Tribal Consultation on Centers for Disease Control and Prevention and Agency for Toxic Substance and Disease Registry's (CDC/ATSDR)

CDC Moving Forward Initiative

12/13/2022 - 02/24/2023

On February 9, 2023, the Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) hosted a tribal consultation on how to strengthen relationships during the implementation of the CDC Moving Forward Initiative, how the agency can better engage with Indian Country through meaningful consultation, tribes' priorities as we transition out of the COVID-19 public health emergency, and on how CDC/ATSDR can better support tribes and tribal communities in the future. Written comments were accepted until 5:00 pm (EST) on February 24, 2023.

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Introduction

On February 9, 2023, CDC/ATSDR hosted an in-person and virtual government-to-government consultation with tribal leaders to receive input and guidance on how to strengthen relationships during the implementation of the CDC Moving Forward Initiative, how the agency can better engage with Indian Country through meaningful consultation, tribes' priorities as we transition out of the federal COVID-19 public health emergency declaration, and how CDC/ATSDR can better support tribes and tribal communities in the future.

This tribal consultation provided an opportunity for leaders from tribal nations and CDC/ATSDR to engage in government-to-government discussion to advance CDC/ATSDR support for and collaboration with American Indian and Alaska Native (AI/AN) tribal nations and to improve the health of AI/AN communities. There were 226 participants, including tribal leaders, CDC/ATSDR senior leaders, and other tribal partners. Comments were accepted from December 13, 2022, to February 24, 2023, 5:00 pm (EDT).

CDC/ASTDR issued a Federal Register Notice on December 13, 2022, announcing the consultation, which included the purpose and details of the meeting. A Dear Tribal Leader Letter (DTLL) was sent to tribal leaders on December 15, 2022, inviting them to the consultation. Additionally, CDC/ATSDR shared information about the virtual consultation session and comment period with various tribal partners according to the CDC/ATSDR Tribal Consultation Policy. The current CDC/ATSDR Tribal Consultation Policy is available on CDC's Tribal Health website.

Specifically, CDC/ATSDR sought feedback from tribal leaders on the following topics:

1. How can the agency strengthen relationships during the implementation of the CDC Moving Forward Initiative?

2. How can the agency better engage with Indian Country through meaningful consultation?

3. What are your tribes' priorities as we transition out of the COVID-19 public health emergency and how can CDC/ATSDR better support tribes and tribal communities moving forward?

This report provides tribal leaders with a summary of recommendations and input received during the consultation period.

CDC received input from seven federally recognized tribes and one tribal partner during the consultation period.

CDC/ATSDR recognizes the need for ongoing and continued education and training of CDC staff working with tribal nations and is committed to working with agency leaders to ensure training is appropriate and available. CDC has summarized tribal leaders' responses to the questions above and provided initial responses to the most frequent comments. The agency will use this

information to continue to update the policies and practices around the implementation of the CDC Moving Forward Initiative.

Detailed Responses to Tribal Leaders' Recommendations During the February CDC/ATSDR Tribal Consultation

This section addresses recommendations made by tribal leaders (or their designees) at the CDC/ATSDR Tribal Consultation held on February 9, 2023, and during the written comment period ending on February 24, 2023. The comments and recommendations received are organized under the following themes: 1) CDC Moving Forward Initiative; 2) Accountability; 3) Health Equity; 4) Data; and 5) Funding.

1) CDC Moving Forward Initiative

Tribal leaders recommended that CDC/ATSDR better inform and continuously inform tribal leaders about CDC Moving Forward. Comments were received concerning the need for CDC/ATSDR staff to be trained on working with tribal nations, how COVID-19 messaging is being sent to tribal nations, and how CDC/ATSDR can learn from tribes.

Summary of CDC Moving Forward Initiative Recommendations:

Tribal leaders specifically identified a need for CDC/ATSDR staff to be aware of and trained in working with tribal nations. Tribal leaders recommend that training be provided to all CDC/ATSDR staff on tribal sovereignty, the nation-to-nation relationship, federal trust responsibility, and other core concepts and CDC/ATSDR's role in fulfilling them.

Tribal leaders are concerned that tribal priorities may not be reflected in the CDC Moving Forward Initiative, and there is a need for greater accountability to ensure their input is reflected in the Moving Forward efforts. Tribal leaders reminded CDC/ATSDR of their trust responsibility and the importance of engaging tribal leaders at the beginning of and often prior to actions being taken, such as CDC Moving Forward. One tribal leader summarized this sentiment as "we say, say nothing about us, without us."

Tribal leaders reminded CDC/ATSDR that the best way to move forward and make progress on public health goals is to hear directly from tribes via tribal consultation, because it benefits all tribes. Tribal leaders believe that early and regular engagement puts CDC/ATSDR in a better position to serve tribal nations, fulfill the federal trust responsibility, and achieve meaningful health equity in Indian Country.

Tribal leaders stated that the reorganization of CDC/ATSDR is the perfect time to hit reset, come together and work in tandem. Strengthening cross-cutting functions identified in CDC Moving Forward and improving personnel resources, expertise, and funding is a welcome step forward.

Tribal leaders have acknowledged that there has been improvement in information sharing and CDC/ATSDR's relationship with tribes is getting stronger, but concerns remain about the

timeliness of the communication regarding the CDC Moving Forward Initiative. Specifically, leaders expressed concern about receiving information after implementation began, and they hope CDC/ATSDR will take tribal comments into full consideration, even if it means rethinking decisions that have already been made in planning the reorganization.

Tribal leaders acknowledged CDC/ATSDR's priorities but asked CDC/ATSDR if they were aware of some of tribal leaders' priorities (e.g., data sharing, missing or murdered Indigenous persons, electronic health records systems, etc.), and if additional consultation will occur on CDC Moving Forward. In addition, tribal leaders stated that they see the reorganization of CDC/ATSDR as a chance to implement necessary systemic and cultural changes that can effectively address the root causes of health inequities, paving the way towards a more equitable future.

Tribal leaders stated that the reorganization of CDC/ATSDR should prioritize a strengths-based organizational culture and focus on cultural humility.

Tribal leaders have emphasized the importance of clear communication from CDC/ATSDR regarding COVID-19, as well as ensuring that all recommendations, guidance, and advice are based on science. Tribal leaders have stated that they have worked hard to protect populations who have high comorbidity rates and susceptibility to infection, therefore, information needs to be accurate. Tribal leaders also stated that it makes their job much harder when they make declarations of guidance and behavior to their tribal citizens and CDC/ATSDR is not as forceful.

Tribal leaders expressed concern about the transition out of the COVID-19 pandemic and inquired about how CDC/ATSDR is taking tribal priorities into consideration as it transitions out of the public health emergency declaration, in addition to how CDC/ATSDR will prepare for the next pandemic. Tribal leaders emphasized the need for tribal leaders and CDC/ATSDR to learn from each other; questioning what and how the agency is learning from tribes when tribes are not consulted at the beginning of the process.

Tribal leaders expressed concern that the administration intends to end the public health emergency without consultation; especially because there is more than one national emergency declaration for the COVID-19 pandemic. In addition, tribal leaders expressed concern about how CDC/ATSDR will collaborate with HHS and sister agencies to ensure that tribal nations are informed of health care coverage, surveillance activities, vaccine programs, etc., that are available to their communities.

Response to CDC Moving Forward Initiative Recommendations:

CDC/ATSDR acknowledges the recommendations made by tribal leaders on the CDC Moving Forward Initiative. CDC/ATSDR also recognizes the importance of engaging tribal nations early and often in the CDC Moving Forward Initiative. CDC is committed to working to continue strengthening our relationship with tribes as we further implement CDC Moving Forward. Early in the implementation of the CDC Moving Forward Initiative, CDC engaged the CDC/ATSDR Tribal Advisory Committee (TAC) during the December 2022 TAC Conference Call and Dr. Mary

Wakefield presented on the CDC Moving Forward work being done to modernize and reorganize the agency. Dr. Wakefield discussed efforts to prepare a more response-ready workforce equipped to respond to future public health emergencies and optimize CDC's web-based content to enhance utility and equity for CDC's public health partners and the people we serve. To that extent, CDC/ATSDR will continue to use the Tribal Advisory Committee (TAC) and other tribal engagements to seek input and guidance from tribal leaders throughout this process.

CDC/ATSDR recognizes the need for ongoing and continued education and training of CDC/ATSDR staff working with tribal nations and is committed to working with agency leaders to ensure training is appropriate and available. CDC/ATSDR also understands the importance of workforce development and is partnering with the National Network of Public Health Institutes (NNPHI), Indigenous Public Health Leaders Program. The program is currently training its second cohort of 50 emerging AI/AN public health professionals who are working with tribal organizations and communities. This six-month program focuses on core public health competencies, including mental health, emergency preparedness, and collaboration amongst stakeholders, to better serve tribal populations.

The CDC Office of Tribal Affairs and Strategic Alliances (OTASA) will continue to recommend training materials and programs produced by tribes as well as work with other agency initiatives to improve tribal engagement across CDC/ATSDR. CDC/ATSDR also recognizes the significance of building relationships at the tribal staff and leadership levels and will continue to improve coordination and communication between partners.

CDC/ATSDR recognizes and appreciates tribal leaders' concerns around the ending of the federal COVID-19 public health emergency declaration. While CDC/ATSDR continues to refine how it will support tribal nations, tribes and partners should reach out to OTASA with any questions or concerns. OTASA will continue to keep tribal nations informed as CDC/ATSDR updates and transitions the emergency response.

2) Accountability

Tribal leaders recommended that CDC/ATSDR ensure they are accountable to tribal priorities and input. Comments were received concerning the need for CDC/ATSDR to be accountable and uphold the federal trust responsibility.

Summary of Accountability Recommendations:

Tribal leaders recommend accountability include measures of effectiveness and evaluation of CDC/ATSDR's work. Tribal leaders also stated that accountability must occur bidirectionally, and tribes are committed to providing direct communication to CDC/ATSDR about the agency's work in Indian Country. Tribal leaders stated that with two-way communication there can be meaningful consultation; reminding CDC/ATSDR that tribal consultation must occur with leaders who have decision-making authority in the agency. In addition, tribal leaders reminded CDC/ATSDR that appropriate follow-up must occur in order to make the engagement meaningful. Tribes indicated a desire and willingness to engage with CDC/ATSDR in a framework of equal

partnership, emphasizing that the relationship between tribal governments and CDC/ATSDR should not be paternalistic.

Tribal leaders stated that CDC/ATSDR must take active measures to ensure AI/AN people and tribes are visible in the creation of policies and data as part of its trust responsibility; this includes sharing information in a timely manner, such as the status of the implementation of the recommendations made by the Government Accountability Office (GAO) in its 2022 report on enhancing HHS data access for Tribal Epidemiology Centers (TECs) or details on how CDC/ATSDR plans to end the COVID-19 public health emergency.

Tribal leaders have stated that CDC/ATSDR and their programs do not always consider tribal needs and funding; this lack of transparency elicits questions about CDC/ATSDR's commitment to upholding their trust responsibility.

Response to Accountability Recommendations:

CDC/ATSDR appreciates the recommendations and acknowledges the need for greater accountability in reporting and following up on tribal leaders' recommendations. CDC/ATSDR will continue to prioritize providing updates to the CDC/ATSDR TAC and HHS Secretary's Tribal Advisory Committee (STAC) through regular TAC conference calls and quarterly STAC meetings, as well as a summary report of the tribal leaders' recommendations received at tribal consultation and CDC/ASTDR's response.

Dr. Leslie Ann Dauphin, the Acting Designated Federal Official for the CDC/ASTDR TAC, stated in her March 2023 CDC updates to the HHS STAC that one of the motivations for the CDC Moving Forward Initiative is to increase transparency and accountability. CDC/ATSDR is also working to conduct a landscape analysis of all CDC/ATSDR funding opportunities to see where and how the agency can reduce administrative burden, increase technical support, and disburse funding more efficiently to partners.

CDC/ATSDR recognizes the need for transparency and will continue to share information widely, and seek input from the CDC/ATSDR TAC, STAC, tribal leaders and tribal serving organizations that may be impacted by CDC/ATSDR's actions. Additionally, CDC/ATSDR sends information on funding opportunities, resources, conferences, and other tribal news to tribal leaders, national tribal-serving organizations, grantees, and others through a biweekly email and other ad hoc communications to ensure timeliness. CDC/ATSDR also asks our HHS sister agencies and national tribal partners to share information with their network to ensure information is distributed as widely as possible.

CDC/ATSDR acknowledges the need to report to tribal leaders on the CDC Moving Forward work and the reorganization as we progress and will strive to improve on the shortcomings identified with the CDC Moving Forward Initiative and upholding our trust responsibility. CDC/ATSDR intends to pursue tribal input on key areas of the Moving Forward Initiative through continued engagement with the TAC as well as continued collaboration with national tribal partners.

CDC/ATSDR also continues to prioritize engagement with tribes more generally. For example, during the August 2022 TAC meeting in Tahlequah, Oklahoma, the CDC National Center for Environmental Health (NCEH) shared plans to hold several regional tribal environmental health summits throughout the nation to address issues raised by tribes during listening sessions and previous engagements with tribes over the last few years. NCEH will hold these summits in partnership with tribal health organizations, the first summit is expected to occur in July 2023. Primary environmental health topics include climate and health, solid waste, and safe water.

CDC/ATSDR is committed to tribal consultation and has increased the number of consultations compared to past years. For example, CDC participated in HHS-led tribal consultation on data sharing on October 13 and October 19, 2022. A summary report of the oral and written comments received from the HHS-led tribal consultation was finalized in January 2023 and is now included on CDC's Tribal Public Health Data website. The CDC's National Institute for Occupational Safety and Health (NIOSH) recently hosted a consultation in February 2022 to obtain public feedback on the AI/AN Worker Safety and Health Strategic Plan, and the final plan was published March 2023. Furthermore, the CDC National Center for Injury Prevention and Control will hold a consultation on the Rape Prevention and Education Program on July 12, 2023. For further information please see CDC/ATSDR Tribal Consultation website.

3) Health Equity

Tribal leaders recommended that CDC/ATSDR continuously apply a health equity lens when working with tribal nations and tribal serving organizations. In their recommendations, tribal leaders identified several health equity topics including cultural humility, COVID-19, life expectancy, and respecting tribes' experience and knowledge about their communities' health.

Summary of Cultural Humility Recommendations(a):

Tribal leaders commented on health inequity as a major issue facing tribal nations. Tribal communities are experiencing some of the worst health outcomes in the U.S. According to the NCHS Data Brief on life expectancy, AI/AN populations are experiencing a significant reduction in life expectancy compared to the general population. To improve health inequities, power must be returned to tribal nations. Flexibility and tribal control should be at the center of the federal government's funding structures. Health inequity is a problem that is best solved within the community, led by tribes, and supported by CDC/ATSDR.

Tribal leaders acknowledge that the relationship between tribes and CDC/ATSDR is getting stronger. Tribal leaders recommend that CDC/ATSDR always approach health equity with cultural humility, while dismantling structures of inequality. The agency should strive for an organizational culture that is strengths-based, recognizing that solutions should come from within the community.

Tribal leaders recommended that CDC/ASTDR should not worry about getting it "all perfect" but should make sure that they are respectful about tribal nations' cultures, norms and values, and not assume to know better than tribes about tribes. Tribes know their people, communities, social and historical context, needs, and strengths best; tribes are the experts in charting a path to health equity for their people. Tribal leaders recommend that nothing should be done without CDC/ATSDR and tribes working together, including sharing of information and providing the flexibility for the implementation of culturally appropriate public health initiatives for tribes. Listening to and understanding tribes should be a foundation for CDC/ATSDR staff working in Indian Country.

Response to Cultural Humility Recommendations (a):

CDC/ATSDR recognizes and acknowledges that cultural humility should be at the forefront of all engagement with tribal nations. CDC/ATSDR agrees the recommendation that CDC/ATSDR and tribes need to work together and share information in an open and learning environment.

CDC/ATSDR is committed to working internally to improve cultural awareness and humility. CDC/ATSDR will offer training, resources, and consulting services to CDC programs to enhance their comprehension of the distinctiveness of tribes and the government-to-government partnership that establishes the basis for our collaboration with tribes. Additionally, CDC/ATSDR is committed to providing more opportunities to seek and receive tribal input on CDC activities.

CDC acknowledges that in order to provide support in improving the health equity and public health outcomes of AI/AN communities, the CDC workforce has to better reflect the communities it serves. In November 2022, CDC hosted its first American Indian, Alaska Native, and Native Hawaiian (AIANNH) Career Day, where AIANNH professionals learned about fellowships, internships, and other pathway programs to begin public health careers at CDC. Additionally, CDC looks forward to supporting future cohorts of the Indigenous Public Health Leadership Program to train public health leaders on core public health competencies, with a focus on key issues affecting tribal communities.

Summary of COVID-19 Recommendations (b):

Tribal leaders enthusiastically commented on their successful and effective role in organizing and administering all aspects of the COVID-19 response in their communities. Many tribal leaders describe the extraordinary commitment of tribal nations throughout the United States on the prevention of COVID-19 infection in their communities, including vaccination, and timely and effective messaging.

Tribal leaders are concerned about the transition out of the COVID-19 public health emergency and the need for tribal nations, CDC/ATSDR and other federal agencies to work together to learn from each other to prepare for the next pandemic. There is much to learn from tribal nations and by treating tribal nations as equal partners, health equity can be obtained. Partnering and identifying what worked will benefit the 574 federally recognized tribes and our nation as a whole.

Tribal nations also expressed concerns about how they will receive COVID-19 vaccines, treatment, and other supplies that may be needed as the number of cases continue to increase.

Response to COVID-19 Recommendations (b):

CDC/ATSDR applauds the work that tribal nations did to respond to the COVID-19 pandemic; lives were saved, and tribes were at the forefront of emergency response activities. CDC/ATSDR would like to thank tribes, tribal serving organizations, and others who not only assisted with COVID-19 prevention, treatment, and vaccination in their communities, but also reached out to and supported communities nearby.

CDC/ATSDR recognizes that many tribal members were and are at high risk and the commitment and dedication of tribal leaders and tribal public health officials should not be ignored.

CDC/ATSDR would also like to acknowledge the need for clear and concise guidance on how, tribes and tribal serving organizations will receive the technical assistance, supplies, vaccines, and treatments they need to protect their communities as the COVID-19 public health emergency declaration transitions. CDC/ATSDR is in the process of updating their tribal support activities and identifying who will be responsible for COVID-19 activities moving forward. At this time, OTASA (tribalsupport@cdc.gov) continues to serve as the primary point of contact for tribes. CDC/ATSDR's COVID-19 landing page Coronavirus Disease 2019 (COVID-19) | CDC also has resources and information on COVID-19, as well as up-to-date guidance. As more information becomes available, OTASA will distribute this information through our bi-weekly email updates.

Summary of Life Expectancy Recommendations (c):

Tribal leaders expressed their concerns with the findings in CDC/ATSDR's Vital Statistics Rapid Release, Number 023 (August 2022) (cdc.gov), which described the disparities in deaths and other health outcomes experienced by AI/AN individuals. Tribal leaders demand a swift and profound response since the inequities are overwhelming and are worsening at alarming rates.

Response to Life Expectancy Recommendations (c):

CDC/ATSDR agrees with tribal leaders' comments on the life expectancy of AI/AN peoples. The findings have our attention. CDC/ATSDR recognizes the unique public health needs of AI/AN communities and is committed to working with tribes to improve and protect the health of tribal communities. CDC/ATSDR also recognizes that such health disparities within Indian Country speak to the importance of enhancing health equity among AI/AN tribal communities and AI/AN persons living in urban areas. CDC/ATSDR continues to work internally and with other federal agencies on how to address this issue. Ensuring representation, particularly in the tribal public health community, is paramount to addressing health disparities and inequities experienced by AI/AN communities and across the nation. CDC/ATSDR will continue to work to improve these efforts

and ensure that our public health workforce is representative of the communities they serve, including tribal communities.

Summary of Recommendations about Respecting Tribes' Experience and Knowledge (d):

Many tribal leaders stated that tribes know their communities best and CDC/ATSDR can learn from tribes. In particular, tribes stated that not all of the 574 federally recognized tribes possess the same level of tribal public health resources, capacity, or needs. However, each tribe has unique knowledge and experiences to offer to CDC/ATSDR and other tribes, highlighting the importance of collaboration and knowledge-sharing within the public health community. CDC/ATSDR needs to garner this knowledge and leverage it in its work. Regarding using CDC's support to share their expertise, one tribal leader stated that "we want to take that equitable approach across the board, which is tough, because that's a lot of work."

Tribes stated that they are willing to meet with CDC/ATSDR and mentor other tribes to share successes and failures. They suggested that CDC/ATSDR hold consultation or listening sessions to develop a process for this knowledge exchange.

Tribal leaders were adamant that CDC/ATSDR "look out and see what a tribe can do with the dollar" and understand how they implement their resources; a prime example is the COVID-19 pandemic, during which, many tribes were the first to act to save lives.

Tribal leaders recommended that CDC/ATSDR work closely with tribal nations to prepare for the next pandemic as each has something to offer; tribes make decisions for themselves on the best way to set priorities and design programs tailored to the needs of their communities. "Tribes know their people, communities, social and historical context, needs, and strengths best – tribes are the experts in charting a path to health equity for their people."

Tribal leaders strongly recommended that they need to be included in planning and decision-making processes; specifically, nothing that affects tribal communities should be discussed, and nothing should happen without tribal leaders at the table. One tribal leader stated, "we say: nothing about us, without us."

Tribal leaders also commented that they wanted sufficient flexibility and support for tribes to design their public health priorities and interventions. This would be both more effective in advancing health equity and more respectful of tribal sovereignty.

Response to Recommendations about Respecting Tribes' Experience and Knowledge (d):

CDC/ATSDR agrees with tribal leaders' comments. CDC/ATSDR can learn much from tribal nations. CDC/ATSDR recognizes and understands that with 574 federally recognized tribal nations, tribal cultures, norms, traditions and values are distinct so we must partner with and listen to tribes. CDC/ATSDR is committed to engagement with tribal nations early and often when proposed actions may affect tribal nations. The agency is also committed to providing more opportunities to engage in discussion and knowledge exchange with tribes and tribal partners.

4) Data

Tribal leaders stated that CDC/ATSDR needs to do a better job in assuring that tribal nations have access to their own data. In addition, they emphasized that TECs are public health authorities, as designated in the 2010 Indian Health Care Improvement Act and should have access to requested data. Tribal leaders pointed to the GAO report on enhancing data access for TECs to highlight this need for data access.

Summary of Tribal Data Access Recommendations (a):

Tribal leaders reiterated that no one should speak on behalf of a tribe and when it comes to tribal data, tribes need access to their own data. Tribes are sovereign nations and CDC/ATSDR must provide data to the tribes as they are public health authorities. Without data about their communities, tribes cannot keep themselves safe and cannot develop appropriate health policies and interventions. Tribal leaders reminded CDC/ATSDR that tribes must have the same access to data as do other public health authorities.

Tribal leaders wanted to remind HHS that the GAO report on enhancing data access for TECs specifies activities that should be performed, including developing guidance and procedures for providing data access to TECs.

Tribal leaders also recommend that HHS, CDC/ASTDR, and the Indian Health Service (HIS) extend the GAO recommendations to all IHS tribal health care clinics and consortiums to improve the relationships between these facilities and the TECs.

