, whether it be a dashboard or publication, Tribes must be consulted on what data gets collected, reported and how it is displayed. Tribes must have a say in how data is used and who sees it. Tribal consultation is required in all instances where their data is being used. **CMS leadership, through robust training, must ensure that CMS staff understand what Tribal data sovereignty is, including how to uphold and honor data sovereignty to ensure Tribes take ownership of, access, and control their data. Alongside**

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[18] See: https://www.cms.gov/files/document/path-forwardhe-data-paper.pdf.
[19] See: https://www.whitehouse.gov/briefing-room/presidential-actions/2022/11/30/memorandum-on-uniform-standards-for-tribal-consultation/ for details about consultation.

ongoing Tribal consultation, the principles of data sovereignty must guide all work that CMS undertakes involving data.

Appreciate Tribal Engagement and Build Authentic Relationships

While no substitute for Tribal consultation on a government-to-government basis, other forms of Tribal engagement can provide much needed Indigenous perspective and insight into policy making, research, and program development. Tribal Advisory Committees (TACs), public listening sessions, and other methods of Tribal engagement all play a role in ensuring Tribal perspectives and Indigenous ways of knowing are included and listened to.

The CMS TTAG provides a wonderful opportunity for CMS to engage with Tribal leaders in a meaningful way. It is an opportunity to build the bidirectional relationship that is so important in Native culture. **CMS must encourage CMS presenters on data information to the CMS TTAG to answer questions in a timely manner and provide updates to the TTAG on a regular basis as appropriate**.

Establish Strengths–Based Tribally Driven Research Priorities

Tribal consultation must be part of any process where the funds distributed impact Tribes and/or their partner organizations. CMS recently announced a new model to test approaches for addressing the behavioral and physical health of people with Medicaid and Medicare.[20] However, despite the impact these approaches will have on Tribal communities, Tribes are not included in the model. **The research performed by anyone at CMS, including the CMS Innovation Center, must include the Tribal voice**.

Respect Indigenous Cultures, Values, and Ways of Knowing

Honor and Understand the Role of Indigenous Cultures

CMS must incorporate Indigenous cultures in its review of any policies that may impact Tribes. For example, it is important when CMS is reviewing Section 1115 waivers, that CMS understands that the data presented might be different for efficacy of traditional healing methods. CMS reviewers must recognize the difference between how Indigenous data may be presented and Western data. The evidence provided by Tribes and Tribal health agencies might be different and these differences should be taken into consideration when determining if a service is to be reimbursed under the 1115 waiver. **CMS must adopt a policy that Tribal**

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[20] See: https://content.govdelivery.com/accounts/USCMSMEDICAID/bulletins/385b956

cultural considerations, ways, and methods are considered, included, and encouraged in 1115 Waivers.

Build Trust through Authentic Relationships and Trustworthy Data Stewardship

There must be trust between the agencies who are collecting or reporting the data and communities, as well as training for those collecting the data. Most often, the missing data is due to the lack of trust among AI/ANs to provide their personal data. It will take time to build up that trust, but **the collectors of the data must work with the community to gain permission and ensure they are adhering to Tribal nation rules, requirements, and protocols to gain cultural understanding, build respect, and foster relationships**.

Enable Equitable Access to Quality Data

One of the questions NIHB asked in the Symposium evaluation survey was: "NIHB advocates on behalf of Indian Country related to data priorities. If you could tell Congress or the President something about data concerns/for Indian Country right now, what would it be?" Of the responses received, the majority brought up concerns related to **data access**. Participants commented on the inaccessibility of data on AI/ANs as a violation of the trust responsibility that the federal government has committed to fulfilling. Despite clear public health authority, Tribes and TECs continue to face immense barriers to accessing data.

Because states govern most public health data systems, states become the *de facto* arbiters of access to public health data. Tribes often find themselves at the mercy of individual relationships between the Tribe and state government officials. Considering the often-fraught history between states and Tribes, this is not a recipe for data equity. **CMS can help with communication and relationship building with states to encourage and/or require states to share data with Tribes and TECs**.

Making federal data accessible is recognizing Tribal sovereignty. Tribal consultation is needed to help coordinate data at the national level to address public health needs. HHS has taken the first steps in calling for Tribal consultation on the HHS Tribal and Tribal Epidemiology Center Data Access Policy[21] on February 6, 2024, as a response to the 2022 GAO report.[22] Once HHS publishes

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[21]See:https://image.connect.hhs.gov/lib/fe4515707564047b741472/m/1/1f0d3948-d9c0-40bf-8f95-e7ad86bec5eb.pdf.
[22] See: https://www.gao.gov/products/gao-22-104698.

their policy, it is imperative that **CMS must respond to the HHS policy in a timely manner.** A timely response will help build trust with Tribes and put AI/ANs on the pathway towards health equity.