Response to Tribal Data Access Recommendations (a):

CDC/ATSDR acknowledges the comments regarding the need for tribes to have public health data about their own communities. CDC/ATSDR has worked closely with HHS and IHS on setting up an interim system where tribes can request datasets that CDC/ATSDR maintains.

While CDC/ATSDR does not currently have tribe specific data, CDC/ATSDR is actively exploring ways to gather and incorporate such data in the future. It is important to ensure that all communities, including tribal communities, are properly represented and accounted for in data analyses and decision-making processes.

On December 30, 2022, CDC/ATSDR launched the Tribal Public Health Data website to provide tribes and TECs with a more streamlined way to identify and request data with AI/AN indicators. CDC/ATSDR will continue to improve tribes' and TECs' access to public health data for decision-making in their communities.

Summary of GAO Report Recommendations (b):

Tribal leaders support and strongly encourage CDC/ATSDR to continue to implement the recommendations issued in the GAO report entitled Tribal Epidemiology Centers: HHS Actions

Needed to Enhance Data Access. In addition, tribal leaders encourage the quick implementation of the GAO report's recommendations, not just for the twelve TECs, but extending that opportunity for tribal health consortiums and other tribal health care facilities.

Response to GAO Report Recommendations:

CDC/ATSDR agrees with the findings and recommendations in the GAO report and has worked closely with HHS and IHS on implementing the recommendations and publishing the CDC/ATSDR Tribal Public Health Data website. CDC/ATSDR recognizes the importance of having accessible, timely, and quality data for making decisions about how to protect and improve our communities' health; the status of TECs as public health agencies; and the sovereign status of tribal nations and how it factors into the collection, analysis, and use of their members' public health data.

CDC/ATSDR also recognizes that with any data sharing or access provision, CDC/ATSDR needs to examine the type of data, their provenance, and any statutory or legal protections that may apply to their management. Given that each data system is unique in terms of data ownership, applicable laws/policies, sharing agreements and content, and because CDC/ATSDR is not the data owner in many cases, CDC/ATSDR must work with state health departments to identify the best processes to share data with federally recognized tribes on a system-by-system basis. CDC/ATSDR is working to balance these considerations and it will take time to work through this.

CDC/ATSDR has fulfilled its role in responding to the GAO recommendations report with the publication of the Tribal Public Health Data Website and guidance document; for further information on data modernization please visit the CDC Data Modernization Initiative website.

Summary of Tribal Epidemiological Data Recommendations(c):

Tribal leaders recommend that CDC/ATSDR provides accessible data to tribal nations and that the data analyses CDC/ATSDR conducts include AI/AN data that has not been erased by racial misclassification.

In addition, tribal leaders stated that they cannot develop effective health policies without effective and accurate data. High-quality, meaningful AI/AN health data are essential for identifying disparities, setting priorities, designing strategies, and highlighting successes related to health equity.

Tribal leaders also commented on H.R. 1397 "Tribal Health Data Improvement Act of 2021," which expands tribal access to public health care data and public health surveillance programs, and reauthorizes the National Center for Health Statistics to take certain actions in the collection and availability of health data for AI/AN people. This bill requires CDC/ATSDR to develop guidance around birth and death record data for state and local health departments on AI/AN people; fund tribes, tribal organizations, Urban Indian Organizations, and TECs via cooperative agreements to analyze and address AI/AN inaccuracies in birth and death records; standardize health data collection on race and ethnicity; and encourage states to enter into data sharing agreements with tribes to improve data accuracy.

Tribal leaders also recommended that CDC/ATSDR address how national surveillance systems deployed during the COVID-19 pandemic will continue to operate.

Response to Tribal Epidemiological Data Recommendations:

CDC/ATSDR acknowledges the tribal leaders' recommendations and is working towards making sure that tribes not only have access to the CDC/ATSDR datasets that they need to protect the health of their communities, but that the datasets are accurate, high quality, and complete. In January 2023, CDC/ATSDR obtained feedback from the TEC consortium on the Tribal Public Health Data website and is working to incorporate that feedback by adding additional information on racial and ethnic classifications in the data available at CDC. This information will be accessible within the tribal access to data chart on the website in summer 2023.

Additionally, in March 2023, CDC/ATSDR and other federal agencies provided input and recommendations to the Office of Management and Budget on the proposed revisions of OMB's Statistical Policy Directive No. 15: *Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*, that CDC/ATSDR anticipates will help address several issues related to racial misclassification in public health data.

CDC/ATSDR plans to develop and pilot test a capabilities-based assessment instrument and method to document data modernization-related capabilities and needs appropriate for use by tribes and tribal public health partners. This will involve establishing a Tribal Expert Working Group to provide feedback, conducting listening sessions to collect tribal input, and pilot testing the tool in nine sites before finalizing and disseminating it across tribal public health organizations. CDC/ATSDR has also taken other actions, such as updating data sharing policies and providing guidance for accessing tribal public health data, to address recommendations and improve data sharing with tribal partners.

CDC/ATSDR launched the Tribal Public Health Data Request Form to help facilitate tribes' access to the data available from CDC/ATSDR. This service is for tribal nations, TECs, and Urban Indian Health Centers. Others may request information from CDC-INFO.

Information about CDC /ATSDR's relevant data sets is available on the Tribal Public Health Data website. If you cannot find your answer there, please contact OTASA by using the Tribal Public Health Data Request Form. OTASA will provide an answer or triage your request to the relevant CDC/ATSDR program for response.

5) Funding

Tribal leaders recommended that CDC/ATSDR prioritize and simplify tribal funding. Tribal leaders reiterated the need for CDC/ATSDR to invest more directly in tribal public health, have set aside funds, and for CDC/ATSDR to develop and implement Notices of Funding Opportunities (NOFOs) that prioritize tribal sovereignty.

Summary of Funding Set Aside and Tribal Prioritization Recommendations (a):

Tribal leaders recommended that CDC/ATSDR invest in tribal public health with sustained public health infrastructure funding; suggesting that for every $1 spent directly funding tribal public health infrastructure, there is a $5 return on the investment. Furthermore, tribal leaders emphasized that one cannot put a price on a life. Tribal leaders also reiterated that there are generations of health inequity stemming from the piecemeal funding approach; this has been demonstrated in the recent report on the decreased life expectancy in AI/AN people.

Tribal leaders recommended that through the CDC Moving Forward Initiative, and in all future work, all of CDC/ATSDR must prioritize tribes. Tribal leaders reemphasized their past recommendation for a 10% set aside, as it is in line with the federal trust and treaty responsibilities. Tribal leaders stressed that these funds should not come through competitive grants, because tribes should not be made to compete against each other. Rather, public health funding to tribes should be broad-based and formula driven.

In addition, tribal leaders remain concerned about not being deemed eligible for preparedness funding, as well as the unreliable and administratively burdensome grant cycle.

Response to Funding Set Aside and Tribal Prioritization Recommendations (a):

CDC/ATSDR cannot commit to enacting a 10% set aside for tribes. However, CDC is taking the intent of this recommendation under consideration as the agency continues to explore better ways to provide resources and other CDC support for tribal public health. A major barrier to implementing this recommendation is the current structure of CDC/ATSDR's budget. The agency's budget, which is directed by Congress, is structured based on disease or public health issue area, and not specific population. While there remains room for improvement, direct funding to tribal nations for tribal public health has increased in recent years. Setting aside 10% of every CDC/ATSDR Center, Institute, and Office's (CIO) budget for tribal nations may have the challenge of disproportionate distribution among tribal nations because of the disparate status and variations of tribal health infrastructures across Indian Country.

Summary of Direct Funding Recommendations (b):

Tribes recommended that CDC/ATSDR provide direct funding to tribes so that they have the opportunity to determine how the funding will be spent and tailor programs to their unique needs. Tribal leaders suggested that if CDC/ATSDR looked to see what tribes are capable of doing in their communities, the agency would understand that the return on investment would be enormous.

Tribal members reminded CDC/ATSDR of their government-to-government relationship with the federal government. Therefore, in order for CDC/ATSDR to uphold their trust and treaty responsibilities funds must flow directly to tribes through the appropriate channels, not through state and local jurisdictions or other partners.

Response to Direct Funding Recommendations (b):

CDC/ATSDR acknowledges and respects the government-to-government relationship that the federal government holds with the 574 federally recognized tribes. CDC is taking this recommendation under consideration as the agency continues to explore better and more efficient ways to provide resources and other CDC support for tribal public health.

CDC/ATSDR strives to maximize its extramural investments as much as possible. In fact, most CDC/ATSDR funding is provided to the field (approximately 78%). However, the agency's budget, which is directed by Congress, is structured based on disease or public health issue area, and not specific population.

Where possible, CDC/ATSDR continues to support tribal specific funding, such as the National Center for Chronic Disease Prevention and Health Promotion's Healthy Tribes program and the National Center for State, Tribal, Local, and Territorial Public Health Infrastructure and Workforce's new cooperative agreement, CDC-RFA-TO-23-0001: Strengthening Public Health Systems and Services in Indian Country. Strengthening Public Health Systems and Services in Indian Country is a new, five-year cooperative agreement with an expected project start date of August 31, 2023. The anticipated base funding for this cooperative agreement is $5 million for 25 recipients, an 800% base funding increase from the previous cooperative agreement's base funding (OT18-1803: Tribal Capacity Building Umbrella Cooperative Agreement).

Summary of NOFO Recommendations (c):

Tribal leaders strongly recommend that all CDC/ATSDR staff who develop and implement NOFOs understand and account for tribal sovereignty in their NOFOs. Tribal leaders ask for all NOFOs to be reviewed by experts, including OTASA staff, who understand and respect tribal sovereignty. In addition, tribal leaders stated that simply listing tribes as eligible for a NOFO is not enough. As sovereign nations, separate NOFOs should be written specifically for tribes.

Response to NOFO Recommendations:

CDC/ATSDR acknowledges and respects tribal sovereignty. CDC/ATSDR is working with all CIOs to ensure that the development and clearance of all NOFOs includes thorough review by staff with the expertise to recognize and address tribal concerns and eligibility, as applicable. However, it is important to note that at times, Congress limits how funds can be allocated and used; CDC/ATSDR will continue to work with our CDC Washington Office, our TAC, and others to make all grants as inclusive and flexible as possible.

Next Steps:

For next steps, CDC will work to incorporate the recommendations and input into the CDC Moving Forward Initiative. After the comments have been incorporated, CDC/ATSDR will provide an update to the CDC/ATSDR TAC. As CDC Moving Forward continues, CDC/ASTDR will use these recommendations as a resource to ensure that tribal nations are part of the solution.

Appendix A: Consultation: Written, Oral, and Other

CDC/ATSDR's Tribal Consultation on CDC Moving Forward Initiative
February 9, 2023
Tribal Consultation Transcript (Oral and Chat Box Testimony)

Dr. Houry: [Good to be] with you today. My name is Dr. Deborah Houry, and I am CDC's Chief Medical Officer and the Deputy Director for Program and Science. CDC would like to acknowledge the Muscogee Nation and Cherokee Nation whose indigenous lands we are on at CDC.

I want to start off by reaffirming our government-to-government relationship. The CDC is committed to working with tribal governments on a government-to-government basis and we strongly support and respect the sovereignty and self-determination of tribal governments in the United States.

Your verbal and written testimony will be fully considered, and we thank you in advance.
Additionally, this Zoom meeting is being recorded for record-keeping purposes only. If you do not wish to be recorded, you can disconnect now.

Thank you for this opportunity to hear from you. I will now turn the meeting over to Councilman Nate Tyler, of the Makah Nation, a member of the CDC/ATSDR Tribal Advisory Committee, and co-facilitator of today's consultation. Thank you.

Chat Message: *Thank you for joining today's Tribal Consultation. Please note, the chat function is to be used by tribal leaders and CDC leaders only.*

Councilman Nate Tyler: All right. I appreciate that. My name is Nate Tyler, Makah Tribal Council.
My Indian name is Či-lap. Či-lap means warrior. My grandfather gave me that name after returning from the first Gulf War. It's a pleasure to welcome you guys, to welcome everybody here, to take part.

You know I am happy to be co-facilitator of this, but to take part of a CDC/ATSDR Tribal Consultation on the CDC Moving Forward initiative, tribal priorities as we transition out of COVID-19 public health emergency, as well as, how the CDC can better support tribes and tribal communities in the future. And, for myself, you know I'd like to start off with prayer. I know you know there are a lot of different religions out there. I grew up as a youth studying in the Baha'i faith. So, I'm going to read a Baha'i prayer. You don't need to stand, but I do want to read this prayer. It's on traveling.
This is my first time, too, so, first time being put in this position, so:

I have risen this morning by Thy grace, O my God, and left my home trusting wholly in Thee, and committing myself to Thy care. Send down, then, upon me, out of the heaven of Thy mercy, a blessing from Thy side, and enable me to return home in safety even as Thou didst enable me to set out under Thy protection with my thoughts fixed steadfastly upon Thee.

There is none other God but Thee, the One, the Incomparable, the All-Knowing, the All-Wise.
Bahá'u'lláh

So once again, welcome.

I'd like to turn the meeting over to Dr. Dauphin, CDC's Acting Designated Federal Official for the Tribal Advisory Committee.

Chat Message from Charity Sabido-Hodges: *Kleco, kleco Cousin Nate...That was very good.*

Dr. Dauphin: Thank you. Councilman Tyler,

As Councilman Tyler mentioned, I am Les Dauphin, Acting Designated Federal Official of CDC Tribal Advisory Committee and Director of the proposed National Center for State, Tribal, Local, and Territorial Public Health Infrastructure and Workforce. I will talk briefly about the internal CDC reorganization, recently announced as part of the CDC Moving Forward initiative, as it relates to CDC tribal work and engagement. Then Dr. Mary Wakefield will present the CDC Moving Forward initiative's goals, and next steps. We will then proceed with consultation.

Before I do so, however, I want to acknowledge there remains work to be done on how and when we engage and work with our tribal partners. Our goal is continually improving tribal engagement. CDC Moving Forward is CDC's effort to take concrete lessons from the COVID-19 response, and how we work with our public health partners, including tribes, and our responses in the way we do our work.
This means not just looking at what we do well, but where we have opportunities to improve. At the heart of CDC Moving Forward is accountability. We have to look unflinchingly at how we operate and ask how we can do better.

CDC honors the government-to-government relations with tribal nations and the work we've done to support tribes. But unquestionably there's room for improvement. CDC is committed to positioning ourselves as a true partner to tribal nations to help you build the public health infrastructure needed to protect all tribal citizens from health threats.

In that spirit of accountability, I want to acknowledge that parts of the Moving Forward initiative, like the internal reorganization announced last month by CDC, have been moving internally, and tribal partners have not been kept up to date, as they should have been on each of these internal steps. Making major changes to an agency as a large as CDC is hard, and there will be missteps and miscommunication; we acknowledge and are accountable for that.

But I also want to emphasize that the internal reorganization steps happening are only one part of the Moving Forward effort, and the most important part of this initiative is still ahead of us. The way we truly strengthen our government-to-government relationship is not through changing boxes on the chart. It's in the day-to-day commitment to listen, build trust, and deliver on what tribes want, and need from CDC. And that is what you'll get from me and from CDC as we enter this next phase of Moving Forward; not perfection, I want to be clear, not perfection, but a daily commitment to building, trust and delivering the services, resources, and information tribes need to protect American Indians and Alaska Natives in every community in the United States.

That is why consultation is so crucial, but also just the first step in a renewed effort to strengthen our government-to-government relationship. So briefly for an overview of the reorganization relevant to the TAC and tribes. [Screen shares organizational chart] CDC Staff, please make sure that we have that circled. Okay perfect.

The most relevant part of the CDC reorganization for CDC's tribal work, is CDC is establishing the center that I mentioned previously: the National Center for State, Tribal, Local, and Territorial Public Health Infrastructure and Workforce. This will combine the critical functions related to supporting tribal, state, local and territorial public health, infrastructure, and workforce, such as our major CDC tribal and jurisdictional grants and cooperative agreements, our partnership and technical support, and key workforce activities.

To create this proposed center, we consolidated functions that currently exist, in the Center for State, Tribal, Local, and Territorial Support, or CSTLTS, and the infrastructure and workforce related functions from the Center for Surveillance, Epidemiology and Laboratory Services, or CSELS. I'm honored to have been asked to serve as Director for this new proposed center, which, like CSTLTS will be the home of CDC's tribal work, the major cooperative agreements supporting tribes, and CDC's Office of Tribal Affairs and Strategic Alliances, which you see circled at the top right in the slide. And, I'm pleased to be joined today by Dr. Seh Welch, who will continue to serve as the Acting Director of this office, OTASA. I'm glad to have Dr. José Montero, formerly CSTLTS director, and the long-time Designated Federal Official of the TAC by my side. The two of us have committed to working together. We pledge to continue to build on the previous work accomplished in the years to come.

As we move forward, we will be listening to you, engaging with you, and elevating your voices at the level that we haven't done before. And this consultation today is just the beginning of this renewed commitment. I'm now honored and happy to introduce Dr. Mary Wakefield, who will provide a brief overview of the CDC Moving Forward initiative.

C*hat Message:* *Thank you to everyone for joining the Tribal Consultation today. Please note, the chat feature is reserved for Tribal Leadership and elected officials only.*

[CDC Moving Forward Slides Projected]

Dr. Wakefield: I was sent to speak from up here, although frankly, I'd be much more comfortable speaking from where Les was speaking, but I'm banished to this podium. So here I am.

It's, as I said, a pleasure to be here and talk with you about the work that we have underway. I'll take the next slide, please. Whomever is controlling that. Thanks. So, Les talked about some of the work that has been underway at the agency related to CDC Moving Forward. This is an initiative that I'm sure from different sources many of you have already heard about, even certainly before today. Maybe in the media, maybe from colleagues, et cetera. I'm going to just highlight a few of the key areas of activity that we, that have already occurred, and that we are driving toward over the next months and frankly, years. And I really want to underscore that this is a process within CDC, and in collaboration with tribal leaders, and tribal communities, and others, that will not be done this month, or three months from now or six months from now. This is a long-term initiative to make significant changes and improvements in the way

this organization does its work. We have opportunities for improvement, and that's the aim of CDC Moving Forward. Just by way of timeline, earlier last year the director initiated a review of the agency, and it was those reviews that were conducted that actually were the trigger for us, one of the major triggers for us being here today talking about this initiative. Les has already spoken to what you see on the right side of this timeline. That is the reorganization effort that has been underway, and that we're now in the process of implementing.

My very few moments with you are going to focus on the far-right side of this timeline. That is, the work of improving our processes, not just our structure to the reorganization, but improving our processes within the agency. That's the work that we are focused on in addition to reorganization, right now. Clearly, consultation with you is critical. As we continue this work, the [re]organization is just a piece of it. How we engage to meet the mission of this agency is equally challenging to improving our structure, and it's where consultations like this, and this is not going to be the last consultation, I'm sure around CDC Moving Forward. We need your input to ensure that we are meeting your expectations of us in improving this agency. So again, my comments have to do with the right side of this chart, and that is the process improvement activities that we have underway.

Over the last couple of months, we have convened teams across the agency, across CDC. We call them priority action teams. They have taken the work of the data that was collected and informed the Director to actually establish CDC Moving Forward. They've taken all of that input, they have talked with external groups and including groups that represent tribes through September, October, November, and that time frame. As well as other outside partners, state health departments, local health departments, and other groups to inform the work of improving processes within the organization. So those priority action teams were stood up, they developed action plans, and now, where we are in January, February is the implementation of those plans. So, we're starting to do the real work through CDC Moving Forward of taking all of that input and beginning to operationalize it. The implementation plans are being led by CDC's senior leaders.

So, as I mentioned the priority action teams were comprised of people from across the agency, looking at solutions to the problems that have been identified in April through July. And now those solutions that have been recommended, are being assigned to senior leaders for implementation. But truth be told, this is the work of everyone within CDC. It's not the senior leaders that are leading it, but this work going forward will involve everyone. Take the next slide, please.

These are our top areas for improvement and in consultation with you today. These are the areas we're focused on, and where your suggestions, and observations, and recommendations to us will be extremely important. With the areas that we're focused on for improvement, are these: first of all, to get the science, the research, the data out much faster, so that it informs whether we're talking about a pandemic, an epidemic, or injury prevention. Every part of the work of the agency we are looking at and thinking about how we can get our scientific findings and data out faster, not just to healthcare providers, but also to the public, to tribal communities, as well as tribal leaders. For example, enhancing laboratory science and quality. Another area of focus. I won't go into that.

And I'll make a couple of additional comments about a few of these key areas. Translating science into guidance and policies that are understandable and are usable by tribal communities, and usable by tribal

health and tribal leaders, is another priority area. Prioritizing our communications, so that we are speaking clearly and in venues that people go to for information is another area for improvement.

And the last two areas developing a workforce within CDC and across the country that is prepared for future emergencies. We know this pandemic is not the last pandemic. We have, and we'll have other emergencies in the future. So, we have a sharp focus on improvement in this area. And, finally promoting partnerships with our external partners, that are results-based focused on achieving outcomes and having impact. And that's why consultation from our perspective is so critically important. That we're engaging with you in ways that are meaningful, and eventually have significant outcomes that are positive outcomes.

The next slide. I'll say just a couple of quick words before I wrap up on just a few of those top areas of improvement. First in terms of sharing, excuse me, sharing scientific findings faster. In this area we're looking at, not just speed, but also partner input early on in the process. We're looking at how we can, within the agency, build in tribal input, and other external input to inform even the priorities of the research that we're conducting, not waiting to just release science on the back end. But hearing from you about what we should be focused on in the science itself. What should the research questions be that CDC should be following and studying, and then producing results that are meaningful and useful to you to improve tribal health. How can we be supportive of your efforts in, in strengthening tribal health. So, science, so sharing, scientific, faster, but also ensuring that they are on point and meeting community's needs.

Next slide, please. Just shifting to one of the other top areas for improvement. This is again focused on not just getting it out faster but ensuring that the policies that are implemented based on that science are practical. They're relevant, and they are easy to understand.

Next slide, please. Next slide, please. And the last area that I wanted to just mention very briefly is the area of promoting results-based partnerships. We know, as Les indicated, that we have opportunity and need for early engagement with our partners, and certainly with tribal leaders because of our government-to-government relationship. We need to be active in that engagement with our partners to develop and hear your priorities and goals, which is what makes meetings like this so critically important. And we need an institutionalized, organized way of receiving timely and meaningful feedback, so we can ensure that our partnerships produce the results in tandem with you, that help us to meet mission and meet your needs as well. We are working, very directly, on health equity within our work as well.

And in all of these areas that I've just described and gone through very quickly, we are looking at metrics--measures of performance. So, this is not in our minds, is not talking about what we aim to do, but it's also measuring, to ensure that we're having impact in these meaningful areas. So bottom line in in terms of producing science, with our partnerships, with the development of our workforce, we are looking for early engagement, substantive input and acting on that in a very a conscientious and deliberate fashion to inform our work as we go forward. So again, changes here are not just about the reorganization. There's more to come on that. It's very much a focus on how we can improve our processes and engagements to get even better outcomes for the public's health, and certainly that is true, very much for a tribal community health as well.

So, I'll stop there with that. That this is the fastest overview I've ever provided on Moving Forward, and I was told not to speak fast, which is my nature. So, this was especially a challenging for me, but I appreciate the opportunity, and certainly to see some familiar faces in the room today as well. Thank you for the opportunity to share just a few highlights of Moving Forward.