CMS holds a wealth of knowledge on various health indicators through many different datasets. However, to make this data more accessible equitably, datasets should be tailored in a more user-friendly, understandable fashion. For Tribes, this may involve the creation of a **CMS Tribal Public Health Data hub**[23] similar to what CDC has created. While not perfect, CDC has provided a list of data sets that have relevant health outcomes for AI/ANs as well as guidance and other documents directing Tribes and Tribal organizations on how to access their data. [24] Additionally, as previously stated, **CMS must include Tribes and TECs in the rollout of new data sources and data sets to ensure Tribes are being accurately represented in the data and that the indicators collected are relevant and meaningful.**

Streamline Processes for Data Sharing

CMS's TDLC is a good first step for providing access to public health data for TECs. However, the data must also be given to Tribes. The process needs to continue to be streamlined so that Tribes and TECs can receive their data in a timely manner for public health purposes without having to create a formal research proposal. **CMS must create a public health access track for Tribes and provide the data for free to Tribes and TECs.** Removing fees for data and/or providing waivers for Tribes to access data with no cost removes a barrier for Tribes to receive their own data and increases equitable data access.

CMS must explore including Tribes in the TDLC and making the TDLC permanent as an ongoing way to have meaningful relationships and discussions with Tribes and TECs around data.

Implement Best Practices for Sharing and Collecting Accurate Race Data

As discussed earlier in this report, there are many data quality issues surrounding accuracy and completeness of race information for AI/ANs. High quality race data is essential for Tribes to understand the impacts of important health issues on Tribal communities. An example of a relevant CMS health issue where the need for race data is critical is **Medicaid unwinding.** Without access to Medicaid data that is broken down by Tribal status and Tribal community, Tribes are unable to

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[23] See: https://www.cdc.gov/tribal/data-resources/tribal-data/index.html.
[24]See:https://www.cdc.gov/tribal/documents/data-resources/tribal-datasharing-guidance.pdf.

determine the impact of unwinding on their communities and provide support for those at risk of losing coverage. This is especially crucial given that Medicaid is a large source of resources and funding for Tribal healthcare systems.

According to an analysis by the Medicaid and CHIP Payment and Access Commission (MACPAC), only thirty states met the "minimum data quality standards necessary for conducting analyses using 2019 race and ethnicity data."[25] CMS is purportedly taking steps to address the issue of missing race data through (1) supporting states with collection and submission of data and (2) developing indirect estimation methods.[26] **To improve the collection of accurate AI/AN race data, CMS must provide guidance and tools to states including Best Practices for AI/AN Data Collection,**[27] **encourage states to collect and submit Medicaid race data, and train providers on personal bias to avoid racial misclassification.**

Eliminate Tribal Fees for Data

Data is sometimes inaccessible due to the fees attached to the data. Speaker Rachael DeMarce said, "[w]e have access to [...] vaccine data from the state of Alaska, which is great. We get it quarterly, and we wanted to get it more regularly so we can take action on it. And it's a vendor, so not the state of Alaska, and they wanted to charge us for this." Vendors often charge Tribes and Tribal organizations fees for accessing data, which contributes to the inaccessibility of data for public health use. This problem exists not only at the state level, but also federally as well. For example, the fee charged by CMS to access the virtual warehouse that gives access to Medicaid and Medicare data is quite expensive. **CMS must waive fees for Tribal data requests**. Ideally, the fee waiver should be relevant in both the TDLC and for Tribes not involved in the TDLC.

CONCLUSION

The recommendations in this report will help to make progress on providing Tribal community members with access to accurate, reliable, timely, and trustworthy data. The resiliency of the AI/AN people is a story that needs to be shared in addition to the current, unique challenges that face our Tribal communities today. And it can only be shared and told if the data is available to tell

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[25] See: https://www.macpac.gov/wp-content/uploads/2022/03/MACPAC-brief_Race-and-Ethnicity-Data-Availability.pdf.
[26] See: https://www.medicaid.gov/sites/default/files/2023-08/2020-race-etncity-data-brf.pdf.
 [27] See: https://www.uihi.org/download/best-practices-for-american-indian-and-alaska-native-data-collection/.

it. NIHB looks forward to working with Tribal nations, Tribal organizations, and federal agencies – including CMS – to continue this conversation and make permanent changes in how Tribal data is shared and accessed.