Dr. Dauphin: Thank you very much, Dr. Wakefield. We appreciate that overview. And, it was brief, but it was very thorough, and we thank you for it.

Okay, at this time, I would like to give a few logistical overviews. First, for participants who have joined by Zoom. Please ensure that your tribal position and tribe are included in your display name. We put instructions on how to do this, change your name, in the chat.

Chat Message (OTASA): *Welcome to the CDC/ATSDR Tribal Consultation Session. Please include your tribal position and tribe in your displayed name. How to Change Your Zoom Display Name:• Go to the top right corner of your Zoom displayed box• Click on the ellipses (three dots)• Select 'Rename'• Enter a new screen name (name, tribal position, tribe)• Select 'OK'• Done OR• Click on name in "Participant's List"• Select 'More' or the ellipses (three dots)• Select 'Rename'• Enter a new screen name (name, tribal position, tribe)• Select 'OK'• Done*

Dr. Dauphin: All right. We are soliciting your consultation on three things: strengthening relationships during the implementation of the CDC Moving Forward initiative, how the agency can better engage with Indian Country for meaningful consultation and tribes' priorities as we transition out of the COVID-19 public health emergency, and on how CDC can better support tribes and tribal communities in the future.

So, I'm going to provide additional meeting logistics. This consultation session, according to the current CDC/ATSDR tribal consultation policy, will be held between federally recognized tribes represented by the tribal president, tribal chair, tribal Governor, or an elected or appointed tribal leader, or their authorized representative and the CDC Director ATSDR Administrator's designee, Dr. Houry. The order of speaking will run as follows: First, Tribal Presidents, Chairpersons, and Governors. Second, Tribal Vice presidents, vice-chairpersons, Lieutenant Governance. Then, elected or appointed tribal officials. And finally, designated tribal officials.

When you begin, please announce your name, title, and tribal nation you are representing for the record. Those who wish to submit written testimony, or who may not have an opportunity to respond during our time today, please email your written comments, or testimony, no later than 5:00 p.m. February 24, 2023, to tribalsupport@cdc.gov. And that will be provided in the Zoom in the chat as well.

I will now turn the meeting over to Councilman Nate Tyler to facilitate the discussion.

Councilman Nate Tyler: Okay, once again, appreciate that Dr. Dauphin for the overview, and the information that you're shared about logistics. We're getting ready to start the discussion portion of this. I know we're really short on time here. Hopefully, everybody can get a chance to give their testimony on behalf of their tribe. I think that's really important to do that. So, if there is any tribal leaders ready to give testimony, raise your hand, and if you're in the room, turn your mic on and offer your testimony, please.

Councilman Nate Tyler: Oh, yeah, to start your testimony, state your name, title, and the tribe you are from, and then also give your testimony, or let the panelists know that you're going to submit your written testimony via email. So, we'll open it up for your testimony at this time.

Chat Message (Councilman Nate Tyler): *Can you put the Tribal Leader Title after your name please.*

Councilman Nate Tyler: Deputy Warner, so I know the CDC is asking you to answer one question, come back and answer the second, come back, come back to answer the third. But, if you're prepared to offer testimony and full for your testimony, and full at this time

Deputy Principal Chief Warner: All right, thank you. Bryan Warner, Cherokee Nation, Deputy Principal Chief, and again, thank you, Councilman Tyler, thank you Dr. Houry, Dr. Dauphin and Dr. Wakefield, I really appreciate the overview. And, for me I'll try to, I'll try to be as succinct as I can on this, but I really, one, one piece for me is what I appreciate the approach and what we've already had a couple of times that we've had to have you to come in, and you've told us about what was going on, and I appreciate the speed of your speech, ma'am. I really love that so, don't, don't ever stop, you know. Yes, ma'am; but when I, when I think about institutional effectiveness and assessment, I really think about a man by last name of Hummingbird told me, it's essentially this, Bryan. It's: What are you doing? How are you doing it, and how are you going to do it better? So, and then with that I feel like if we're really all here together to look at that assessment and that effectiveness, you know we're getting ready to implement this. So, we're going to see some results on the other end. But if we're, if we're tethered to that that institutional effectiveness and assessment, then we're not going to miss good by trying to be perfect. You know, and I think that is something that as we move forward, you know a lot of people, they want to worry about being perfect, I think, as far as tribal consultations, you know the relationship, the relationship between tribes and the CDC is getting stronger. That's my opinion.

I do have the seat as the TAC chair, and being on the TAC for a few years, and I have seen some improvement. As I, and my team sitting behind me, they assure me that we will continue to reach out and to because accountability is a two-way street, it's not just one way, so the tribe as the CDC is, we're asking you to be accountable in your measures and your effectiveness, and what you're doing. We will also be accountable in giving you the direct communication. I think, when we start to look about this Moving Forward as we kind of as we kick this can down the road, and these things start to implement, you come back and give us these updates. We will always be inviting you to come at any TAC meeting to give us these updates, but consultation...sometimes we have a little more than a handful of tribes now that are public health accreditation; that it went through the that process. I think, reaching out to some of those, some of the others that are in this process where they're at the infancy stages, they're in the middle, or they're getting towards end, I think, coming in and touching base with them. I don't want to leave any of the other tribes out at all, because I would be willing to say as a consultation, the Cherokee nation, I know the Chickasaw Nation is in this process. We would be willing to put something together to come in and consult with those tribes around, and to see, hey? That so you know, as tribes are growing, the CDC is growing.

So, a reorganization is something that it's just part of the growth process. So, I see that being able to be improving. Maybe as you start to look at some of the smaller tribes and the medium-size, and the larger

tribes, and you know we don't want to leave anybody out. We want to take that equitable approach across the board, which is tough, because that's a lot of work.

But then I think you can come back after you've had some initial, maybe one-on-one, one to ten meetings with ten to fifteen different tribes. Maybe we have something at a national level where we come in, and we have a consultation or a listening session to do something like that.

Better engage. You know that that talks about number two ah priorities. As we transition out, we need boots on the ground. You know we need, when we talk about public health infrastructure and what we're doing, we're, you know we're, we're also building a template for our other divisions within the Cherokee Nation to look at and understand public health, and I think, in order to do that, you know I've got, I've got the A-Team at the Cherokee Nation, our Public Health Department. We have reorganized that group. They used to be stacked up underneath health. We've moved them out from health, they are on their own. So that is a, for me, that's a historical thing that we've done, and it may not have been done without the pandemic. I know the, the leadership there. I've always had their ear, and they've always had mine, and that's something that I felt very strong about, because I believe in what they do. I believe in public health because we're all living entities of public health, so that continuation, but direct, you know, when you look at coming out of COVID. Some of the things that you're going to continue to hear is that direct funding to the tribes. We're not trying to leave any organizations out or any technical assistance groups, but we want to make sure that our, our tribes have that opportunity to tailor that money.

Because, as Councilman Tyler says, I love this, look out and see what a tribe can do with the dollar, you know, and understanding that. And we know that when we invest money into public health, it used to be like it, was it for every dollar we spent, the return on investment was five dollars. It may be even more today. You look at that, but you really can't put a price on life out there. You can't, you know, and our communities are living entities, and within those entities are the human beings that that live there that make things happen. They, they are the commerce, they are the economic development drivers and different things. And, as you've seen throughout the pandemic without the tribal nations across the United States, and in particular, I know for sure, in Oklahoma, the efforts to get out vaccines, the efforts to get out the messaging. We were, as everybody we were all working, and as a symphony as you guys were putting out your message, we were putting out tribal related messages so that our people understood those things and everything. So, I think there that you know, as I told Dr. Walensky today, there's a really good time to hit that reset button, and you know we're not going to scratch everything that we've done. But let's come together, and we will work in tandem, so Wado, Councilman Tyler. That is testimony. Thank you.

Chat Message (OTASA): *Attendees, please update your Zoom display name to include your tribal position and tribe. Thank you.*

Councilman Nate Tyler: Appreciate that Deputy Warner, Chief Deputy Warner. Is there anybody else in the room wanting to give testimony? [Pause] Any Chairman, Presidents, Chiefs on Zoom that wants to give testimony?

Chat Message (OTASA): *Please note, the chat feature is reserved for Tribal Leadership and elected officials only.*

Chat Message (OTASA): *Welcome to the CDC/ATSDR Tribal Consultation Session. Please include your tribal position and tribe in your displayed name. How to Change Your Zoom Display Name:• Go to the top right corner of your Zoom displayed box• Click on the ellipses (three dots)• Select 'Rename'• Enter a new screen name (name, tribal position, tribe)• Select 'OK'• Done OR• Click on name in "Participant's List"• Select 'More' or the ellipses (three dots)• Select 'Rename'• Enter a new screen name (name, tribal position, tribe)• Select 'OK'• Done*

Chat Message (Councilman Nate Tyler): *Will Micklin, who are you representing?*

Councilman Nate Tyler: Okay. Will Micklin, Vice President Tlingit and Haida, I'm going to turn it over to you if you can turn your camera on, if you're able to. If you have the bandwidth to do that, please turn your camera on and give your testimony.

Will Micklin: [Speaking in indigenous language] Can you hear me?

Councilman Nate Tyler: Yes.

Will Micklin: [Speaking in indigenous language] My Tlingit name is Yaan Eesh. My English name is, Will Micklin. I am Fourth Vice President for the Central Council of Tlingit and Haida Indian tribes of Alaska. We are the regional tribe in Southeast Alaska, thirty-five thousand, one hundred and thirty-eight square miles, all of Southeast Alaska, East of the one hundred and forty-first meridian, thirty-five thousand plus tribal citizens, and Richard J. Peterson, is our President. Thank you for the opportunity to speak. I'll, I'll be brief.

I just have two recommendations. One is for continued attention to implementing the GAO report on Tribal Epidemiology Centers, entitled HHS Actions Needed to Enhance Data Access.

It's geared to the 12 Tribal Epidemiology Centers in Indian Country and the essential recommendation is to develop guidance on how TEC's, Tribal Epidemiology Centers should request data and develop agency procedures on responding to those specific requests. HHS concurred on those recommendations and their expedited implementation, which is important, not just for the 12 TECs, but extending that opportunity for tribal health consortiums.

There are many in Southeast Alaska, the Southeast Alaska Regional Health Consortium that represents tribes in Southeast Alaska, and the opportunity to participate in that program is important and making sure that data is both accessible and provided and incorporated in CDC analyses is of critical importance.

Secondly, and this is specific to the epidemiology recommendation, that the role of CDC with tribes; with the example of the current COVID-19 pandemic is clear in the expression of recommendations based on CDC analysis and journal science in support of those conclusions. The example I provide is the non-pharmaceutical interventions that are critical to epidemiological measures to control community transmission and mitigate a pandemic that includes masking, physical distancing, the limited travel, and avoidance of congregate situations wherever possible, and of course, quarantine and isolation where required. But also, guidance for building operations during this and other pandemics, ventilation in buildings, upper-room ultraviolet germicidal irradiation, the UVGI or UVC as is currently in deployment, and that as well, the UVGI for healthcare settings. All these are important and important, based on clear

declarations of guidance and advice. We have worked hard to protect our populations, who have high comorbidity, susceptibility to infection.

We have demonstrated high rates of infection and impact of current infection and long COVID situations, and it makes our job much harder when we make declarations of guidance and behavior to our tribal citizens and the CDC is not as forceful. And where we require masks, the CDC may say it's a matter of personal choice. All these are important because we are trying to mitigate harm to our tribal citizens, and we think the science supports the affirmative position of CDC and other considerations, we think are not as important as the consequence of harm to our populations. If we don't apply what is our accepted epidemiological measures for control of a pandemic, whether epidemic or endemic. So those are our specific recommendations. We thank you for the opportunity, and we will endeavor to provide written remarks. Thank you. [Speaking in indigenous language].

Councilman Nate Tyler: Thank you for your comments, Vice President Micklin. You can email your comments to tribalsupport@cdc.gov by February 24th, 5:00 p.m. Eastern. Are there any other tribal presidents, chairman, vice-chairman, vice presidents, governors, or chiefs, willing to offer testimony at this time?

Chat Message (Kameron Runnels): *How am I able to make a comment not sure if my video or audio is working.*

Councilman Nate Tyler: Kameron Runnels, you have your hand raised. I see you in the chat not knowing if you're able to have the capacity to offer testimony.

Kameron Runnels: Hello!

Councilman Nate Tyler: We can hear you. What? What is your title?

Kameron Runnels: Hi! My name is Kameron Runnels. I'm the Vice Chairman of the Santee Sioux Nation Tribal Council in Nebraska and I'm also Vice Chairman of the Great Plains Tribal Leaders' Health Board, and I just wanted to make a comment on the kind of mirroring what the last gentleman just spoke on about access to data.

I spoke about this, you know, a couple months ago, to the IHS Director. You know tribes, you like, you can't develop effective health policies, for there are people without accurate data. You know HHS is required by law to provide this data to tribes. It's an epidemiology centers, but they have not, or they, they don't, and this reluctance to allow tribes to access this data required by law prevents tribes from addressing health problems in their communities. When HHS does not follow their own rules for data sharing, our communities suffer. You know we can't manage disease, and ultimately, ultimately more of our people die before their time. And the solution is simple, must follow existing law and provide tribes with the data we need to protect our members. HHS should give tribes the same access to data as it does other public health authorities. I'll just, I'll leave it at that. And thank you, and that's it.

Councilman Nate Tyler: Thank you Vice Chairman Runnels. At this time is there anybody else? [pause] In the waiting room or participants actually ready to offer testimony? [pause]

The floor is now open for anybody that wants to offer testimony.

Connie Barker.

Legislator Connie Barker: Thank you. Connie Barker, Tribal Legislator for the Chickasaw Nation, and I would just like to just actually skip down to number three, first. And when we're talking about tribes' priorities and now that the COVID-19 public health emergency, and how it is transitioning out. What I think tribes would like to see is, how do we prepare for the next pandemic? And what are what are we partnering with the CDC to do, to learn from each other, not only to learn from the agency, but what are the agencies learning from the tribes? And, as we said yesterday, or maybe it was this this morning, when we were visiting with Dr. Walensky, some of the Oklahoma tribes were the first to act, and they outworked the State of Oklahoma, when it came to sending out PPE, vaccines, keeping our hospital doors open, clinics open, to where we could treat patients saving the lives of a lot of tribal members that maybe would have died if they hadn't have that tribal hospital to go to. And so, it's a share of information, not just sitting and listening to the experts here, because, like what Dr. Walensky said this morning, this is the first pandemic that's happened since the inception of the CDC.

So, we were all caught off guard but, maybe how to prepare for the next one. And as she said this morning, it's not just going to be, if, but it could be when--you know when the next one. So just a sharing of information, I think, would kind of help us both move forward through a partnership of doing what's best for not only tribal members, but for our nation as a whole.

Councilman Nate Tyler: Thank you, Connie Barker, Appreciate that. So, it is open. Anybody willing to give testimony?

Dr. Sharon Stanphill.

Dr. Sharon Stanphill: Thank you. And Sharon Stanphill, Chief Health Officer Cow Creek Band of Umpqua Tribe of Indians, a tribal representative. One of the things I want to address is number one. As we were just shared the great presentation of the Moving Forward initiative and about the Center, and we saw the org chart, and where we are on the org chart at the tail end of the timeline. I'm hoping that tribes were brought in quite early, that as you developed at the org chart, and all of the positions. I didn't see any tribal liaisons with the divisions. But yet there were no other positions added as of yet. So, I just want to make a statement that in the State of Oregon, whereas our homeland, we have a phrase, and we say, say nothing about us, without us. Right? You hear that. And, the State of Oregon does an amazing job with assuring that the nine tribes and our Urban Indian Health Service, NARA, that we all are included, and that nothing gets past the tribes from the very, very beginning; before legislation is started before anything happens.

And so, I just want to say I saw the six top areas of improvement, and they're wonderful. But I'm wondering how the tribes given you, do you have our lists of every single one of those things, whether it's data sharing, infrastructure, which, by the way, the tribes of the Northwest, I think one hundred percent of all of them are just wanting to make sure that happens. All of our electronic health record systems, all the things that you're already aware of. Missing and murdered indigenous women, all of the things that are our top priorities, and how you'll restructure here, have we come in, way at the beginning, so that you are

aware of all these things, and you'll plug those in and continue to have consultation on those. So, it's kind of an overarching, how your relationship with us could be better?

And that goes into number two. The consultation, that you would have it very, very early, so that you haven't planned your org chart, you haven't put your whole department together, and you've got your top six priorities that we're integrated into every one of those way from the beginning. And I'll close by saying again, in the state of Oregon, we have tribal liaisons at every single level, so we always, always have somebody; just in case, you get a little step ahead we'll slow you down and say, "Wait, we haven't consulted the tribes yet," and we're way at the beginning, so that would my request. Thank you.

Councilman Nate Tyler: Thank you, Dr. Stanphill. Any other participants on the Zoom, raise your hand if you're willing to offer testimony.

[pause]

Written testimony can be submitted by February 24th, 5:00 p.m. Eastern. Email your written documentation to tribalsupport@cdc.gov.

Councilman Nate Tyler: And in your email note that this is for consultation. Any other participants on the Zoom, raise your hand if you want to give consultation...public comments.

[pause]

Chat Message (OTASA): *If any tribal leader wants to submit written additions to the Tribal Consultation Session, please email your comments no later than 5:00 pm (EST) February 24, 2023, to tribalsupport@cdc.gov. Thank you.*

Councilman Nate Tyler: All right. If there is no other testimony, at this time, prior to turning it back over to Dr. Dauphin, I'd like to thank everybody that took part in this testimony. I think it's really important to advocate for your tribe, when you advocate for your tribe, you're advocating for all tribes, so I think that's important to know, and it has been said that Dr. Stanphill said it best I think, you engage tribes at the earliest moment, if it's going to affect us. Any adverse effect, bring us in early, so appreciate you stating that. At this time, I'll turn it over to Dr. Dauphin. Thank you.

Dr. Dauphin: Thank you Councilman Tyler. I want to thank you all for your testimony today. And as another reminder, all tribal nations are welcome to submit written testimony by February 24th at 5:00 p.m. EST to tribalsupport@cdc.gov.

We appreciate your time and thoughtful input. And Councilman Tyler, I want to thank you for facilitating this. We really appreciate it, and I will turn it back over to you for some closing remarks.

Councilman Nate Tyler: All right. I sure do appreciate it. I gave my closing remarks a minute ago, but I'll say it, and I'll say it once again. It's really important to bring us in at the earliest convenience. Well, not even convenience. It's not even convenient. If it affects tribes bring us to the table at the highest level. As sovereigns, consultation is at the highest level. And that is an expectation from tribes. We don't want to

meet with, I know it's it was brought up about tribal liaisons, but we don't want to meet, you know, tribal leader - tribal liaison. I would want to meet tribal leader to the director or assistant director, and that's that, you know. That's the only way we can get any kind of movement you hear directly from the tribes. And it means a lot to tribes when it happens that way. So, I do appreciate all tribal leaders that took part in this.

Like I said it, it doesn't just benefit your tribe, it benefits all tribes. Not all five hundred and seventy-five tribes are going to take part in this consultation. I wish even half would do it. If half the tribes in the United States did take part in this, I think it would go a long ways, but I do truly appreciate it, and I think everybody else does appreciate those that are taking part, those that have been taking part, during this last year and a half through this consultation process across the board.

And one other thing tribal leaders on the phone or on the Zoom, if you want to take part in these advisory committees, sign up, submit, we do need help across the board, not just in CDC, but other advisory committees. When you do that, you know it goes a long ways, puts you at the table, puts you at the highest level, lets you advocate for your people, lets you advocate for your tribes and hammer home the issues that do impact us as sovereign nations.

So once again I do appreciate the CDC, appreciate the CDC for the last two days. It's been a good two- day get together for us as tribal leaders at the table. So once again, you appreciate it, and I will once again close in prayer. And once again, you don't have to stand. Like I said I did grow up as a young kid taking part in the Bahá'í Faith. That was when I was a kid, I haven't done it since I was a little kid, so you know it's been quite a while, but I do want to close with a prayer for protection.

"Immeasurably exalted art Thou, O Lord!

Protect us from what lieth in front of us and behind us, above our heads, on our right, on our left, below our feet and every other side to which we are exposed. Verily Thy protection over all things is unfailing." - The Báb.

So once again appreciate it. Safe travels to everybody and see you guys, at the next meeting.

Adjourned. Thank you.

Dr. Dauphin: This consultation session is now closed. Thank you, Councilman Tyler.

****

CDC/ATSDR Tribal Testimony Chat Comments:

Julie Shasteen, CDC to Everyone:

Welcome to the CDC/ATSDR Tribal Consultation Session. Please include your tribal position and tribe in your displayed name.

How to Change Your Zoom Display Name:

- Go to the top right corner of your Zoom displayed box
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- Enter a new screen name (name, tribal position, tribe)
- Select 'OK'
- Done

OR

- Click on name in "Participant's List"
- Select 'More' or the ellipses (three dots)
- Select 'Rename'
- Enter a new screen name (name, tribal position, tribe)
- Select 'OK'
- Done

Julie Shasteen, CDC to Everyone:

Thank you for joining today's Tribal Consultation. Please note, the chat function is to be used by tribal leaders and CDC leaders only.

Charity Sabido-Hodges to Everyone:

Kleco, kleco Cousin Nate...That was very good

Julie Shasteen, CDC to Everyone:

Thank you to everyone for joining the Tribal Consultation today. Please note, the chat feature is reserved for Tribal Leadership and elected officials only.

Julie Shasteen, CDC to Everyone:

Welcome to the CDC/ATSDR Tribal Consultation Session. Please include your tribal position and tribe in your displayed name.

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- Click on name in “Participant’s List”
- Select ‘More’ or the ellipses (three dots)
- Select ‘Rename’
- Enter a new screen name (name, tribal position, tribe)
- Select ‘OK’
- Done

Councilman Nate Tyler to Everyone:

Can you put the Tribal Leader Title after your name please

Julie Shasteen, CDC to Everyone:

Attendees, please update your Zoom display name to include your tribal position and tribe. Thank you.

Councilman Nate Tyler to Charity Sabido-Hodges and all panelists:

thanks, where are you from

Julie Shasteen, CDC to Everyone:

Please note, the chat feature is reserved for Tribal Leadership and elected officials only.

Julie Shasteen, CDC to Everyone:

How to Change Your Zoom Display Name:

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- Done

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- Select ‘More’ or the ellipses (three dots)
- Select ‘Rename’
- Enter a new screen name (name, tribal position, tribe)
- Select ‘OK’

- Done

Julie Shasteen, CDC to Everyone:

If any tribal leader has written additions for the Tribal Consultation Session, you are encouraged to submit them to TribalSupport@cdc.gov before Feb 24 at 5 pm (EST).

Councilman Nate Tyler to Everyone:

Will Micklin, who are you representing

Will Micklin to Hosts and panelists:

Will Micklin, Vice President, Tlingit&Haida

Kameron Runnels to Everyone:

how am I able to make a comment not sure if my video or audio is working

Julie Shasteen, CDC to Kameron Runnels and all panelists:

Raise your hand and you will be invited to speak. If you cannot use your audio, please add a comment in the chat.

Rasha Al Rawi, CDC to Kameron Runnels and all panelists:

Please use the "raise hand" feature and state your tribe

Julie Shasteen, CDC to Kameron Runnels and all panelists:

Thank you for your comments. They are being recorded and will be incorporated as part of this Tribal Consultation summary.