APPENDIX A: NIHB TRIBAL HEALTH EQUITY DATA SYMPOSIUM AGENDA

Monday, September 25, 2023

8:30 AM | **Breakfast (fruit & pastries)**

9:00 AM | **Prayer and Opening Remarks from the National Indian Health Board**
- William Smith (Valdez Native Tribe), Chairperson and Alaska Area Representative, National Indian Health Board (NIHB)

9:15 AM | **Health Equity Update from CMS**
- Meagan Khau, MHA, Director, Centers for Medicare and Medicaid Services (CMS), Office of Minority Health, Data Analytics & Research Group

9:30 AM | **Keynote: "Decolonizing Data: Restoring Culture, Building Beauty"**
- Abigail Echo-Hawk (Pawnee), MA, Executive Vice President, Seattle Indian Health Board, and Director, Urban Indian Health Institute

10:00 AM | **Keynote: "Indigenizing Data: Mapping a Path Toward Health Equity"**
- Dr. Myra Parker (Mandan-Hidatsa-Cree), JD, MPH, PhD, Associate Professor, University of Washington School of Medicine

10:25 AM | **Morning Break**

10:40 AM | **Panel: Culturally Relevant Data Collection Methods**
- "Being a Good Relative: Community and Indigenous Grounded Principles for Bridging Data Disparities and Implementing Culturally Safe Research Approaches to Address Youth Suicide"
  - Dr. Michelle Kahn John (Dine), PhD, RN, PMHNP-BC, GNP, Research Associate, Johns Hopkins University School of Nursing
- Abigail Echo-Hawk (Pawnee), MA, Executive Vice President, Seattle Indian Health Board, and Director, Urban Indian Health Institute
- Dr. Myra Parker (Mandan-Hidatsa-Cree), JD, MPH, PhD, Associate Professor, University of Washington School of Medicine
- Moderator: Dr. Susan Karol, MD, Chief Medical Officer, CMS, Division of Tribal Affairs

11:35 AM | **We are More than Numbers: The Impacts of Different Counts and Definitions of Alaska Native and American Indian People**
- Rachael DeMarce (Little Shell Tribe of Chippewa Indians and Blackfeet Nation), MPH, MPA, Analytics Engagement Manager, Alaska Native Tribal Health Consortium (ANTHC)
- Ben Han, Analytics Architect, ANTHC

12:00 PM | **Lunch (boxed lunches – sandwich or salad)**

1:00 PM | **Optimizing Collection of Self-Reported Race, Ethnicity, & Language Data**
- Denise Schofield, Executive Director, Data Strategy, Blue Cross Blue Shield Association (BCBSA)
- Nancy Scherden, Managing Director of Brand Insights, BCBSA

1:20 PM | **Roundtable: Promising Practices to Improve How Race & Ethnicity Data Are Used in Public Health, Health care, and Research**
- "Moving Beyond Race and Ethnicity Data Collection to Define AI/AN Communities"
  - Sujata Joshi, MSPH, Project Director/Epidemiologist, Northwest Portland Area Indian Health Board (NPAIHB)
- "Results from the National Tribal Health Conference Roundtable on Race and Ethnicity Standards"
  - Dr. Rochelle Ruffer, PhD, Tribal Health Data Project Director, NIHB
- "Current Strategies for Improvement through an Intergenerational Lens"
  - Delight Satter (Confederated Tribes of Grand Ronde), MPH, Senior Health Scientist, Centers for Disease Control and Prevention (CDC)
- Denise Schofield, Executive Director, Data Strategy, BCBSA
- Moderator: AC Locklear II (Lumbee), JD, Federal Relations Director, NIHB

2:35 PM | **Poster Session and Afternoon Break**

3:15 PM | **Facilitated Discussion: Identifying the AI/AN Population**
- Facilitator: Carrie Field, MPH, Policy Analyst, NIHB

4:50 PM | **Closing Remarks**

5:00 PM | **Adjourn**

Tuesday, September 26, 2023

8:30 AM | Breakfast (fruit & pastries)

9:00 AM | Welcome

9:05 AM | Keynote: Measuring Health Equity with a Tribal Lens: Leaning on Strengths, Sovereignty, and Indigenous Identity
- Dr. Donald Warne (Oglala Lakota), MD, MPH, Co-Director, Johns Hopkins Center for Indigenous Health