Julie Shasteen, CDC to Everyone:

If any tribal leader wants to submit written additions to the Tribal Consultation Session, please email your comments no later than 5:00 pm (EST) February 24, 2023 to tribalsupport@cdc.gov. Thank you.

Julie Shasteen, CDC to Everyone:

If interested - email tribalsupport@cdc.gov

Julie Shasteen, CDC to Everyone:

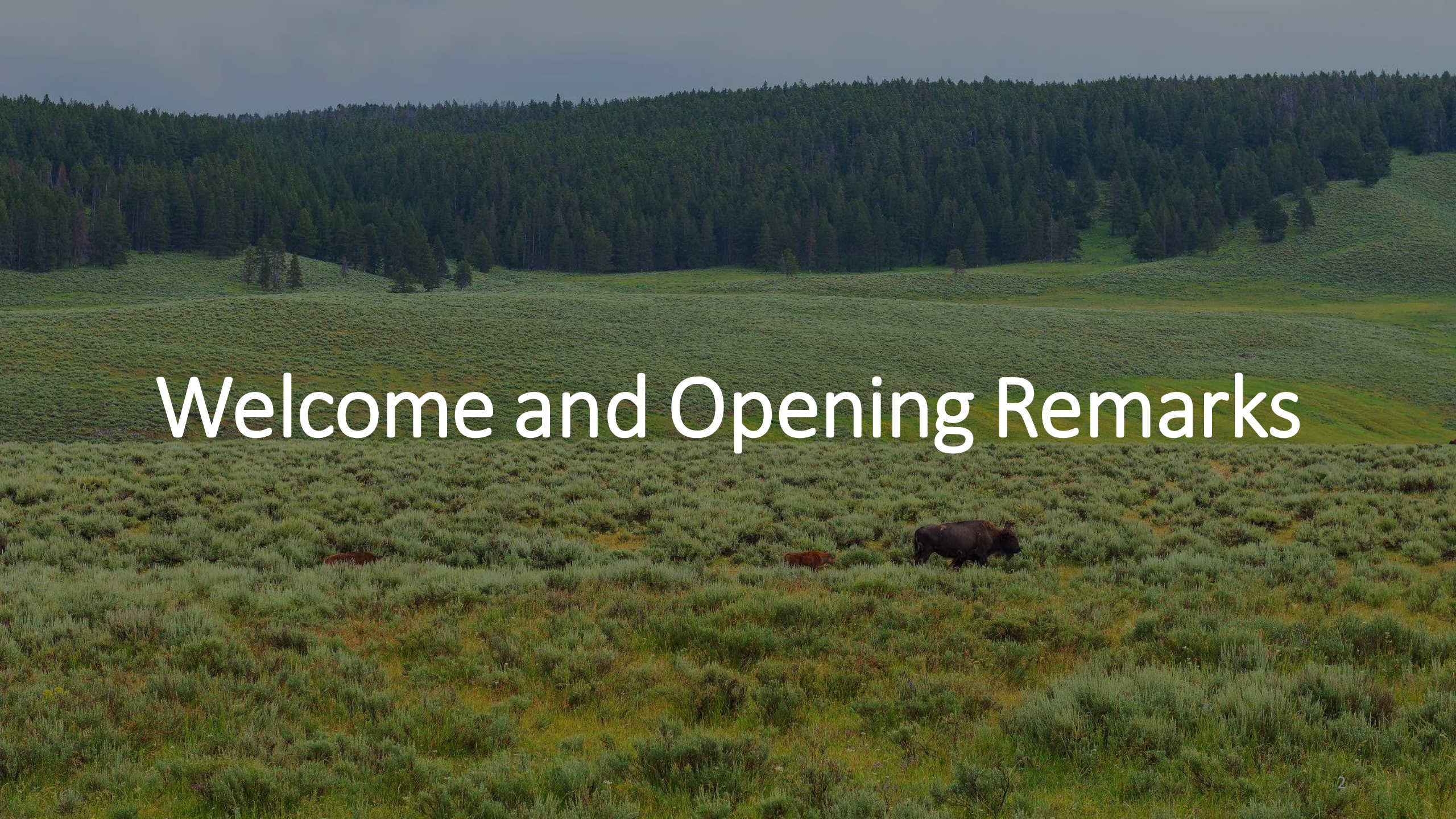
Thank you all

CDC/ATSDR Tribal Consultation – CDC Moving Forward Initiative PowerPoint Presentation

CDC/ATSDR Tribal Consultation – CDC Moving Forward Initiative

February 9, 2023

4:00 – 5:00 pm (EST)



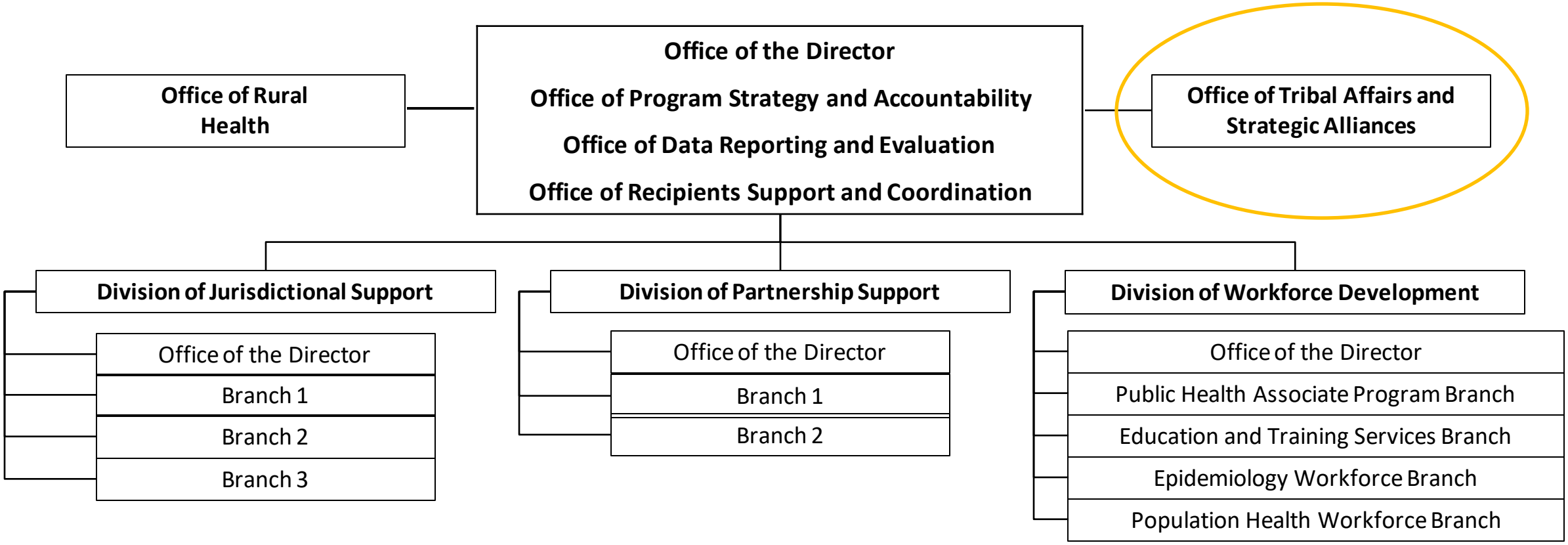
Welcome and Opening Remarks

Consultation Participants and Roles

The government-to-government relationship between the United States and federally recognized Indian Tribes dictates that the principal focus for consultation by CDC is with Indian Tribes, individually or collectively.

Overview of CDC Moving Forward Initiative

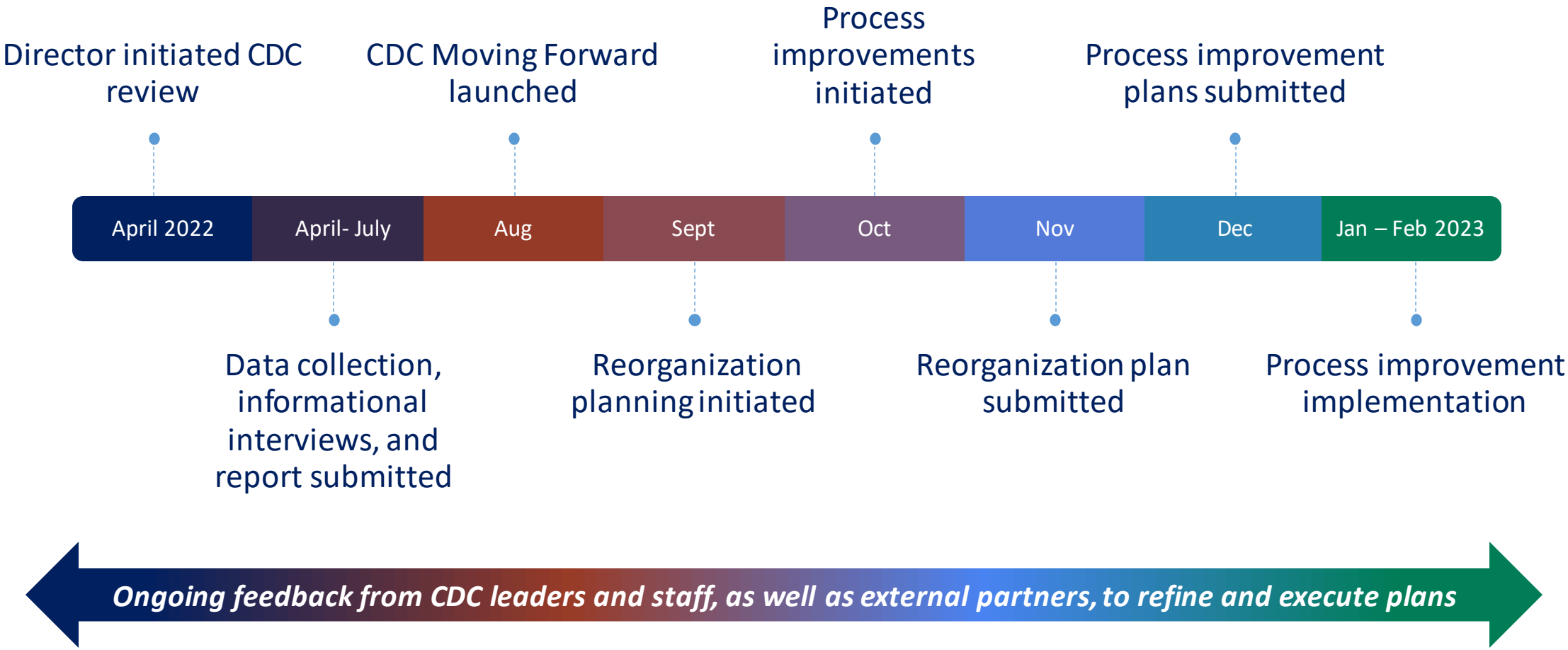
Proposed National Center for State, Tribal, Local and Territorial Public Health Infrastructure and Workforce



CDC Moving Forward

February 9, 2023

CDC Moving Forward: Timeline



Top Areas for Improvement

- Share Scientific Findings and Data Faster
- Enhance Laboratory Science and Quality
- Translate Science into Practical, Easy-to-Understand Policy
- Prioritize Public Health Communications
- Develop a Workforce Prepared for Future Emergencies – CDC and Nationwide
- Promote Results-Based Partnerships

Share Scientific Findings and Data Faster

- Reduce, streamline, and expedite scientific clearance process
- Deploy standard language clarifying current level of scientific understanding; use of various strategies for getting information out for public and public health use and consider a new CDC platform to share preliminary findings
- Work collaboratively with tribes' jurisdictions to facilitate data collection, interoperability, and reporting

Translate Science into Practical, Easy-to-Understand Policy

- Implement standardized policy development process for guidance documents, including an engagement strategy with external partners

- Consider guidance using best available science and examine implementation benefits, harms, equity impact, feasibility, and external partners and community considerations, resulting in actionable public health guidance

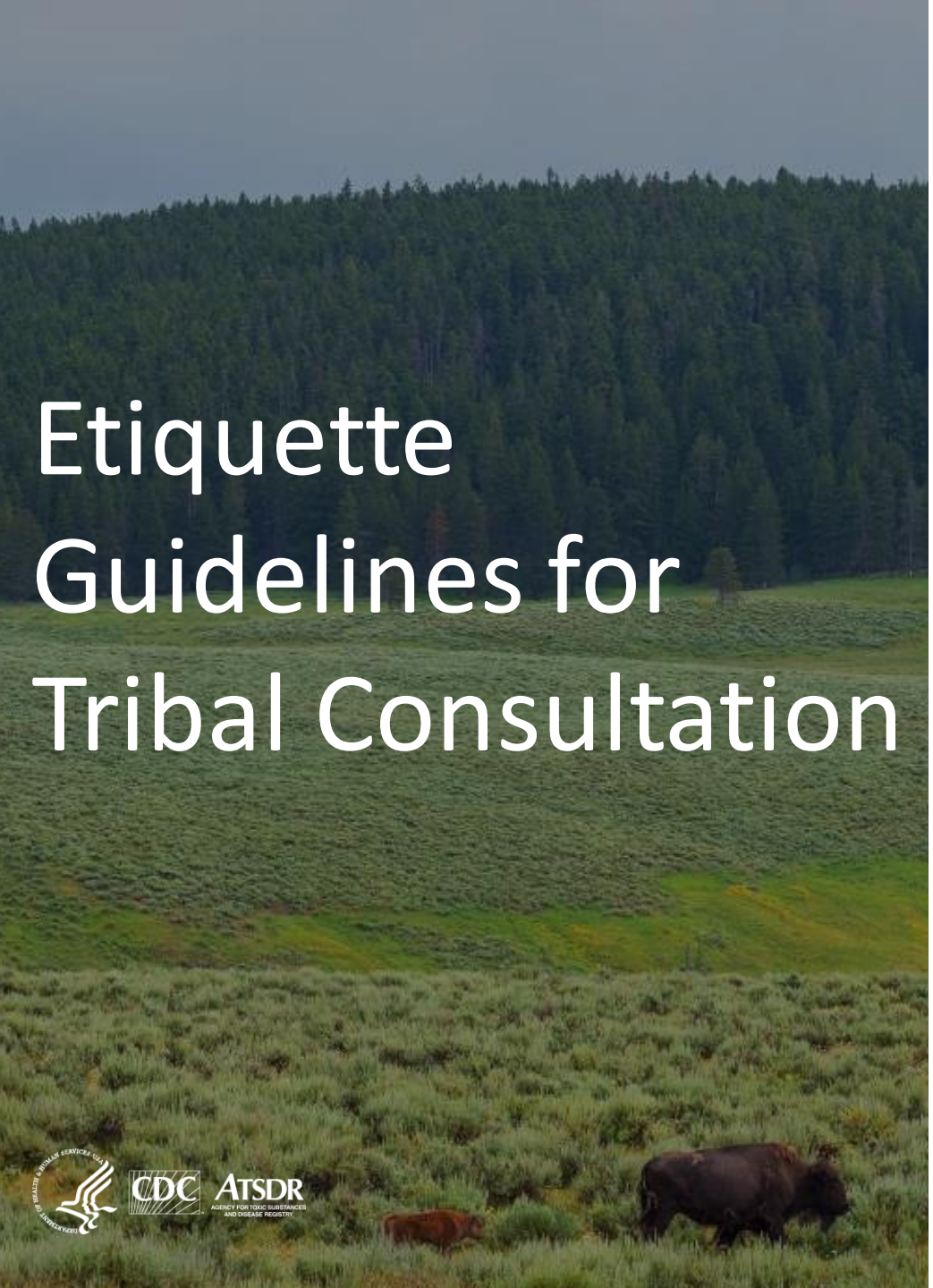
Promote Results-Based Partnerships

- Establish agency-wide grantee satisfaction survey to identify needed improvements
- Develop common reporting standards and equity focus for funding opportunities and promote peer-to-peer technical assistance

Presentation/Speaker Protocol

The order in which we will follow is:

1. Tribal Presidents/Chairpersons/Governors
2. Tribal Vice-Presidents/Vice-Chairpersons/Lt. Governors
3. Elected or Appointed Tribal Officials
4. Designated Tribal Officials



Etiquette Guidelines for Tribal Consultation

- All attendees must keep their mic on mute during the meeting unless speaking.
- Members of the public must keep their video camera off and may not speak during meeting proceedings.
- For those on the phone, to unmute your phone press *6.
- When asking a question or making a comment, click the ‘Participants’ button at the bottom of the Zoom screen and select the ‘Raise Hand’ option located on the right-hand side of the screen.

Guided Questions

1. How can the agency strengthen relationships during the implementation of the CDC Moving Forward Initiative?
2. How can the agency better engage with Indian Country through meaningful consultation?
3. What are your tribes' priorities as we transition out of the COVID-19 public health emergency and how can CDC/ATSDR better support tribes and tribal communities moving forward?

Tribal Testimony

Summary and Closing

Thank you

Please submit written comments by February 24, 2023, by 5:00 pm (EST) to tribalsupport@cdc.gov

CDC/ATSDR's Tribal Consultation on CDC Moving Forward Initiative
February 9, 2023
Written Testimony

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Chuck Hoskin Jr.
Principal Chief
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Bryan Warner
Deputy Principal Chief
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February 24, 2023

Director Rochelle Walensky
Centers for Disease Control and Prevention
C/O Office of Tribal Affairs and Strategic Alliances
Center for State, Tribal, Local, and Territorial Support
tribalsupport@cdc.gov

Director Walensky,

Thank you for this opportunity for consultation on the CDC Moving Forward initiative. The CDC is critical for advancing the government's trust responsibility towards the health and wellness of our people.

At Cherokee Nation, we are especially focused on improving public health and working effectively with the CDC. We operate the largest Tribal health care system in the nation and are one of six Tribes with an accredited Public Health Department. My administration has made health and wellness one of our top priorities, and Cherokee Nation Deputy Principal Chief Bryan Warner serves as chair of the CDC's Tribal Advisory Committee.

I appreciate the work being done in the CDC Moving Forward plan to strengthen the agency's cross-cutting functions, including health equity, science, communications, and policy, and to break down silos among CDC CIOs that may interfere with clear communications and rapid response to public health threats. Improving the personnel resources, expertise, and funding support for cross-cutting functions is a welcome step forward.

In that same regard, Tribal relations and support should be viewed as a cross-cutting function that is just as important as any other.

While in the past we have had excellent relations with some CIOs within CDC, others rarely if ever consider Tribal needs. The current lack of integration is reflected in the latest OMB Native American Crosscut totals for the CDC's FY 2022 appropriations, which showed only 0.79% of CDC funding is for programs that benefit Native Americans. Even worse, the CDC has not reported an increase in funding for the Native American Crosscut in several years. This means we are doing worse than maintaining Tribal resources; we are losing ground.

That is unacceptable when Indian Country experiences many of the worst public health outcomes in the U.S. According to the CDC's most recent report on life expectancy of American Indians and Alaska Natives, we are now expected to live 6.6 years less than in the 50 years preceding the report. AI/AN life expectancy today is the same as it was for the general U.S. population in 1944. From the standpoint of both health equity and overall health, these metrics reveal deep deficiencies in meeting the trust responsibility and the most basic CDC mission to protect health and well-being.

That is why in this reorganization and on an ongoing basis, CDC needs to prioritize integrating support for Tribal Nations across all parts of the agency. For example, the proposed Executive Board to assess and recommend agency priorities each year should include permanent representation of an expert on Tribal priorities and sovereignty.

To give a specific example of how the disconnect between CIOs and Tribal nations is felt, we often see Notices of Funding Opportunities that, even when they do mention Tribes are eligible for funding, do not account for the unique position of Tribes as sovereign nations. They may include requirements such as a letter from a state chronic disease director or other state officer, which is never appropriate to ask of a Tribe with sovereignty that is fully independent of state sovereignty. Listing Tribes as eligible for a NOFO is not enough if we are lumped in with non-sovereign organizations.

To address this issue, I ask that the reorganization make sure that all NOFOs from the CDC are reviewed before release by an expert in best practices for respecting tribal sovereignty.

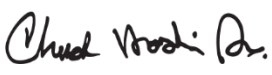
In the bigger picture, Tribes need sustained public health infrastructure funding that takes a holistic view of health, including social determinants of health. The piecemeal approach is not effective at addressing generations of health inequities. At present, Tribes have not even been deemed eligible for preparedness dollars, much less offered sustained funding outside of an unreliable and administratively burdensome grant cycle.

It is concerning that this opportunity for Tribal consultation has come far along into the CDC's reorganization process. For this to be a meaningful consultation, I hope the CDC will take Tribal comments into full consideration, even if it means rethinking decisions that have already been made in planning the reorganization. With that said, I am confident that we can together find solutions that advance both CDC's goals and the priorities of Tribal nations.

Given how far along the agency is in this process, there is heightened need for accountability measures that demonstrate how Tribal priorities are reflected in the initiative. I urge you to establish those accountability measures and clearly communicate to Tribes how they have been implemented, with opportunity for a follow-up consultation based on the response.

Thank you again for this opportunity to comment and for your attention to the needs of Cherokee Nation and all Indian Country.

Wado,



Cherokee Nation Principal Chief Chuck Hoskin, Jr.

Ewiiaapaayp Tribal Office
Ewiiaapaayp Band of Kumeyaay Indians
4054 Willows Road
Alpine, CA 91901
TEL: (619) 368-4382
FAX: (619) 445-9126
E-mail: ceo@ebki-nsn.gov

VIA EMAIL
tribalsupport@cdc.gov

February 9, 2023

Celeste Philip, MD, MPH
Acting Director, Center for State, Tribal, Local, and Territorial Support Deputy Director for Non-Infectious Diseases (DDNID)
Centers for Disease Control and Prevention

re: CDC/ATSDR Tribal Consultation

Dear Dr. Philip,

The Ewiiaapaayp Band of Kumeyaay Indians (the "EBKI") is a federally recognized Tribal government in east San Diego County, California. EBKI is pleased to submit recommendations to the Center for Disease Control tribal consultation regarding the engagement of CDC with Tribes.

Please refer to the U.S. Government Accountability Office (GAO) Report to Congress dated March 2022 entitled, "Tribal Epidemiology Centers – HHS Actions Needed to Enhance Data Access" (GAO-22-104698). In this report the GAO made five recommendations, including that *" ... HHS clarify the data it will make available to TECs as required by federal law; and that CDC and IHS develop guidance on how TECs should request data, and develop agency procedures on responding to such requests."* HHS concurred with these recommendations. However, as of this writing the Tribe is not aware of such specific executive actions taken by the administration (HHS, CDC, and Indian Health Service (IHS)) to implement the five GAO recommendations.

We further recommend the HHS, CDC, and IHS extend the GAO recommendations to all IHS Tribal healthcare clinics and consortiums as a necessary measure to extend access and beneficial outcomes for Tribes by sharing data and analyses with all Tribal health care entities and not limit this improved relationship to the twelve Tribal Epidemiological Centers.

We also recommend the administration support the approval by the 118th Congress of the prior bill from the 117th Congress that was H.R. 1397 entitled, "Tribal Health Data Improvement Act of 2021." This bill expands tribal access to public health care data and public health surveillance

programs. It also reauthorizes through FY2025 the National Center for Health Statistics, which is part of the Centers for Disease Control and Prevention (CDC), and requires the CDC to take certain actions to address the collection and availability of health data for American Indians and Alaska Natives.

Specifically, the Department of Health and Human Services must (1) establish a strategy for providing data access to Indian tribes and tribal epidemiology centers; and (2) make available all requested data related to health care and public health surveillance programs and activities to the Indian Health Service, tribes, tribal organizations, and tribal epidemiology centers.
Next, the CDC must make grants to and enter into contracts with tribes, tribal organizations, and tribal epidemiology centers for data collection and related activities.

Among other activities, the CDC must (1) develop guidance for state and local health agencies to improve birth and death record data for American Indians and Alaska Natives; (2) enter into cooperative agreements with tribes, tribal organizations, urban Indian organizations, and tribal epidemiology centers to analyze and address certain inaccuracies related to records for American Indians and Alaska Natives; (3) adopt uniform standards for the collection of health data on race and ethnicity; and (4) encourage states to enter into data sharing agreements with tribes and tribal epidemiology centers to improve the quality and accuracy of health data.

We further recommend the CDC consult with Tribes to develop effective guidelines for the ongoing SARS-COV-2 pandemic, which would be a foundation for establishing an effective plan for future public health emergencies.

We recommend CDC guidance developed in consultation with Tribes that establishes an affirmative and declarative plan that includes:

- Full vaccination and boosters
- Masking in-doors or in congregate settings
- Physical distancing
- Work at home infected and when possible and to the extent practicable
- Limited travel with enhanced use of videoconferencing and teleconferencing
- Ensure availability of supplemental medications (e.g., Paxlovid)
- Enhanced ventilation and filtration of residential and commercial buildings (e.g., ASHREAE), with minimum air exchanges per hour (e.g., MERV 13 to 16), and HEPA filtration at 0.3 microns or lesser, and including far ultraviolet systems in commercial, health care, and education settings.

For example:

Guidance for Building Operations During COVID-19 Pandemics
https://www.ashrae.org/file%20library/technical%20resources/ashrae%20journal/2020journaldocuments/72-74_ieq_schoen.pdf

Ventilation in Buildings
https://www.cdc.gov/coronavirus/2019-ncov/community/ventilation.html#refphf

Upper-Room Ultraviolet Germacidal Irradiation (UVGI)
https://www.cdc.gov/coronavirus/2019-ncov/community/ventilation/UVGI.html

Upper-Room Ultraviolet Germicidal Irradiation Guidance for Healthcare Settings
https://www.cdc.gov/niosh/docs/2009-105/pdfs/2009-105.pdf?id=10.26616/NIOSHPUB2009105

It is a mistake to discount new COVID-19 cases just because death rate remains relatively low, and in the context of reduced testing, with virtually no tracing, and with a reduced emphasis on non-pharmaceutical interventions. The CDC is betting the U.S. health care system can produce vaccines adaptative to virus variants and mutations at as fast a pace as the virus is mutating. This is a bet that will not succeed and its consequence threatens the health and general welfare of Tribes and their Tribal citizens.

The CDC must appreciate the health risk to Tribes given the high incidence of infection and poor health outcomes, including fatalities, among Tribes.

Nor may the CDC rely upon the excuse than no one saw this coming. The recommendations from the "Crimson Contagion" pandemic exercise held in 2019 that forewarned of the impact of a coronavirus is0 now public. [https://ia801901.us.archive.org/30/items/crimson-contagion-2019/Crimson_Contagion_2019.pdf]. Every mistake this exercise warned against was made, and every recommendation it presented was ignored.

The CDC knows how to defeat a pandemic. We know other public health emergencies will arise. We must act to protect those we love and ourselves – or we risk greater setbacks from a virus that has demonstrated great adaptative abilities to increase transmissibility and cause long-term injury.

We recommend the CDC consult with Tribes to establish effective COVID-19 measures based on sound and accepted epidemiological principles.

Finally, we wish to take this opportunity to address the CDC consultation requirement now that the administration intends to end the public health emergency in May 2023.

First, the CDC communications and consultation with Tribes about ending the COVID-19 public health emergency (PHE) has been missing. Tribes are confused. Many are confused. Tribes do not understand the situation right now and what it means for Tribes. We need clarity.

First, there is not one national emergency declaration surrounding the COVID-19 pandemic. There are five. Each has a different purpose for a different part of the U.S. Federal government. These five emergency "buckets" are:

1. FDA
2. Stafford Act (i.e., FEMA)
3. Public Health Emergency

4. National Emergency
5. PREP Act

Together, these are responsible for uncatalogued number of flexibilities available throughout the pandemic. For example, the emergency use authorization for vaccines occurred under bucket #1. Extending Medicaid to more people happened under bucket #3 (although this recently changed; see below).

These different mechanisms created a complicated system that needs to be untangled without terminating all at once. To help prevent this, the five buckets of emergencies are ending at different times. Buckets #3 and #4 are ending in May 2023. All the others are yet to be determined. (#5 is fodder for lawyers).

Throughout the pandemic CDC has asserted "we have the tools." The May termination of buckets #3 and #4 means different things for different tools:

Antigen tests. Supply is going be impacted, but not necessarily because of the PHE. It's dependent on Congressional budget. The tests are already commercialized. The U.S. bought a stockpile of antigen tests for the USPS program this past winter and still has a stockpile for the coming months. It's not clear when this supply will run out.

The industry (i.e. test makers) are unwilling to produce a surplus of tests because demand is unknown. Without a guaranteed purchase (like from the government) or knowledge that more waves are coming to drive demand, they are hesitant to manufacture more. It's not clear whether antigen tests, and which ones, will be available on retail shelves after the emergency like they are now.

In addition, the PHE requires health insurers to reimburse for up to eight antigen tests, per person, per month. After May, insurers will be able to choose whether to reimburse for those tests or not. *What will be the effect for IHS?*

Vaccines. The FDA emergency (#1 above) is not ending. This means COVID-19 vaccines will still be available. However, available is different from *accessible*. Vaccines will be covered by the IHS until the stockpile (vaccines which the U.S. government bought from pharma) dries up. After the stockpile dries up or we get a Fall 2023 new formula booster, the vaccine will be covered by HIS, or by private insurance (through employment) or public insurance (Medicaid, Medicare, etc.) for the 92% of Americans who have health coverage. IHS vaccines are free, with no co-pay required. And also free for those covered by the Affordable Care Act. *Will this change?*

Paxlovid. This supply apparently has a large stockpile. Once that stockpile is gone, it will be privatized. The price will be determined by Pfizer, and the price that individuals pay at the pharmacy will depend on health insurance. What does this mean for IHS?

Monoclonal antibodies/Evushield. Apparently, these don't work against the newest subvariants, and pharma doesn't want to make more because the market keeps evaporating (because the virus

keeps changing). For people for whom Paxlovid doesn't work or the vaccine doesn't confer protection (e.g., organ transplant patients), it's not clear what protections there will be. The most vulnerable will be less protected than before. What precautions are available for IHS?

National surveillance. Apparently, this will continue to some extent:

- **Genomic surveillance:** It's our understanding the wastewater program will remain for now.
- **Test positivity rates:** Will likely go away because CDC can't compel labs to report.
- **Hospitalizations:** CDC will still get data, but the frequency will likely slow down.
- **Vaccine uptake:** Will likely remain, as CDC is working with states to continue monitoring.
- **Pharmacy testing:** May go away. This turned out to be CDC's fastest way to evaluate vaccine effectiveness. So Tribes may be effected by a delayed system in order to know how well our vaccines are working, which is disappointing.

What monitoring of COVID-19 will be available to IHS? Knowing if and when we are in a new wave to inform our behaviors, for example, will get more and more challenging.

Healthcare coverage. One of the most impactful tools during the emergency was Medicaid's continuous coverage. During pre-pandemic times, states regularly checked whether people enrolled in Medicaid were still eligible. These "checks" were removed during the pandemic. When these "checks" resume on April 1, between 5.3 and 14.2 million adults and children will lose Medicaid coverage. (Technically, this *was* under bucket #3, but the Omnibus bill passed in December uncoupled Medicaid from the PHE. So this doesn't have to do with the PHE ending, but it's still a big change we are going to see starting April 1.)

How will Medicaid coverage changes effect IHS and Tribes?

National vs. state. vs. local

Each state has its own authorities and emergency mechanisms. Everything will look different depending on the State a Tribe is within (or multiple States). States are responsible for the transition from Medicaid continuous coverage back to "checks." Some states will follow up with people to let them know they are missing information so they don't get dropped; some states will update mailing addresses proactively so people don't lose coverage; some states will do nothing. Will HHS/CDC inform Tribes of State Medicaid procedures, and encourage States to take no measures that reduce coverage?

Wastewater surveillance is additionally dependent on the state or locality budget, for example. This means wastewater monitoring may change based on State funding, regardless of a CDC grant. Will CDC inform Tribes of such changes?

Conclusion. Tribes need clear guidance about what happens once the U.S. terminates "buckets" #3 and #4, and further potential actions. There are still a lot of unanswered questions, and the situation is in flux. HHS/CDC/IHS consultation with Tribes is urgent, and clear information and guidelines are needed.

If you have any questions or concerns at any time, please feel free to contact the Tribe's Chief Executive Officer, Mr. Will Micklin, by telephone at (619) 368-4382, or by email at ceo@ebki-nsn.gov. Thank you.

Sincerely,

Robert Pinto Sr
Tribal Chairman
Ewiiaapaayp Band of Kumeyaay Indians

117TH CONGRESS
1ST SESSION

S. 1397

To amend the Public Health Service Act with respect to the collection and availability of health data with respect to Indian Tribes and Tribal organizations, and for other purposes.

IN THE SENATE OF THE UNITED STATES

APRIL 27, 2021

Ms. SMITH (for herself, Ms. MURKOWSKI, Mr. TESTER, Mr. DAINES, Ms. WARREN, and Mr. CRAMER) introduced the following bill; which was read twice and referred to the Committee on Indian Affairs

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A BILL

To amend the Public Health Service Act with respect to the collection and availability of health data with respect to Indian Tribes and Tribal organizations, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Tribal Health Data Improvement Act of 2021''.

SEC. 2. COLLECTION AND AVAILABILITY OF HEALTH DATA WITH RESPECT TO INDIAN TRIBES.

(a) DATA COLLECTION.—Section 3101(a)(1) of the Public Health Service Act (42 U.S.C. 300kk(a)(1)) is amended—

(1) by striking '', by not later than 2 years after the date of enactment of this title,''; and

(2) in subparagraph (B), by inserting ''Tribal,'' after ''State,''.

(b) DATA REPORTING AND DISSEMINATION.—Section 3101(c) of the Public Health Service Act (42 U.S.C. 300kk(c)) is amended—

(1) by amending subparagraph (F) of paragraph (1) to read as follows:

''(F) the Indian Health Service, Indian Tribes, Tribal organizations, and epidemiology centers;''; and

(2) in paragraph (3), by inserting ''Indian Tribes, Tribal organizations, epidemiology centers,'' after ''Federal agencies,''.

(c) PROTECTION AND SHARING OF DATA.—Section 3101(e) of the Public Health Service Act (42 U.S.C. 300kk(e)) is amended—

(1) in paragraph (2)—

(A) by striking ''..'' and inserting ''.'';

(B) by striking ''The Secretary shall'' and inserting the following:

''(A) IN GENERAL.—The Secretary shall''; and

(C) by adding at the end the following:

''(B) EPIDEMIOLOGY CENTERS AND INDIAN TRIBES.—With respect to data access for epidemiology centers and Indian Tribes, the Secretary shall establish a data sharing strategy, in consultation with the Secretary's Tribal Advisory Committee, for purposes of providing access to data to the epidemiology centers and Indian Tribes that protect data privacy and security and data governance while ensuring that epidemiology centers and Indian Tribes have access to data sources necessary to accomplish their public health responsibilities and plans for use.''; and

(2) by adding at the end the following new paragraph:

''(3) TRIBAL PUBLIC HEALTH AUTHORITY.—Beginning not later than 180 days after the date of the enactment of the Tribal Health Data Improvement Act of 2021, the Secretary shall make available all requested data collected pursuant to this

title with respect to health care and public health surveillance programs and activities, including such programs and activities that are federally supported or conducted, to—

''(A) the Indian Health Service;

''(B) Indian Tribes and Tribal organizations; and

''(C) epidemiology centers.''.

(d) TECHNICAL UPDATES.—Section 3101 of the Public Health Service Act (42 U.S.C. 300kk) is amended—

(1) by striking subsections (g) and (h); and

(2) by redesignating subsection (i) as subsection (h).

(e) DEFINITIONS.—After executing the amendments made by subsection (d), section 3101 of the Public Health Service Act (42 U.S.C. 300kk) is amended by inserting after subsection (f) the following new subsection:

''(g) DEFINITIONS.—In this section:

''(1) The term 'epidemiology center' means an epidemiology center established under section 214 of the Indian Health Care Improvement Act, including any epidemiology center serving Indian Tribes regionally or serving urban Indian organizations na-

tionally that is receiving funding from the Indian Health Service.

''(2) The terms 'Indian Tribe' and 'Tribal organization' have the meanings given to the terms 'Indian tribe' and 'tribal organization', respectively, in section 4 of the Indian Self-Determination and Education Assistance Act.''.

(f) TECHNICAL CORRECTION.—Section 3101(b) of the Public Health Service Act (42 U.S.C. 300kk(b)) is amended by striking ''DATA ANALYSIS.—'' and all that follows through ''For each federally'' and inserting ''DATA ANALYSIS.—For each federally''.

SEC. 3. IMPROVING HEALTH STATISTICS REPORTING WITH RESPECT TO INDIAN TRIBES.

(a) TECHNICAL AID TO STATES AND LOCALITIES.—Section 306(d) of the Public Health Service Act (42 U.S.C. 242k(d)) is amended by inserting '', Indian Tribes, Tribal organizations, and epidemiology centers'' after ''jurisdictions''.

(b) COOPERATIVE HEALTH STATISTICS SYSTEM.—Section 306(e)(3) of the Public Health Service Act (42 U.S.C. 242k(e)(3)) is amended by inserting '', Indian Tribes, Tribal organizations, and epidemiology centers'' after ''health agencies''.

(c) FEDERAL-STATE-TRIBAL COOPERATION.—Section 306(f) of the Public Health Service Act (42 U.S.C. 242k(f)) is amended—

(1) by inserting ", the Indian Health Service," after "Commerce and Labor";

(2) by inserting ", Indian Tribes, Tribal organizations, and epidemiology centers" after "State and local health departments and agencies"; and

(3) by striking "he shall" and inserting "the Secretary shall".

(d) REGISTRATION AREA RECORDS.—Section 306(h)(1) of the Public Health Service Act (42 U.S.C. 242k(h)(1)) is amended—

(1) by striking "in his discretion" and inserting "in the discretion of the Secretary"; and

(2) by striking "Hispanics, Asian Americans, and Pacific Islanders" and inserting "American Indians and Alaska Natives, Hispanics, Asians, and Native Hawaiian and other Pacific Islanders".

(e) NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS.—Section 306(k) of the Public Health Service Act (42 U.S.C. 242k(k)) is amended—

(1) in paragraph (3), by striking ", not later than 60 days after the date of the enactment of the

Health Insurance Portability and Accountability Act of 1996,'' each place it appears; and

(2) in paragraph (7), by striking ''Not later than 1 year after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996, and annually thereafter, the Committee shall'' and inserting ''The Committee shall, on a biennial basis,''.

(f) GRANTS FOR ASSEMBLY AND ANALYSIS OF DATA ON ETHNIC AND RACIAL POPULATIONS.—Section 306(m)(4) of the Public Health Service Act (42 U.S.C. 242k(m)(4)) is amended—

(1) in subparagraph (A)—

(A) by striking ''Subject to subparagraph (B), the'' and inserting ''The''; and

(B) by striking ''and major Hispanic subpopulation groups and American Indians'' and inserting '', major Hispanic subgroups, and American Indians and Alaska Natives''; and

(2) by amending subparagraph (B) to read as follows:

''(B) In carrying out subparagraph (A), with respect to American Indians and Alaska Natives, the Secretary shall—

''(i) in consultation with Indian Tribes, Tribal organizations, the Tribal Technical Advisory Group of the Centers for Medicare & Medicaid Services maintained under section 5006(e) of the American Recovery and Reinvestment Act of 2009, and the Tribal Advisory Committee established by the Centers for Disease Control and Prevention, and in coordination with epidemiology centers, develop guidance for State and local health agencies to improve the quality and accuracy of data with respect to the birth and death records of American Indians and Alaska Natives;

''(ii) confer with urban Indian organizations to develop guidance for State and local health agencies to improve the quality and accuracy of data with respect to the birth and death records of American Indians and Alaska Natives;

''(iii) enter into cooperative agreements with Indian Tribes, Tribal organizations, Urban Indian organizations, and epidemiology centers to analyze and address misclassification and undersampling of American Indians and Alaska Natives in data systems at the Federal, State, and local levels, with respect to—

''(I) birth and death records; and

''(II) Federal, State, and local health care and public health surveillance systems, including with respect to chronic and infectious diseases, unintentional injuries, environmental health, child and adolescent health, maternal health and mortality, foodborne and waterborne illness, reproductive health, and any other notifiable disease or condition;

''(iv) adopt, based on local, statewide, Tribal, and national best practices, uniform standards for the collection of health data on race and ethnicity;

''(v) encourage States to enter into data sharing agreements with Indian Tribes and epidemiology centers to improve the quality and accuracy of public health data regarding American Indians and Alaska natives, including by addressing misclassification and undersampling of American Indians and Alaska Natives in State and local public health data systems, including with respect to vital statistics, chronic and infectious diseases, unintentional injuries, environmental health, child and adolescent health, maternal health and mortality, foodborne and waterborne illness, reproductive health, and any other notifiable disease or condition;

''(vi) encourage States to adopt, based on local, statewide, Tribal, and national best practices, uniform standards for the collection of health data on race and ethnicity; and

''(vii) 180 days after the date of enactment of the Tribal Health Data Improvement Act of 2021 and biennially thereafter, issue a report on—

''(I) which States have data sharing agreements with Indian Tribes, Tribal Organizations, urban Indian organizations, or epidemiology centers to improve the quality and accuracy of health data, listed by data system name; and

''(II) actions taken by the Director of the Centers for Disease Control and Prevention to encourage States to enter into data sharing agreements with Indian Tribes, Tribal Organizations, urban Indian organizations, and epidemiology centers to improve the quality and accuracy of health data.''.

(g) DEFINITIONS.—Section 306 of the Public Health Service Act (42 U.S.C. 242k) is amended—

(1) by redesignating subsection (n) as subsection (o); and

(2) by inserting after subsection (m) the following:

''(n) In this section:

''(1) The term 'epidemiology center' means an epidemiology center established under section 214 of the Indian Health Care Improvement Act, including any epidemiology center serving Indian Tribes regionally or serving urban Indian organizations nationally that is receiving funding from the Indian Health Service.

''(2) The terms 'Indian Tribe' and 'Tribal organization' have the meanings given to the terms 'Indian tribe' and 'tribal organization', respectively, in section 4 of the Indian Self-Determination and Education Assistance Act.

''(3) The term 'Urban Indian organization' has the meaning given to that term in section 4 of the Indian Health Care Improvement Act.''.

(h) AUTHORIZATION OF APPROPRIATIONS.—Section 306(o) of the Public Health Service Act, as redesignated by subsection (g), is amended to read as follows:

''(o) To carry out this section, there is authorized to be appropriated $185,000,000 for each of the fiscal years 2021 through 2025.''.

○

United States Government Accountability Office

Report to Congressional Addressees

March 2022

TRIBAL EPIDEMIOLOGY CENTERS

HHS Actions Needed to Enhance Data Access

GAO-22-104698

GAO Highlights

Highlights of GAO-22-104698, a report to congressional addressees

TRIBAL EPIDEMIOLOGY CENTERS

HHS Actions Needed To Enhance Data Access

Why GAO Did This Study

AI/ANs have experienced long-standing problems accessing health care services and worse health outcomes than the general U.S. population, such as a life expectancy that is 5.5 years shorter than the U.S. average, according to IHS. To provide tribes with public health support, Congress required the establishment of TECs and, in 2010, authorized their access to HHS data. The COVID-19 pandemic highlighted the need to understand TECs' access to epidemiological data to help AI/AN communities prevent and control diseases.

The CARES Act includes a provision for GAO to report on its ongoing COVID-19 monitoring and oversight efforts. Also, GAO was asked to examine TECs' access to epidemiological data. This report (1) describes TECs' access to and use of epidemiological data, and (2) examines factors that have affected TECs' access to HHS epidemiological data. GAO reviewed HHS policies and documents and documentation of TECs' data requests. GAO also interviewed officials from CDC, IHS, and all 12 TECs.

What GAO Recommends

GAO is making five recommendations, including that HHS clarify the data it will make available to TECs as required by federal law; and that CDC and IHS develop guidance on how TECs should request data, and develop agency procedures on responding to such requests. HHS concurred with these recommendations.

View GAO-22-104698. For more information, contact Michelle B. Rosenberg at (202) 512-7114 or RosenbergM@gao.gov.

What GAO Found

Among the 12 tribal epidemiology centers (TEC), which are public health entities serving American Indian and Alaska Native (AI/AN) communities across the U.S., access to epidemiological data varied. Federal law authorizes TECs' access to data from the Department of Health and Human Services (HHS), including data from HHS's Centers for Disease Control and Prevention (CDC) and Indian Health Service (IHS), for a variety of public health purposes. However, according to TEC officials, access to non-public HHS data, such as CDC data on positive COVID-19 tests or IHS data on patient diagnosis codes, varied among TECs. TEC officials also described challenges accessing some CDC and IHS data, such as the inability to access certain CDC data on infectious diseases and other conditions. TECs used available epidemiological data to monitor the spread of COVID-19 and to conduct other analyses that support public health decision-making in AI/AN communities. However, TEC officials told GAO that their access to data influences the analyses they are able to conduct, and that a lack of access can limit their ability to provide AI/AN communities with meaningful information needed for decision-making.

The presence of CDC and IHS data sharing systems and agreements between the agencies and TECs have facilitated TECs' access to a range of epidemiological data, including on COVID-19 cases and the health of IHS facility patients. However, a number of factors have also hindered TEC access to HHS data, including

- **A lack of policies affirming TECs' authority to access HHS data**. Officials from seven of 12 TECs indicated that some CDC and IHS officials with whom they interacted when requesting data did not recognize that HHS is required by federal law to provide data in its possession to TECs. According to IHS and CDC officials, as of November 2021, HHS had not clarified the specific data that TECs are entitled to access under federal law.

- **A lack of guidance for TECs on how to request data, and agency procedures on how to respond to such requests**. CDC and IHS had not developed guidance for TECs on how to submit data requests or established written agency procedures for reviewing and responding to these requests as of November 2021, according to agency officials. CDC and IHS officials told GAO that they did not believe that guidance or procedures related to TECs' data access was needed, because TECs' requests were infrequent and they believed they had successfully responded to their needs. However, officials from six TECs told GAO that the process to request and obtain data was unclear and inconsistent within HHS. In addition, officials from seven TECs reported facing delays receiving CDC or IHS data, with some delays lasting over 1 year. According to TEC officials, these delays or limitations in accessing data made it difficult for them to adequately support tribal and community leaders, as they work to understand and address the health needs of AI/AN in their communities, including during the COVID-19 pandemic.