9:45 AM | Panel: Getting to Yes: Data Sharing between States and Tribes
- "Collaborating with State partners to promote Tribal Health Data Equity"
  - Pharah D. Morgan, MS, MPH, Lead Epidemiologist, Rocky Mountain Tribal Leaders Council, Tribal Epidemiology Center (RMTLC TEC)
- "Data Sharing to Support Tribes through Medicaid Unwinding"
  - Jessica Imotichey, MLS, MPH, (Chickasaw), Health Policy & Legislative Analyst, Chickasaw Nation Department of Health
- "Enhancing Health IT in Tribal Communities"
  - Krystal Schramm (Little River Band of Ottawa Indians), MS, Senior Technical Business Analyst, Michigan Health Information Network
- Moderator: Chairperson Janet Alkire (Standing Rock Sioux Tribe), Member-At-Large and Great Plains Area Representative, NIHB

11:00AM | Morning Break

11:15 AM | Learning from COVID: Communicating Data to the Public with Visualizations and Social Media
- Darby Galligher (Miami Tribe of Oklahoma), MPH, Communications Coordinator, NIHB
- Jeannie Le, MPH, Data Visualization Analyst, NIHB

11:35AM | Tribal Environmental Health Priorities: From Data to Action
- Brett Weber, MPA, Environmental Health Programs Director, NIHB
- Aliza Bolling, CDC Public Health Associate Program Associate, CDC

12:15 PM | Lunch (boxed lunches – sandwich or salad)

1:15 PM | Panel: Data Flow Between Tribes and Federal Agencies: Challenges and Opportunities
- "Data Modernization at the Indian Health Service: Opportunities to Improve Interoperability and Data Sharing"
  - Mitchell Thornbrugh, (Muscogee Creek Nation), Chief Information Officer and Director for the Office of Information Technology, Indian Health Service (IHS)

- "Federal Data Sharing Obligations"
  - Aila Hoss, JD, Associate Professor of Law, Indiana University McKinney School of Law
- "Current Issues in Federal Data Sharing with TECs and Tribes"
  - Dr. Meghan Curry O'Connell, (Cherokee), MD, MPH, Chief Public Health Officer, Great Plains Tribal Leaders' Health Board
  - Chris Alibrandi O'Connor, JD, Deputy Director, Mid-States Region, Network for Public Health Law
- AC Locklear II (Lumbee), JD, Federal Relations Director, NIHB
- Moderator: Ms. Amber Torres (Walker River Paiute Tribe), Phoenix Area Representative, NIHB

2:35 PM | **Afternoon Break**

2:50 PM | **Case Study: Lessons from COVID: How Partnerships and GIS Can Facilitate Data Sharing and Improve Health Equity**
- Dr. Amanda Lam, MD, MPH, Informatics and Data Services, Epidemiologist, Pima County Health Department
- Tyler Baccam, MS, Epidemiology Intelligence Unit (EIU) Surveillance Epidemiologist, Pima County Health Department

3:20 PM | **Interactive Session: Putting it into Practice: Story as Data and Data as Story**
- Anamalia Suʻesuʻe, MA, PhD student, Department of Psychology, Graduate Research Assistant, Office of Public Health Studies, University of Hawaiʻi at Mānoa
- Dawn Hunter, JD, MPH, Director, Health Equity, Network for Public Health Law

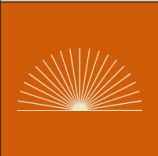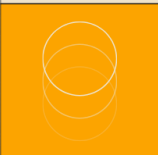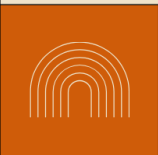4:45 PM | **Closing Remarks from NIHB**

5:00 PM | **Adjourn**

APPENDIX B: RESULTS OF FACILITATED DISCUSSION ON DATA STEWARDSHIP

National Indian Health Board

Becoming a "Good Steward" of Tribal Data

On September 26, 2023, 175 members of Tribes, Indian healthcare organizations, and government agencies gathered for the 2023 Tribal Health Equity Data Symposium. The results of a facilitated discussion on stewardship of Tribal data are summarized here.

Tribal Sovereignty

Recognize and respect Tribal sovereignty, including data sovereignty. Weave in Tribal consultation on a regular basis.

Reciprocity

Honor data as a gift and always share back findings with the community. Rather than only preventing harm, use data to benefit individuals and the community.

Transparency

Be clear about how data is accessed, used, and shared, including potential future uses.

Confidentiality

Outline protections to keep data safe and ensure privacy and confidentiality. Train staff on data management and security protocols.

Trust

Work with the community to gain cultural understanding, build respect, and foster relationships. Tailor your approaches to the unique voices and priorities of each community.