Contents

Abbreviations

AI/AN	American Indian and Alaska Native
CDC	Centers for Disease Control and Prevention
COVID-19	Coronavirus Disease 2019
HHS	Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
IHS	Indian Health Service
TEC	tribal epidemiology center
WONDER	Wide-ranging Online Data for Epidemiological Research

U.S. GOVERNMENT ACCOUNTABILITY OFFICE
441 G St. N.W.
Washington, DC 20548

March 4, 2022

Congressional Addressees

American Indians and Alaska Natives (AI/AN) have experienced long-standing problems accessing needed health care services and have poorer health than the general U.S. population. For example, AI/ANs have a life expectancy that is 5.5 years shorter than the U.S. average, and a Coronavirus Disease 2019 (COVID-19) infection rate 3.5 times higher than non-Hispanic whites.[1] Legislation enacted in 1992 required the establishment of tribal epidemiology centers (TEC) to provide epidemiological functions and public health support for tribes, tribal organizations, and urban Indian communities.[2] Today, 12 TECs, which are public health organizations that are funded, in part, by the Centers for Disease Control and Prevention (CDC) and the Indian Health Service (IHS), serve AI/AN tribal and urban communities across the nation by investigating diseases of concern and responding to public health emergencies, among other activities. TECs conduct this work to better understand health risks for AI/ANs, eliminate health disparities, and prevent and control diseases.

Legislation enacted in 2010 directed the Secretary of the Department of Health and Human Services (HHS) to grant TECs access to HHS data

[1]See Indian Health Service, Indian Health Disparities Fact Sheet, (Rockville, Md.: October 2019), accessed November 19, 2021, https://www.ihs.gov/newsroom/factsheets/disparities/; and U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, *COVID-19 Among American Indian and Alaska Native Persons – 23 States, January 31 – July 3, 2020,* Morbidity and Mortality Weekly Report, vol. 69 no. 34 (Aug. 28, 2020).

[2]Indian Health Amendments of 1992, Pub. L. No. 102-573, § 210, 106 Stat. 4526, 4551.

and clarified that TECs are to be treated as public health authorities.[3] Specifically, federal law directs the Secretary of HHS to provide TECs with HHS data and other protected health information for research and for preventing and controlling disease, injury, or disability—which, for the purposes of this report, we refer to as epidemiological data.[4] HHS agencies hold a wide range of epidemiological data. For example, CDC maintains data on diseases, such as COVID-19 and influenza, and factors that affect health, such as suicide and immunizations. Further, IHS maintains data on AI/ANs who receive care through its network of health care providers, including federally and tribally operated hospitals and clinics.[5] Other entities, such as state governments, also maintain epidemiological data that may be provided to TECs, in TECs' capacity as public health authorities.

Access to timely, reliable, and identifiable epidemiological data is vital to disease surveillance and other epidemiological functions.[6] These data are central to decision making, as they can help AI/AN communities define priorities, develop health improvement strategies, acquire resources, and implement effective interventions. TECs rely on the sharing of existing epidemiological data accumulated by federal, state, or local governments;

[3]Patient Protection and Affordable Care Act, § 10221, Pub. L. No. 111-148, 124 Stat. 119, 935 (incorporating S. 1790) (codified at 25 U.S.C. § 1621m(e)). In particular, the law provides that TECs are to be considered as public health authorities for the purpose of the Health Insurance Portability and Accountability Act (HIPAA). Public health authorities are responsible for public health matters as part of their official mandate, and they can include federal, state, territorial, or Indian tribal agencies. Under HIPAA, certain entities, such as health care providers, health plans, and health care clearinghouses, may grant public health authorities access to protected health information for the purposes of preventing and controlling disease, among other things. Protected health information includes individually identifiable health information on a person's health condition and care. 45 C.F.R. §§ 160.103, 164.501, 164.512.

[4]45 C.F.R. § 164.512(b)(1)(i). Epidemiological data may include a variety of health-related data on diseases, health events (such as birth defects, injuries, and non-infectious diseases), and populations.

[5]IHS provides health care services to AI/ANs either directly through a system of federally operated IHS facilities or indirectly through facilities that are operated by other tribes. As of November 2021, IHS, tribes, and tribal organizations operated 45 hospitals and 368 health centers as well as a range of other types of health facilitates—of which, 23 hospitals and 50 health centers were federally operated IHS facilities.

[6]Disease surveillance is the process of reporting, collecting, analyzing, and exchanging information related to cases of infectious diseases, such as COVID-19 and influenza.

however, questions have been raised about TECs' ability to access HHS and state epidemiological data, including CDC's COVID-19 data.

In 2020, the COVID-19 pandemic highlighted the need to understand TECs' abilities to access federal, state, and local epidemiological data that can help AI/ANs make decisions about how to prevent and control diseases in their communities. The CARES Act includes a provision for GAO to report on its ongoing monitoring and oversight efforts related to the COVID-19 pandemic.[7] In addition, you asked us to examine factors that have affected TECs' access to epidemiological data, including access to COVID-19 data. In this report, we

1. describe TECs' access to and use of HHS and state epidemiological data, and
2. examine factors that have affected TECs' access to and use of HHS epidemiological data.

To describe TECs' access to and use of HHS and state epidemiological data, we reviewed documents and interviewed officials from two HHS agencies—CDC and IHS—and all 12 TECs.[8] Documents we reviewed included notices of funding for HHS programs that support TEC operations, reports documenting TECs' progress towards meeting these programs' objectives, and publicly available analyses published by the 12 TECs over the past 3 years.[9] Further, we reviewed documents related to

[7]Pub. L. No. 116-136, § 19010(b), 134 Stat. 281, 580 (2020).

[8]Specifically, we interviewed the directors of, or director-appointed designees from, each of the 12 TECs: (1) Alaska Native Epidemiology Center; (2) Albuquerque Area Southwest Tribal Epidemiology Center; (3) California Tribal Epidemiology Center; (4) Great Lakes Inter-Tribal Epidemiology Center; (5) Great Plains Tribal Epidemiology Center; (6) Inter Tribal Council of Arizona, Inc. Tribal Epidemiology Center; (7) Navajo Epidemiology Center; (8) Northwest Tribal Epidemiology Center; (9) Oklahoma Area Tribal Epidemiology Center; (10) Rocky Mountain Tribal Leaders Council Epidemiology Center; (11) United South and Eastern Tribes, Inc. Tribal Epidemiology Center; and (12) Urban Indian Health Institute. For the purposes of this report, we refer to these individuals as TEC officials.

In addition, we reviewed documents and spoke with officials from CDC and IHS because TEC officials told us they requested access to data held by these two HHS agencies from January 2018 through April 2021.

[9]We reviewed notices of funding for the current funding cycle for HHS programs, including CDC's Tribal Epidemiology Centers Public Health Infrastructure program and IHS's Epidemiology Program for AI/AN Tribes and Urban Communities. We reviewed the most recently available progress reports for these programs.

TECs' access to CDC, IHS, and state epidemiological data from January 2018 through November 2021, including agency agreements to share data with TECs. We also interviewed officials from CDC, IHS (including from IHS headquarters and four IHS area offices that serve tribes in different geographic regions across the U.S.), and all 12 TECs; we asked officials about TECs' access to and use of HHS and state epidemiological data, as well as how tribes and others use TECs' analyses.[10]

To examine factors that affected TECs' access to and use of HHS epidemiological data, we interviewed officials from the 12 TECs, CDC, and IHS—including officials from IHS headquarters and the four IHS area offices noted above. From these interviews, we identified the most frequently mentioned factors that affected TECs' access to and use of HHS epidemiological data. We also interviewed stakeholders selected to provide a variety of perspectives on TECs' access to and use of data.[11] To further describe and examine factors affecting TEC access to and use of data, we reviewed available documentation showing CDC and IHS responses to TECs' data requests from January 2018 through November 2021. We also reviewed agency documents including data sharing policies and agreements, cooperative agreements, TECs' progress reports, and documents summarizing agency efforts to enhance TECs' access to and use of data. We assessed factors affecting TECs' access to and use of epidemiological data in the context of HHS's strategic objective of improving surveillance, epidemiology, and laboratory services by facilitating information exchange. We also assessed these factors in the context of IHS's strategy of assuring data sharing to solidify partnerships with TECs.[12]

We conducted this performance audit from January 2021 to March 2022 in accordance with generally accepted government auditing standards.

[10]IHS is divided into 12 physical areas of the U.S. Each area has a unique group of tribes that an area office works with on a day-to-day basis. We interviewed officials from four IHS area offices: Albuquerque, Great Plains, Nashville, and Oklahoma City. We selected these offices to obtain a range of perspectives on sharing data with TECs from different geographic locations.

[11]Specifically, we interviewed representatives from two tribal governments, the National Indian Health Board, Council of State and Territorial Epidemiologists, Association of State and Territorial Health Officials, and the National Association of County and City Health Officials.

[12]Department of Health and Human Services, *Strategic Plan FY 2018-2022* (Washington, D.C.: Feb. 28, 2018); and Indian Health Service, *Strategic Plan FY 2019-2023* (Rockville, Md.: July 9, 2019).

Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Background

Department of Health and Human Services

HHS works to improve the health of the nation. To achieve this goal, HHS and its agencies undertake a range of activities, including providing health care and implementing public health efforts. For example,

- *IHS.* IHS provides health care to over 2 million AI/ANs who are members or descendants of federally recognized tribes.[13] IHS provides care through a network of facilities, including federally and tribally operated hospitals and health centers. IHS headquarters is responsible for setting national health care policy, ensuring the delivery of comprehensive health services, and advocating for the health needs and concerns of AI/ANs. IHS's 12 area offices are, among other things, responsible for monitoring federally operated IHS facilities' operations and finances, working with the local tribes, and providing guidance and technical assistance.
- *CDC*. CDC is the nation's lead public health agency. Its role is to detect and respond to new and emerging health threats, use science and technology to prevent disease, and train the public health workforce, among other things. As part of its work, CDC conducts disease surveillance by collecting, analyzing, and exchanging information related to cases of infectious and chronic diseases that can be used to improve public health. It also provides technical assistance and guidance to states, territorial, tribal, and local health agencies.

HHS maintains a variety of epidemiological data, including monitoring systems and other protected health information, that can be used to conduct research for the purposes of preventing and controlling disease, injury, and disability in populations such as AI/AN communities. Epidemiological data maintained by the CDC include data collected

[13]IHS was established within the Public Health Service in 1955. Federal health services to maintain and improve the health of AI/ANs are consonant with and required by the federal government's historical and unique legal relationship with, and resulting responsibilities to, the American Indian people. 25 U.S.C. § 1601.

through surveillance systems on diseases, conditions, and other factors that affect health, such as immunizations. These data may include information on age, sex, race and ethnicity, and other demographics. A variety of sources, such as health care providers, laboratories, funeral homes, and state and local health departments, voluntarily submit these data to CDC. Epidemiological data maintained by IHS include patient registration and health encounter data for individuals receiving care from all federally operated IHS facilities and some of its tribally operated facilities. These data include information on patient date of birth, diagnoses, and treatments.

Tribal Epidemiology Centers

The 12 TECs have the mission of improving AI/AN health by identifying and understanding public health problems and disease risks, strengthening public health capacity, and developing solutions for disease prevention and control.[14] These centers work to fulfill this mission by performing seven core epidemiological functions specified in federal law, including assisting with identifying health priorities, making recommendations for improving health care delivery systems, and providing disease surveillance to promote public health.[15] (See text box.) TECs perform these functions in consultation with and at the request of tribes, tribal organizations, and urban Indian organizations.

Tribal Epidemiology Center (TEC) Core Functions

Federal law identifies seven core functions for TECs to perform in consultation with and at the request of Indian tribes, tribal organizations, and urban Indian organizations.

- Collect data and monitor progress made towards meeting health status objectives.
- Evaluate delivery, data, and other systems that affect the improvement of Indian health.
- Identify highest priority health status objectives and services needed to achieve them.
- Make recommendations for targeting needed services.
- Make recommendations to improve health care delivery systems.
- Provide epidemiologic technical assistance.
- Provide disease surveillance, and assist in promoting public health.

Source: GAO summary of federal law. | GAO-22-104698

[14]See Tribal Epidemiology Centers, “About”, accessed on December 2, 2021, tribalepicenters.org/about/.

[15]25 U.S.C. § 1621m(b).

To help facilitate TECs' access to epidemiological data, federal law provides that TECs are to be treated as public health authorities.[16] Public health authorities are responsible for public health matters as part of their mandate, including using surveillance to identify health problems, identifying risk factors for health problems, and implementing and evaluating interventions to respond to health problems. Public health authorities include agencies within the federal government, states, and tribes—as well as others who are acting under a contract or grant from such an agency. To enable public health authorities to carry out their responsibilities, federal law specifies that they may be provided with protected health information, which includes individually identifiable information on a person's health condition and care.[17] Federal law also directs the Secretary of HHS to grant TECs access to protected health information in the possession of the Secretary, including data, monitoring systems, and delivery systems.[18]

Each TEC is unique, and TECs vary in terms of their structure, size, IHS service area, and populations served.

- *Structure.* All TECs are housed within various types of broader organizations that serve AI/AN tribal and urban communities, including organizations that also serve as an Indian health board, health organizations that specialize in caring for AI/ANs, area-wide tribal councils, and a Tribal Department of Health.[19]
- *Size.* TECs vary in size. As of November 2021, the number of staff at each TEC ranged from seven to 62, and the number of epidemiologists—public health workers that investigate patterns and causes of disease and injury—at each TEC ranged from two to 13.
- *IHS area.* Ten of the 12 TECs' service areas align with IHS areas. Two TECs' service areas span two or more IHS areas.[20]

[16]Pub. L. No. 111-148, § 10221, 124 Stat. at 935 (incorporating S. 1790) (codified at 25 U.S.C. § 1621m(e)(1)).

[17]45 C.F.R. § 164.512(b)(1)(i).

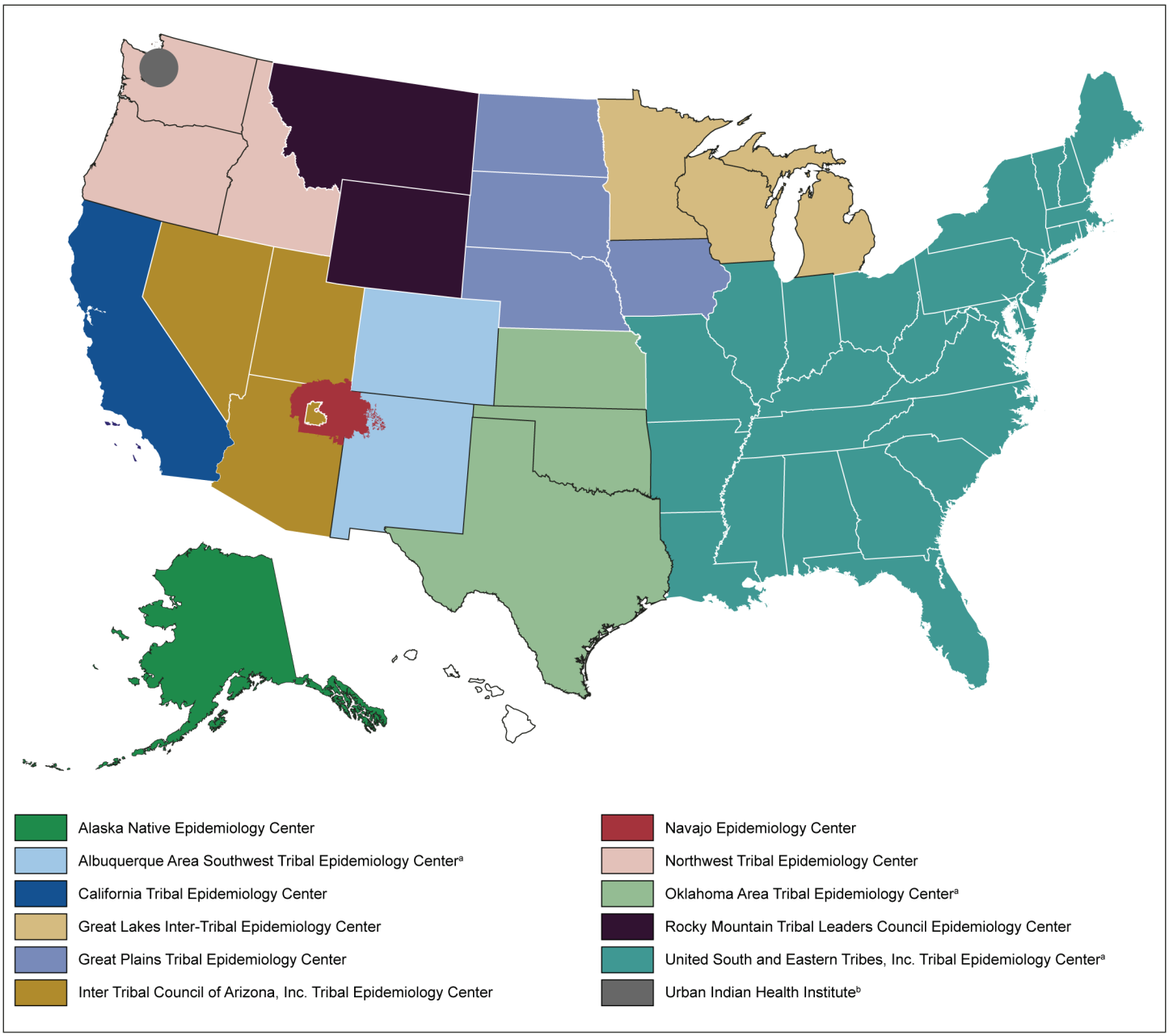
[18]Pub. L. No. 111-148, § 10221, 124 Stat. at 935 (incorporating S. 1790) (codified at 25 U.S.C. § 1621m(e)(2)).

[19]Area Indian health boards across the U.S. work, in part, to develop health policy and programs to promote and protect the health of the communities they serve.

[20]The Inter Tribal Council of Arizona, Inc. Tribal Epidemiology Center serves tribes in the Phoenix and Tucson IHS areas and the Urban Indian Health Institute serves urban Indians nation-wide.

- *Populations served.* Most TECs serve AI/AN communities in more than one state. Specifically, nine TECs serve AI/AN populations in two or more states, two TECs each serve AI/AN populations in one state, and one TEC serves urban Indians across the U.S. (See figure 1 for a map of TECs' service areas.)

Figure 1: Tribal Epidemiology Centers' (TEC) Service Areas



Source: Centers for Disease Control and Prevention. | GAO-22-104698

Notes: Hawaii is not included in any of the TECs' service areas.

[a]Three TECs serve tribes in Texas: Albuquerque Area Southwest Tribal Epidemiology Center, Oklahoma Area Tribal Epidemiology Center, and United South and Eastern Tribes, Inc. Tribal Epidemiology Center.

[b]The Urban Indian Health Institute is located in Seattle, Washington and serves urban Indians across the U.S.

TECs' Access to Epidemiological Data Varied, and TECs Used Available Data for Analyses to Support Tribal Decision-Making

TECs' Access to Epidemiological Data Has Varied

All TECs had access to a range of epidemiological data that HHS and states make publicly available, including national and regional data from CDC and IHS on certain diseases and conditions, vital statistics, vaccines, and populations. For example, TECs had access to COVID-19 case, death, and testing data at the state and county levels, which CDC makes publicly available through its COVID-19 data tracker. TECs also had access to other epidemiological data through CDC's Wide-ranging Online Data for Epidemiological Research (WONDER). This online database houses publicly available data on U.S. births, deaths, and cancer diagnoses, among other things.

TECs also reported having access to some additional epidemiological data, but the specific data to which they had access varied. For example,

- *CDC COVID-19 data.* As of November 2021, officials from 10 TECs told us they had access to CDC COVID-19 data for their service area through HHS Protect, HHS's online repository for COVID-19 data; however, the types of data varied.[21] Officials from all 10 of these TECs told us they had access to CDC's COVID-19 case surveillance

[21]HHS Protect is HHS's central repository for COVID-19 data that are collected through various HHS agencies, including CDC, and others at the federal, state, and local levels. CDC data may not reflect real-time conditions, as states and territories voluntarily submit data to CDC, may not submit their data to CDC in real time, and may also submit corrections and updates to their data. Further, certain data, including race and ethnicity data, maintained in HHS Protect may not be complete because states and territories voluntarily submit it.

data, including positive tests, hospitalizations, and deaths; officials from the remaining two TECs chose not to access CDC's COVID-19 case data.[22] Officials from six TECs told us they also had access to COVID-19 vaccination data through HHS Protect.[23]

- *IHS patient registration and health encounter data.* Officials from nine TECs told us they had access to IHS patient registration and health encounter data as of November 2021, such as patient diagnosis and procedure codes.[24] However, how the data were accessed varied across the TECs. Officials from eight of these nine TECs told us that IHS provided extracts of these data as of a certain point in time at different frequencies, which ranged from quarterly to annually. Officials from the remaining TEC told us they had direct, real-time access to data through IHS's electronic health record system for certain tribally operated facilities in their service area.[25] Further, the types of data to which the nine TECs had access varied. Specifically, officials from six of the nine TECs told us they had access to patient

[22]An official from one of the two TECs that chose not to access CDC's COVID-19 case data told us that the TEC had not requested access to the data because the TEC had access to higher quality data from states in its service area. An official from the other TEC told us the TEC had not requested access to the data because the agency had not provided the TEC complete information and corresponding security requirements for the data. CDC officials told us that all 12 TECs were provided the same information on accessing the COVID-19 case data through HHS Protect, including information on data security requirements.

[23]CDC officials told us that, in June 2021, they offered all 12 TECs access to COVID-19 vaccine data, which includes data on vaccines administered throughout the country, including at IHS, tribal, and urban Indian facilities. CDC officials told us that they had communicated with TECs on multiple occasions since the data were first offered to TECs, providing them with information on how to secure access to COVID-19 vaccine data. Further, CDC officials told us this outreach was ongoing, as of November 2021.

[24]Officials from the remaining three TECs told us that they did not have access to IHS patient registration and health encounter data as of November 2021. IHS maintains data on patient registrations, including names, addresses, and AI/AN status; and patient encounters, such as patient's diagnostic and procedure codes, provider notes, and provider type. These data are submitted by participating facilities operated by IHS, tribes, and urban health centers on a regular basis. These facilities submit data through data systems, including IHS's electronic health record system—the Resource and Patient Management System. IHS maintains raw data from participating facilities in its National Data Warehouse. IHS processes raw data into data tables, which are then copied into IHS's Epidemiological Data Mart. However, some personally identifiable variables, such as name and address, are not copied in to the Epidemiological Data Mart.

[25]The TEC official told us that the TEC received approval from its local IHS area office to access data for tribally operated facilities through IHS's electronic health records system. Officials from this IHS area office confirmed the TEC's level of access. Further, these officials told us that, to gain access to these data, the TEC was required to obtain approval from the tribal nation operating the facility.

registry data with certain patient identifiers removed—such as name, address, and social security number; while officials from the other three TECs told us that they had access to data that included some of these identifiers.

- *Other IHS data.* Officials from six TECs told us that they had access to other IHS data, which the agency provided in response to some TEC requests. For example, officials from one TEC told us that they had access to facility-level immunization data, such as the number of shingles vaccines administered to adults over age 60, for IHS facilities in their area. An official from another TEC told us they requested specific data points, such as the number of clinics in their area using a certain type of COVID-19 test, and they received these data from the local IHS area office.
- *State data.* As of November 2021, officials from all 12 TECs told us they had access to epidemiological data directly from at least one state health department in their service area. However, the amount and type of data to which TECs had access varied by state. For example, one TEC told us they had access to three types of data in one state—COVID-19 case surveillance data, cancer registry, and birth and death records—and access to nine types of data in another state, including communicable diseases (such as measles), traumas, and hospital discharges.

While TECs had access to some epidemiological data, officials from all 12 TECs we interviewed described challenges accessing other data from CDC, IHS, or states. For example,

- *Challenges accessing CDC data.* Officials from three TECs told us they requested access to non-publicly available data from CDC's National Notifiable Disease Surveillance System, which tracks the incidence of infectious diseases, such as influenza and tuberculosis, and noninfectious conditions, among other things.[26] However, CDC officials stated that the agency has not provided access to these data as of November 2021 because CDC does not have a system to share these data with anyone outside the agency. Our review of selected CDC responses to TEC data requests from January 2018 to November 2021 identified another challenge. Specifically, CDC

[26]CDC makes some data collected through its National Notifiable Disease Surveillance System publicly available. For example, CDC makes weekly and annual tables on the number of tuberculosis cases nationally and by state available through CDC WONDER.

denied one TEC's request for individual-level data on sexually transmitted diseases, which potentially could be used to identify individuals, based on guidelines that prohibit the agency from sharing these data with any entity other than IHS.[27]

- *Challenges accessing IHS data.* Officials from four TECs told us they had requested access to IHS patient registration and health encounter data related to substance use diagnoses and treatment. However, as of November 2021, TECs typically were not receiving these data because, according to IHS officials, IHS redacts these data from extracts shared with TECs to comply with federal regulations governing substance use disorder patient records.[28] Agency officials also told us that IHS could provide TECs with some substance use disorder data that conform to federal regulations that govern substance use disorder patient records, which would likely require data to be aggregated at the state or IHS area level. However, IHS had not provided these data to TECs as of November 2021. Our review of selected IHS responses to TEC data requests identified another challenge. IHS officials asked one TEC to submit a request for COVID-19 vaccination data in their service area as a member of the general public rather than as an entity with public health authority status. Specifically, IHS officials asked the TEC to submit a Freedom of Information Act request, which is a type of request the general public can submit to access certain federal records.[29] According to the officials, this was part of the normal process for gaining access to IHS data.

[27]Specifically, CDC cited Council of State and Territorial Epidemiologists and CDC data release guidelines for the National Notifiable Disease Surveillance System. These guidelines specify that individual-level data on sexually transmitted diseases, which potentially could be used to identify individuals, may only be released to the Epidemiology Branch of IHS. CDC officials told us that they can make more aggregated data available to TECs.

[28]The one TEC that has direct, real-time access to data through IHS's electronic health record system told us their access includes substance use disorder data. This TEC's access to substance use disorder data is limited to tribally operated facilities in their service area that use IHS's electronic health record system and serve tribes that provided approval. Federal law protects the confidentiality of substance use disorder patients by restricting the circumstances in which federally assisted programs, including programs that are managed by a federal office or an entity receiving any federal funding, can disclose information that would identify a person as having a substance use disorder. See 42 U.S.C. § 290dd-2; 42 CFR Part 2. In 2020, the CARES Act amended federal law to permit de-identified records relating to substance use disorder to be disclosed to public health authorities. See Pub. L. No. 116-136, § 3221(c), 134 Stat. at 376; 42 U.S.C. § 290dd-2(b)(2)(D).

[29]5 U.S.C. § 552.

- *Challenges accessing state data.* Officials from three TECs told us they had not been able to access any data from at least one or more states in each of their service areas because a state's rules around data sharing were restrictive, among other reasons.

TECs Used Available Epidemiological Data to Conduct a Range of Analyses to Support Tribal Decision-Making

Officials from all 12 TECs told us they used available epidemiological data from CDC, IHS, or states to conduct a range of analyses to support tribal public health decision-making, including for leaders of health programs, area health boards, or health care facilities. TEC officials told us they analyzed epidemiological data to fulfill their core functions, such as identifying health priorities, making recommendations for health service needs, and conducting disease surveillance.

Our review of TECs' reports and publicly available analyses showed that TECs have used available epidemiological data to, among other things, identify and track the leading causes of mortality and morbidity of AI/ANs in their service areas, develop community health profiles outlining the health status and needs of AI/ANs in their service areas, and conduct surveillance on the spread of COVID-19 in their communities. Table 1 provides examples illustrating the range of epidemiological analyses TECs have conducted.

Table 1: Examples of Analyses Conducted by Tribal Epidemiology Centers (TEC)

Example of TEC analyses	Description of analyses
Injury atlas	Analyzed state data to describe the leading causes of injury-related death and hospitalizations, and help identify effective prevention efforts.
Special reports for tribal health departments	Analyzed surveillance data over a 2-year period to identify the top chronic diseases and infectious diseases.
Community health profiles	Analyzed epidemiological data from the Centers for Disease Control and Prevention (CDC), the Indian Health Service, states, or others to examine the health status of American Indian and Alaska Native (AI/AN) communities, monitor progress towards meeting health objectives, and identify and prioritize public health needs. These profiles have been completed at the tribal, region, or national level.
Coronavirus Disease 2019 (COVID-19) reports	Analyzed surveillance data and other information to develop reports summarizing the status of COVID-19 in their service area. Reports included a map showing the geographic distribution of the disease, the number of confirmed COVID-19 cases across one state, a list of program closures due to disease outbreaks, and a list of tribes that declared a state of public health emergency.
Interactive dashboards	Analyzed CDC, state, and other data to develop interactive graphics on the incidence of disease and health outcomes related to COVID-19, leading causes of death, maternal and child health, and demographics. These dashboards can provide data at the service area, state, and county levels.
Data assessments	Examined federal, state, and tribal data on COVID-19 and other priority areas to identify gaps in the accessible data, and identified alternative data sources to fill them.
Data registry	Maintained data on AI/ANs within TEC service areas, and used these to assess and improve the quality of other data, such as state-level cancer registries or death records.

Source: GAO analysis of TEC reports and publicly available analyses. | GAO-22-104698

Officials from all 12 TECs told us that they conducted analyses for and at the request of tribes, tribal organizations, urban Indian health programs, or IHS. These TEC officials told us that their analyses are used by AI/AN communities and their leaders to help make decisions about public health interventions, programs, and policies. For example,

- An official from one TEC told us the TEC completed a series of community health assessments to examine health risk factors for tribes in one state, which tribes used to help identify their most urgent health needs and prioritize their public health efforts.
- Another TEC reported examining outcomes and trends among the AI/ANs participating in a diabetes program, which could be used to inform future programs to improve diabetes care, prevention, and outcomes.

TEC officials also told us that their access to data influenced the analyses they were able to conduct. They noted that data access, or the lack of access, affects their ability to provide tribal and urban health organization

leaders with information needed for public health decision making. For example, officials from some TECs told us that their inability to access IHS data on substance abuse diagnosis and treatment limited their ability to assess and assist tribal leaders in responding to the opioid epidemic. When data are not available, some TEC officials noted difficulties in observing trends in the health of their AI/AN populations and providing meaningful information to tribal leaders and others about the prevalence, incidence, and burden of disease. Some TEC officials told us that their lack of access to data limits their ability to conduct analyses, which can make it difficult for tribal leaders, as they work to identify the needs of their communities and make informed decisions about how to address those needs. In addition, some officials noted that it may also limit their tribes' ability to explain their health needs to others and, therefore, may limit opportunities for tribes to receive funding to address those needs.

While HHS Has Some Systems to Share Data with TECs, Its Lack of Policies, Guidance, and Procedures Hinders Access

Data Sharing Systems and Agreements Have Facilitated TECs' Access to Data

Data sharing systems and agreements have facilitated TECs' access to HHS epidemiological data. Specifically, the presence of data sharing systems like HHS Protect—HHS's central repository for COVID-19 data—has facilitated TECs' access to CDC's COVID-19 data, including case surveillance data on the number of positive cases, hospitalizations, and deaths, as well as vaccination data. As of November 2021, officials from 10 TECs reported gaining access to COVID-19 case surveillance data through HHS Protect, and officials from six TECs reported gaining access

to COVID-19 vaccination data through HHS Protect.[30] In another example, the presence of IHS's Epidemiology Data Mart has facilitated TECs' access to excerpts of patient registration and health encounter data collected from all federally operated and some tribally operated facilities in each TEC's jurisdiction. As of November 2021, 10 TECs have established data sharing agreements with IHS to access these data, according to our review of the data sharing agreements.[31] Other data sharing systems have also facilitated TECs' access to a variety of epidemiological data, including CDC's publicly available WONDER system, data.cdc.gov portal, and COVID-19 data tracker.

While the presence of data sharing systems and agreements has facilitated TECs' access to data, TECs have been unable to access data in some cases where such systems and agreements have not been established or do not meet the needs of the TECs. For example, as previously noted, CDC officials told us that they have been unable to share detailed surveillance data on nationally notifiable diseases, such as influenza and tuberculosis, with TECs because the agency does not have a system that enables them to readily share these data.[32] Similarly, not all TECs had been able to negotiate data sharing agreements with IHS and

[30]CDC officials told us that they have not required TECs to sign a data sharing agreement in order to access COVID-19 case surveillance data; however, they have required TECs to sign a data sharing agreement in order to access COVID-19 vaccination data. Prior to accessing data in HHS Protect, all TECs have been required to sign HHS's Rules of Behavior for the Use of HHS Information and IT Resources Policy, according to CDC officials.

[31]Two of these TECs had not accessed IHS's Epidemiology Data Mart data as of November 2021. One of these TECs signed its data sharing agreement in September 2021. According to IHS officials, after the agreement is signed, the TEC must train and credential a staff person to work with the data and the agency must compile the appropriate data for the TEC; these steps were in process as of November 2021. The other TEC signed its agreement in 2013 but TEC officials told us that they have not accessed these data because the TEC has direct, real-time access to data through IHS's electronic health record system for certain tribally operated facilities in its service area.

[32]CDC officials told us that the agency plans to share these data with TECs, but they have not established a time frame for initiating or implementing this plan. According to CDC officials, the staffing and resource needs of the COVID-19 response have significantly limited CDC's ability to work on expanding access to other data. However, officials also noted that CDC is now working to expand the availability of public health data, including on nationally notifiable diseases, by making targeted investments in public health data infrastructure.

CDC as of November 2021.[33] Although IHS officials told us that the agency is open to negotiating the terms of its data sharing agreements, officials from two TECs told us that as of November 2021, they had been unable to negotiate a data sharing agreement with IHS for the Epidemiology Data Mart; therefore, they do not have access to that data. In addition, officials from three TECs that had active data sharing agreements with IHS told us that their current data sharing agreement did not fully meet their needs because IHS had not provided data as frequently as they had requested. Similarly, officials from two TECs told us that their TECs had not yet accessed any COVID-19 data in HHS Protect as of November 2021, including one TEC that told us that it had been waiting since April 2020 for CDC to clarify relevant data security policies.[34]

Lack of Policies, Guidance, and Procedures Hinders TECs' Access to Data

A lack of HHS policies affirming TECs' authority to access HHS epidemiological data, as well as guidance and procedures related to TEC requests for such data, have hindered TECs' access to HHS epidemiological data. Officials from seven TECs indicated that some CDC and IHS officials with whom they interacted when requesting data did not recognize that HHS is required by federal law to provide data in its possession to TECs.[35] For example, officials from five TECs told us that they were asked by CDC and IHS officials to submit requests for data as entities without any public health authority standing—for example, as researchers or as public citizens through a Freedom of Information Act request. Rather than having TECs' access to data affirmed through HHS policies, officials from six TECs told us that their access to HHS data depended, in part, on their ability to build strong relationships with CDC

[33]TEC officials we interviewed also reported a range of experiences accessing data from states in their service areas. Officials from all 12 TECs told us that they had been able to access at least one dataset directly from at least one state in their service area. However, officials from three TECs told us that they had been unable to establish data sharing agreements with, or obtain access to any data from, at least one state in their service area; therefore, these TECs were limited to using only publicly available data from that state.

[34]The second TEC had not pursued access to COVID-19 data in HHS Protect because of concerns about the data's quality, according to a TEC official we interviewed. CDC officials told us that all 12 TECs were provided the same information on accessing COVID-19 case data through HHS Protect, including information on data security requirements.

[35]25 U.S.C. § 1621m(e)(1–2); 45 C.F.R. § 164.512(b)(1)(i).

and IHS officials.[36] Officials from one TEC explained that they must request data repeatedly and negotiate access each time.

HHS has a strategic objective to improve surveillance, epidemiology, and laboratory services by facilitating information exchange, and IHS has a strategic goal of assuring data sharing to solidify partnerships with TECs. Yet according to CDC and IHS officials, as of November 2021, HHS had not clarified the specific data that TECs are entitled to access under federal law.[37] Furthermore, as discussed above, we identified one CDC policy that agency officials interpreted as prohibiting the sharing of certain epidemiological data with TECs, which was cited by CDC officials when they denied a TEC's request for data.

CDC and IHS had also not developed guidance for TECs on how to submit data requests or established written agency procedures related to responding to these requests as of November 2021, according to agency officials. IHS officials from headquarters told us that they use a framework for reviewing TECs' requests for data. However, they had not documented or shared this framework with TECs, in part, because the review process can vary and requests are adjudicated on a case by case basis. Officials from one of the four IHS area offices we interviewed told us that it followed an HHS checklist for sharing protected health information when reviewing TEC data requests, but officials from the other three area offices said that they did not have a policy with respect to sharing data with TECs.[38] Separately, CDC developed a process for TECs to request COVID-19 case surveillance and vaccination data once the agency was ready to make these data available to the TECs. However, this process is specific to these data sets and does not extend to other data maintained by the agency.

CDC and IHS officials reported that they believed they had been responsive to each TEC's needs. Specifically, officials from both agencies reported making data available to TECs as permissible by law, participating in regular meetings with TEC officials, as well as providing

[36]Similarly, officials from eight TECs also reported a lack of clarity or understanding of the role of TECs by at least some state officials, which they say similarly limited their access to data. In addition, officials from six TECs told us that some state officials did not recognize the public health authority status of TECs.

[37]See 25 U.S.C. § 1621m(e).

[38]Officials from two of these IHS area offices told us that they had not shared any data with their area's TEC, and officials from one area office told us that they had only shared aggregate de-identified data with the TEC.

technical assistance and information. CDC and IHS officials told us that they believed that additional guidance for TECs on how to request data and agency procedures related to responding to such requests was unnecessary, because TEC requests were infrequent and they believed they had successfully responded to their needs.

However, officials from six TECs told us that the process to request and obtain data from CDC and IHS was unclear and inconsistent within and between the agencies. Specifically, TEC officials collectively told us that it was unclear what data were available to them, who were the appropriate agency contacts to whom to direct their requests, when they could expect to receive a response, what type of information to provide that would enable a timely response, and what criteria were used to review their requests.

A lack of clarity in TECs' authority to access data, and guidance and procedures to request and respond to requests, likely contributed to delays TECs have faced obtaining access to CDC and IHS data. Specifically, officials from seven TECs told us that they have faced delays receiving CDC or IHS responses to their data requests, and officials from four of these TECs told us that these delays were significant—over 1 year long. For example,

- During the COVID-19 pandemic, TECs experienced delays in receiving access to COVID-19 case and vaccination data from CDC. Specifically, one TEC requested COVID-19 case surveillance data from CDC in May 2020. According to TEC officials, CDC officials told them that they could not share the data with the TEC because the data included protected health information that the TEC did not have authority to receive. Later, CDC officials acknowledged a significant miscommunication about this issue and began working to develop a method to provide the data to the TEC. In late June, nearly 6 weeks after the initial request, CDC provided the TEC with access to the requested data. CDC later developed a method for providing the remaining TECs with access to COVID-19 case surveillance data for their regions and began offering it to them. Further, TECs began requesting COVID-19 vaccination data as early as 7 months before it was first provided to a TEC. Specifically, one TEC requested these data from IHS in January 2021, and another TEC requested the data from CDC in April 2021. In June 2021, CDC began outreach to the TECs to offer them access to COVID-19 vaccination data, and CDC officials told us the agency received the first official request for data (a completed data access form) from a TEC in July 2021. In August

2021, CDC first provided a TEC with access to CDC COVID-19 vaccination data, which includes IHS COVID-19 vaccination data.

- One TEC faced a multi-year delay obtaining IHS data. Specifically, a TEC official told us that the TEC verbally requested data in August 2018, and an IHS official told him to delay sending a written request for the data until a study using similar data was completed in August 2019. Our review of the TEC's correspondence with IHS beginning with the TEC's August 2019 written request showed multiple requests for status updates over the next 18 months. IHS and TEC officials confirmed that a data use agreement was signed in March 2021. More than 1 year and a half after the TEC's written request and nearly 3 years after the TEC's initial verbal request, IHS provided the TEC with the data, according to the TEC official.
- An official from one TEC told us that the TEC faced a nearly 8-year delay obtaining IHS Epidemiology Data Mart data. Specifically, an official from the TEC told us that despite IHS signing a data sharing agreement to provide Epidemiology Data Mart data in December 2012, and ongoing communications with agency officials about receiving the data, the TEC did not receive data from IHS until September 2020. IHS officials told us that they had not provided data during that period because the TEC did not request data until December 2019, at which time IHS began working with the TEC to train and credential its staff to access the data.

Officials from seven TECs told us that they had stopped making new requests for CDC or IHS data—for example, due to their recent experiences and the agencies' delayed responses to other requests. TEC officials indicated that the resulting delays or limitations in accessing CDC or IHS epidemiological data have made it difficult for them to adequately support tribal and community leaders as they work to understand and address the health needs of AI/ANs in their communities, including during the COVID-19 pandemic.

Data Quality and Timeliness Can Affect TECs' Use of Data

Officials from 10 TECs told us that their ability to use CDC or IHS data was limited due to significant concerns about the data's quality or timeliness. For example, officials from eight of the 10 TECs with access to COVID-19 case surveillance data from HHS Protect told us that they were unable to use these data because the system included incomplete and inaccurate data, such as on patients' race and ethnicity as well as COVID-19 cases. In addition, one additional TEC reported using COVID-19 case surveillance data from HHS Protect to assess the completeness

of race and ethnicity data in states' case reports to CDC.[39] In September 2020, we reported that race and ethnicity information was missing for about 64 percent of total COVID-19 cases reported to CDC as of July 31, 2020, and we recommended that CDC take steps to ensure the complete and consistent collection of demographic data.[40] CDC has since implemented our recommendation, and agency officials told us that the completeness of case surveillance data on race and ethnicity had improved since our September 2020 report.[41] However, CDC officials acknowledged that gaps remain and are likely to persist due to a variety of reasons, including because the nation's public health system is decentralized and state reporting to CDC is voluntary. In addition, CDC officials noted that improving the quality and availability of race and ethnicity data requires the entire public health system to undertake significant modernization efforts, such as by implementing electronic case reporting and electronic laboratory reporting.

Officials from six TECs reported that IHS Epidemiology Data Mart has limitations that prevent TECs from using it for certain analyses. Specifically, some TEC officials told us that they would ideally like to use these data to conduct active public health surveillance, which requires timely, almost real-time access to data. However, TECs do not have real-time access to these data and, as such, cannot use the data for this purpose.[42] Officials from three TECs told us that their use of these data was limited to understanding the regional IHS user population or monitoring long-term trends in the health of their communities—for example, by examining the prevalence of certain diseases. IHS officials told us that their patient data are generally about 30 days old, and they provide their most current data to TECs at the time they create their Epidemiology Data Mart files. IHS is planning to implement a new

[39]The TEC found that, as of February 2021, race and ethnicity data were missing for 49 percent of all COVID-19 cases reported to CDC. It also noted that this lack of completeness obscures the true burden of disease experienced by AI/AN communities, directly affects the ability of public health authorities to address these effects, and limits policy makers' ability to make data-driven decisions for equitable policy and resource allocation. See Urban Indian Health Institute, *Data Genocide of American Indians and Alaska Natives in COVID-19 Data* (Seattle, Wash.: Feb. 15, 2021).

[40]See GAO, *COVID-19: Federal Efforts Could Be Strengthened by Timely and Concerted Actions,* GAO-20-701 (Washington, D.C.: Sept. 21, 2020).

[41]For example, CDC officials told us that as of November 15, 2021, 66 percent of COVID-19 cases reported to the agency included complete race and ethnicity information.

[42]IHS provides Epidemiology Data Mart files to TECs at intervals ranging from quarterly to annually.

centralized electronic health records system in the next 10 years, which officials stated may enhance the timeliness of their patient data.

CDC and IHS officials acknowledged that there are limitations with their data, and the data likely cannot meet all information needs of TECs to fully realize their functions as regional public health authorities. These officials told us that TECs would likely need to rely on data from a variety of sources, including states, in order to fulfill their responsibilities. While officials from five TECs told us that state data was useful to them in conducting some epidemiological analyses, officials from 11 of the 12 TECs told us that they either faced challenges obtaining data from states or using available state data due to poor data quality.

TECs' Capacity Can Affect Their Access to and Use of Data

TECs' internal capacity—that is, their resources and abilities—can affect their access to and use of epidemiological data. Seeking access to data can require a significant investment of resources, according to some TEC officials we interviewed. Officials from nine TECs suggested that having better access to higher quality data would enable them to use their resources more efficiently—thereby expanding their capacity to serve their tribes—or to conduct more effective work for their tribes. In addition, to enhance their capacity to serve their tribes, officials from five TECs told us that they were looking to hire additional staff.

CDC and IHS have programs aimed at supporting and enhancing the capacity of all TECs to serve their tribes. Through these programs, the agencies award funds and provide technical assistance to TECs. Specifically, IHS's Tribal Epidemiology Center program provides TECs with funding to support TECs' epidemiology and public health functions, including by supporting data analysis and disease surveillance.[43] In addition, CDC's Tribal Epidemiology Centers Public Health Infrastructure program provides funds to all 12 TECs to build data infrastructure, increase staff capacity, and establish partnerships. Table 2 summarizes IHS and CDC programs to support and enhance TECs' capacity to serve their tribes.

[43]Federal funding for this program increased between fiscal years 2019 and 2021 due to COVID-19 supplemental funding.

Table 2: Indian Health Service (IHS) and Centers for Disease Control and Prevention (CDC) Programs to Support and Enhance Tribal Epidemiology Centers' (TEC) Capacity, Fiscal Year 2021

Agency	Program name	Program goal	Total annual program funding for TECs
IHS	TEC	Strengthen public health capacity, and fund tribal organizations in identifying relevant health status indicators and priorities to support public health interventions that reduce morbidity and mortality in the population using sound epidemiologic principles.	$10.4 million
CDC	Tribal Epidemiology Centers Public Health Infrastructure	Expand TECs' ability to perform their core functions by building data infrastructure, increasing staff capacity, and establishing partnerships.	$7.8 million

Source: GAO summary of IHS and CDC information. | GAO-22-104698

TECs may also receive funding and resources from other federal and non-federal programs or sources. For example, aside from the programs noted above, officials from six TECs told us they received funding and support to enhance their capacity to serve their tribes through other CDC programs.[44] CDC, IHS, and TEC officials told us that agency officials provide technical assistance to TECs and attend periodic meetings to address issues that apply to all TECs. To help facilitate the sharing of data between states and TECs, CDC funded a program that aimed to help TECs establish working relationships with appropriate state officials. In addition, in 2021, CDC funded the development of a toolkit to document best practices in obtaining and sharing AI/AN health data.[45]

Conclusions

TECs are uniquely positioned to perform a range of analyses to support tribal decision-making and ultimately help reduce health disparities faced by AI/AN communities. CDC and IHS provide TECs with a variety of resources to fulfill their missions, including funding, technical assistance, and data. Although Congress directed HHS to provide TECs with access to their data, HHS has not yet developed a policy outlining the data, including monitoring systems, delivery systems and other protected health information, in its possession that it will make available to TECs, pursuant to federal law. In the absence of an HHS policy affirming TEC access to data, some TECs have faced a lack of clarity among CDC and IHS officials about their authority to access the agencies' data. CDC and

[44]These programs include CDC's Good Health and Wellness in Indian Country program, which aims to improve AI/AN tribal health, focusing on health promotion and disease prevention.

[45]This toolkit is available at https://nativedata.npaihb.org/.

IHS have also not developed guidance for TECs on how to request data, or agency procedures on how to respond to such requests. As a result, TECs reported facing an unclear and inconsistent process for requesting data and receiving agency responses, which likely contributed to delays TECs faced in accessing CDC and IHS data. Because TECs provide tribes with data to support tribal decision-making, delays or limitations in TECs' access to data may limit the ability of tribes to make informed decisions about how to address their communities' health needs and reduce the health disparities faced by their communities.

Recommendations for Executive Action

We are making a total of five recommendations, including one to HHS, two to CDC, and two to IHS. Specifically,

The Secretary of HHS should develop a policy clarifying the HHS data (including monitoring systems, delivery systems, and other protected health information) that are to be made available to TECs as required by federal law. (Recommendation 1)

The Director of CDC should develop written guidance for TECs on how to request data. Such guidance should include information on data potentially available to TECs, how to request data, agency contacts, criteria the agency will use to review such requests, and time frames for receiving an agency response to data requests. (Recommendation 2)

The Director of CDC should develop and document agency procedures on reviewing TEC requests for and making data available to TECs. These procedures should include a description of data potentially available to TECs, agency contacts, criteria for reviewing TEC data requests, and time frames for responding to TEC requests. (Recommendation 3)

The Director of IHS should develop written guidance for TECs on how to request data. Such guidance should include information on the data available to TECs, how to request data, agency contacts, criteria the agency will use to review such requests, and time frames for receiving an agency response to data requests. (Recommendation 4)

The Director of IHS should develop and document agency procedures on reviewing TEC requests for and making data available to TECs. These procedures should include a description of the data available to TECs, agency contacts, criteria for reviewing TEC data requests, and time frames for responding to TEC requests. (Recommendation 5)

Agency Comments and Our Evaluation

We provided a draft of this report to HHS for review and comment. In its comments, which are reprinted in appendix I, HHS concurred with our recommendations. HHS also provided technical comments, which we incorporated as appropriate.

HHS noted that it will take steps to develop a policy clarifying the HHS data that are to be made available to TECs.

Regarding our recommendations to develop guidance and agency procedures related to TECs' access to and requests for CDC data, HHS noted that CDC is committed to ensuring that TECs have access to the epidemiological data they need to fulfill their public health mission. HHS also noted that CDC will strive to balance the goals of the recommendations, its responsibilities as a data steward, and obligations to protect personally identifiable and other legally protected data. Further, HHS noted that the large volume of data CDC receives limits CDC's ability to create a menu of all data sources. Given this, HHS requested a minor revision to the wording of these recommendations, which we made. To implement these recommendations, CDC plans to identify the data that TECs want access to, and it will develop a process for requesting data and agency procedures for responding to such requests.

Regarding our recommendations related to access to and requests for IHS data, HHS noted that IHS has a long-standing commitment and approach to sharing epidemiological data with TECs that is informed by tribal input. HHS noted that formalizing IHS procedures and guidance will serve to enhance transparency and may streamline data access for TECs. HHS reported that IHS has already assessed existing TEC data sharing agreements and reviewed its protocols for responding to TEC requests. IHS plans to develop the recommended guidance and procedures in order to promote appropriate, timely, and efficient data sharing with TECs.

We are sending copies of this report to the appropriate congressional committees, the Secretary of Health and Human Services, and other interested parties. In addition, the report will be available at no charge on the GAO website at http://www.gao.gov.

If you or your staff have any questions about this report, please contact me at (202) 512-7114 or rosenbergm@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made key contributions to this report are listed in appendix II.

Michelle B. Rosenberg
Director, Health Care

List of Addressees

The Honorable Patrick Leahy
Chairman
The Honorable Richard Shelby
Vice Chairman
Committee on Appropriations
United States Senate

The Honorable Ron Wyden
Chairman
The Honorable Mike Crapo
Ranking Member
Committee on Finance
United States Senate

The Honorable Patty Murray
Chair
The Honorable Richard Burr
Ranking Member
Committee on Health, Education, Labor, and Pensions
United States Senate

The Honorable Gary C. Peters
Chairman
The Honorable Rob Portman
Ranking Member
Committee on Homeland Security and Governmental Affairs
United States Senate

The Honorable Rosa L. DeLauro
Chair
The Honorable Kay Granger
Ranking Member
Committee on Appropriations
House of Representatives

The Honorable Frank Pallone, Jr.
Chairman
The Honorable Cathy McMorris Rodgers
Republican Leader
Committee on Energy and Commerce
House of Representatives

The Honorable Bennie G. Thompson
Chairman
The Honorable John Katko
Ranking Member
Committee on Homeland Security
House of Representatives

The Honorable Carolyn B. Maloney
Chairwoman
The Honorable James Comer
Ranking Member
Committee on Oversight and Reform
House of Representatives

The Honorable Richard E. Neal
Chairman
The Honorable Kevin Brady
Republican Leader
Committee on Ways and Means
House of Representatives

The Honorable Tom O'Halleran
House of Representatives

Appendix I: Comments from the Department of Health and Human Services

DEPARTMENT OF HEALTH & HUMAN SERVICES

OFFICE OF THE SECRETARY

Assistant Secretary for Legislation
Washington, DC 20201

February 15, 2022

Michelle B. Rosenberg
Director, Health Care
U.S. Government Accountability Office
441 G Street NW
Washington, DC 20548

Dear Ms. Rosenberg:

Attached are comments on the U.S. Government Accountability Office's (GAO) report entitled, **"*TRIBAL EPIDEMIOLOGY CENTERS: HHS Actions Needed To Enhance Data Access*"** (GAO-22-104698).

The Department appreciates the opportunity to review this report prior to publication.

Sincerely,

Melanie Anne Egorin

Melanie Anne Egorin, PhD
Assistant Secretary for Legislation

Attachment

GENERAL COMMENTS FROM THE DEPARTMENT OF HEALTH & HUMAN SERVICES ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S DRAFT REPORT ENTITLED – TRIBAL EPIDEMIOLOGY CENTERS: HHS ACTIONS NEEDED TO ENHANCE DATA ACCESS (GAO-22-104698)

The U.S. Department of Health & Human Services (HHS) appreciates the opportunity from the Government Accountability Office (GAO) to review and comment on this draft report.

Recommendation 1
The Secretary of HHS should develop a policy clarifying the HHS data (including monitoring systems, delivery systems and other protected health information) that are to be made available to TECs as required by federal law. **(Recommendation 1)**

HHS Response
HHS concurs with GAO's recommendation.
The Office of Intergovernmental & External Affairs (IEA) will coordinate with all relevant parties to provide recommendations on a policy that can be implemented by the Department.

Recommendation 2
The Director of CDC should develop written guidance for TECs on how to request data. Such guidance should include information on the data available to TECs, how to request data, agency contacts, criteria the agency will use to review such requests, and time frames for receiving an agency response to data requests. **(Recommendation 2)**

HHS Response
CDC concurs with GAO's recommendation.
CDC is committed to ensuring that TECs have access to the epidemiological data they need to ensure they can fulfill their critical public health mission and concurs with the core of this recommendation—to make data sharing easier, less burdensome, and clearer for TECs. However, CDC wants to clarify that its responsibilities as a data steward, obligations to protect personally identifiable or other legally protected data, relationships with the jurisdictions and partners from whom it receives data, and the sheer volume of data CDC receives limits CDC's ability to simply create a menu of all data sources that TECs could plausibly have interest in receiving. As such, CDC seeks to balance the goals of this recommendation with the realities of the current data ecosystem.

To address this nuance and effectuate the core goals of the recommendation, namely a clear policy and process that enables better communication between TECs and CDC and appropriate access to data, CDC requests the minor revisions to the recommendation below.

For recommendation 2, CDC requests the following edit:
The Director of CDC should develop written guidance for TECs on how to request data. Such guidance should include information on ~~the~~ data potentially available to TECs, how to request data, agency contacts, criteria the agency will use to review such requests, and time frames for receiving an agency response to data requests.

GENERAL COMMENTS FROM THE DEPARTMENT OF HEALTH & HUMAN SERVICES ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S DRAFT REPORT ENTITLED – TRIBAL EPIDEMIOLOGY CENTERS: HHS ACTIONS NEEDED TO ENHANCE DATA ACCESS (GAO-22-104698)

To implement this recommendation, CDC will work to identify what data sources TECs want access to that are not already publicly available, establish a process for the requesting of that data, and develop a CDC procedure for handling such requests consistent with GAO's recommendation.

Recommendation 3
The Director of CDC should develop and document agency procedures on reviewing TEC requests for and making data available to TECs. These procedures should include a description of the data available to TECs, agency contacts, criteria for reviewing TEC data requests, and time frames for responding to TEC requests. **(Recommendation 3)**

HHS Response
CDC concurs with GAO's recommendation.
CDC is committed to ensuring that TECs have access to the epidemiological data they need to ensure they can fulfill their critical public health mission and concurs with the core of this recommendation—to make data sharing easier, less burdensome, and clearer for TECs. However, CDC wants to clarify that its responsibilities as a data steward, obligations to protect personally identifiable or other legally protected data, relationships with the jurisdictions and partners from whom it receives data, and the sheer volume of data CDC receives limits CDC's ability to simply create a menu of all data sources that TECs could plausibly have interest in receiving. As such, CDC seeks to balance the goals of this recommendation with the realities of the current data ecosystem.

To address this nuance and effectuate the core goals of the recommendation, namely a clear policy and process that enables better communication between TECs and CDC and appropriate access to data, CDC requests the minor revisions to the recommendation below.

For recommendation 3 CDC requests the following edit:
The Director of CDC should develop and document agency procedures on reviewing TEC requests for and making data available to TECs. These procedures should include a description of ~~the~~ data potentially available to TECs, agency contacts, criteria for reviewing TEC data requests, and time frames for responding to TEC requests.

To implement this recommendation, CDC will work to identify what data sources TECs want access to that are not already publicly available, establish a process for the requesting of that data, and develop a CDC procedure for handling such requests consistent with GAO's recommendation.

Recommendation 4
The Director of IHS should develop written guidance for TECs on how to request data. Such guidance should include information on the data available to TECs, how to request data, agency contacts, criteria the agency will use to review such requests, and time frames for receiving an agency response to data requests. **(Recommendation 4)**

GENERAL COMMENTS FROM THE DEPARTMENT OF HEALTH & HUMAN SERVICES ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S DRAFT REPORT ENTITLED – TRIBAL EPIDEMIOLOGY CENTERS: HHS ACTIONS NEEDED TO ENHANCE DATA ACCESS (GAO-22-104698)

Recommendation 5

The Director of IHS should develop and document agency procedures on reviewing TEC requests for and making data available to TECs. These procedures should include a description of the data available to TECs, agency contacts, criteria for reviewing TEC data requests, and time frames for responding to TEC requests. **(Recommendation 5)**

HHS Response

HHS concurs with GAO's recommendations 4 and 5.

For many years, TECs have had mechanisms to access essentially all epidemiologic data housed by IHS within its central national data warehouse, with the exception of substance use disorder data as prohibited by law. IHS has a long-established commitment and mechanism for broad data sharing to TECs established via the Epidemiology Data Mart (EDM).[1] Since 2018, IHS has established data sharing efforts with TECs to expand beyond largely de-identified EDM data sharing to include personal identifiable information (PII) data primarily to support data linkage efforts. There are now 3 such PII expansion projects with 2 TECs established since 2018. These established projects demonstrate IHS' commitment to expand data sharing to TECs where permissible and where requested to facilitate their work as public health authorities.

In addition, IHS respects Tribal sovereignty and implements its policy that consultation with Indian Tribes will occur to the extent practicable and permitted by law before any action is taken that will significantly affect Indian Tribes. As a result, IHS considers Tribal input addressing how IHS stewards and shares the health data of Tribal members before implementing agency actions. For example, not all Tribes support broad data sharing to TECs. IHS' approach to data sharing with TECs is therefore informed by Tribal input garnered through formal consultation processes in balance with the various statutes and regulations that also inform such data sharing.

Formalizing existing procedures and guidance will serve to enhance transparency and may streamline data access for TEC partners. IHS has already conducted an internal assessment of existing TEC data sharing agreements along with previous and current actions taken to develop and support them. In addition, the IHS has inventoried and reviewed internal adjudication protocols for TEC data requests. These preliminary steps will inform the development of relevant procedures and guidance as recommended by GAO. The IHS will continue efforts to develop the recommended procedures and guidance. Once completed, the IHS will conduct outreach to TECs to solicit TEC partner review and feedback on the proposed guidance. The IHS will monitor subsequent implementation and adapt procedures and guidance as necessary to promote appropriate, timely, and efficient data sharing with TECs.

[1] See the IHS Tribal Leader Letter, May 4, 2012, available at https://www.ihs.gov/sites/newsroom/themes/responsive2017/display_objects/2012_Letters/05-04-2012%20DTLL%20Data%20Sharing%20Contract.pdf.

Appendix II: GAO Contact and Staff Acknowledgments

GAO Contact

Michelle B. Rosenberg, (202) 512-7114 or RosenbergM@gao.gov

Staff Acknowledgments

In addition to the contact named above, Kristi Peterson (Assistant Director), Kristin Ekelund (Analyst-in-Charge), and Patricia Roy made key contributions to this report. Also contributing were Todd Anderson, Sonia Chakrabarty, Vikki Porter, Lisa Rogers, and Caitlin Scoville.

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National Indian Health Board

February 24, 2023

Rochelle Walensky, MD, MPH
Director, Centers for Disease Control and Prevention
1600 Clifton Road NE
Atlanta, GA 30329–4027

Re: CDC's Moving Forward Initiative

Dear Director Walensky:

On behalf of the National Indian Health Board (NIHB), I write to you regarding the recent Tribal consultation on CDC's Moving Forward initiative. We applaud CDC's efforts to change not only how CDC is organized and how it operates, but also its culture—to orient the agency toward timely action and a focus on health equity. While undertaking this change, this is a prime opportunity to position CDC to better serve Tribal nations, fulfill the federal trust responsibility, and lay critical groundwork for meaningfully advancing health equity in Indian Country.

This reorganization could not come at a more urgent time. The COVID-19 pandemic made it impossible to ignore the stark disparities in deaths and other health outcomes experienced by American Indians and Alaska Natives (AI/ANs). On August 31, 2022, the Centers for Disease Control and Prevention (CDC) released the Provisional Life Expectancy Estimates for 2021, which reported a severe drop in life expectancy for AI/ANs–decreasing by 6.6 years from 2019 to 2021. Not only do AI/ANs, on average, die younger than all other Americans, but this disparity is worsening at an alarming rate. Our peoples' life expectancy today is the same as it was for the average American in 1944. Such a crisis of inequity demands a swift and profound response.

To be effective, this response must honor and recognize Tribal sovereignty, the federal trust responsibility, and how colonization and U.S. government policies drive the severe health inequities we face. As CDC raises health equity to an agency-wide priority, moving forward will require both a nuanced understanding of the unique context of Tribal health equity and a commitment to action.

Root causes of AI/AN health inequities. CDC has the opportunity to lead by example and use the Moving Forward initiative to address the systemic issues at the root of AI/AN health. Along with the commonly discussed "social determinants of health" like housing, economic stability, healthcare, transportation, food, etc., the legacies of colonization are powerful drivers of many of the health inequities Tribal communities are experiencing.

The systemic issues that give rise to AI/AN health inequities are rooted in the long history of harmful federal Indian policies: genocide; uprooting AI/ANs from homelands and Tribal community structures; bans on cultural practices and language; forced relocation to reservations; abusive boarding schools;

and others. Lingering legacies of colonization have become institutionalized in government policies, systems, and structures and continue to cause harm.

The Moving Forward initiative and re-organization of the CDC is an unprecedented opportunity for making the kinds of systemic and cultural changes needed to effectively address these key drivers of health inequities and set the stage for a more equitable future.

To address these key drivers and advance health equity, CDC should prioritize these five areas during the reorganization:

1. Tribal Sovereignty & the Nation-to-Nation Relationship
2. Federal Trust Responsibility
3. Disrupting Structures of Inequity and Shifting the Balance of Power
4. Visibility of American Indians & Alaska Natives
5. Honoring Indigenous Knowledge & Cultural Lifeways

I. Tribal Sovereignty & the Nation-to-Nation Relationship

Tribal sovereignty. Respecting and upholding Tribal sovereignty must come first and foremost in any public health work in Indian Country. As sovereign governments, Tribal nations have inherent authority and responsibility to meet their citizens' healthcare and public health needs.

Respecting Tribal sovereignty, in large part, means honoring self-determination – supporting Tribes to make decisions for themselves on the best way to set priorities and design programs tailored to the needs of Tribal communities to advance health equity. In addition, Tribal sovereignty opens options and potential approaches to health equity that may differ from other communities or populations. For example, Tribal sovereignty allows Tribes to use Tribal law as a powerful tool for protecting public health and advancing health equity in Tribal communities. Ensuring sufficient flexibility and support for Tribes to design their public health priorities and interventions is both more effective in advancing health equity and more respectful of Tribal sovereignty.

Nation-to-nation relationship. Like all sovereign nations, Tribes maintain nation-to-nation relationships with the U.S. government. Therefore, any federal public health programs and health equity initiatives must flow through the appropriate diplomatic channels that respect the authority of Tribal governments. Because of the central importance of Tribal sovereignty, implementing federal public health initiatives in Tribal communities necessitates special attention to the significant nuances and complexities that arise at this intersection of jurisdictions. Too often, we see CDC focused on funding and partnership structures around states and local governments, but not Tribes. CDC must entirely rethink these structures to appropriately build in Tribal nations as it works to improve public health of the whole country. As we know all too well from the COVID-19 pandemic, public health challenges do not end at a particular geographic or jurisdictional border.

To give a specific example of why recognizing Tribal sovereignty is important, we often see Notices of Funding Opportunities (NOFOs) that do not account for the unique position of Tribes as sovereign nations. These may include requirements such as a letter from a state chronic disease director or other

state officer, which ignores the nation-to-nation relationship and is never appropriate to ask of a sovereign Tribe. Listing Tribes as simply eligible for a NOFO does not go far enough.

To address this issue, we ask that the reorganization make sure that all NOFOs from the CDC are reviewed before release by an expert in best practices for respecting Tribal sovereignty. In addition, CDC should provide training on Tribal sovereignty, the nation-to-nation relationship, and the federal trust responsibility to ensure that anyone involved in implementing CDC programs properly understands these core concepts, in addition to CDC's specific role in upholding them. Tribal sovereignty must be recognized as a matter of course in the agency's daily operations.

II. Federal Trust Responsibility

The federal trust responsibility is integral to the unique legal and political relationship the U.S. maintains with Tribal governments. This relationship has been established through and confirmed by the U.S. Constitution, treaties, federal statutes, executive orders, and judicial decisions. In exchange for Tribal lands, the United States signed treaties with Tribal nations promising certain rights and services, including the protection of health and well-being. These treaties are the foundation of the federal government's trust responsibility to protect the interests of Indian Tribes and communities. Since ensuring good health and well-being for AI/ANs is part of the federal trust responsibility, anything that constitutes a barrier to fulfilling the trust responsibility is also a barrier to achieving health equity. Conversely, dedication to fulfilling the trust responsibility advances health equity.

CDC's Moving Forward initiative is a prime opportunity to reexamine the critical role CDC plays in fulfilling the federal trust responsibility. A piecemeal, grant-dependent approach to public health is inappropriate, as we have clearly seen how ineffective it is at supporting public health in Indian Country through the decrease of life expectancy over time. Instead, a cross-agency 10 percent Tribal set-aside would be in line with fulfilling the federal trust responsibility and addressing the long history of neglect that has led to the current state of health inequities. Funding should not be coming through competitive grants to Tribal nations, which only serve to force underserved Tribal nations to compete with each other. Grant administration is also a resource intensive burden that is not feasible for many Tribal nations. Instead, funding to Tribes should be broad-based and formula driven.

III. Disrupting Structures of Inequity and Shifting the Balance of Power

The health inequities experienced by AI/ANs are rooted in the history and ongoing legacy of colonization – on the structures and policies introduced and maintained by the U.S. government. One way colonization led to drastic health inequities was by stripping Tribal nations of their political power and self-determination. Because Tribes were systematically excluded from decision-making and subjected to paternalistic federal policies for several hundred years, government policies, programs, and systems have not served the needs of AI/AN people. To achieve health equity, these structures of inequity must be dismantled, and power must be returned to Tribal nations – including within the realm of public health.

Tribal consultation. One of the essential forms of Tribal inclusion in governance is Tribal consultation. Because Tribes are sovereign nations, any time a federal government agency contemplates a policy change that will impact a Tribe or its citizens, that agency has an obligation and responsibility to pursue timely, meaningful, robust Tribal consultation. Meaningful consultation requires two-way communication and collaboration, not just informing Tribes about decisions that have already been made. Consultation should be with government officials with decision-making authority, as well as with agency subject-matter experts and designated Tribal liaisons. Follow-up from the consultation and application of the Tribal perspectives shared are also necessary for consultation to be meaningful.

Tribal empowerment in governance. Tribes also need to be included in government decision-making in other ways, like by expanding pathways for AI/ANs to become CDC employees and public health professionals, being responsive to the CDC Tribal Advisory Committee, and including Tribes on agency task forces and committees. For example, the proposed Executive Board to assess and recommend agency priorities each year should include permanent representation of an expert on Tribal priorities and sovereignty. During this reorganization and on an ongoing basis, CDC needs to prioritize integrating support for Tribal nations across all parts of the agency.

IV. Visibility of American Indians & Alaska Natives

For decades, it was the policy of the United States to terminate and assimilate AI/AN people to eradicate AI/AN peoples and cultures from existence. While Tribes have been remarkably resilient in preserving their communities and cultures despite these persistent challenges, AI/ANs are commonly invisible in the larger American cultural context. If AI/ANs continue to be unseen, the inequities will continue. Federal agencies like CDC must take active measures to ensure AI/AN people and Tribes are visible in two critical arenas: policy creation and data.

Inclusion & visibility in policy creation. Tribes must be included in every step of policy creation. Often the impact of policies on Tribes is treated as an afterthought, instead of ensuring Tribes are at the table throughout the policy development process. As a result, the policies themselves often leave out Tribes entirely and the cycle of invisibility continues. This is an especially significant risk for large scale initiatives like Moving Forward – Tribes need to be actively included throughout the process.

Visibility in data. High-quality, meaningful AI/AN health data is essential for identifying disparities, setting priorities, designing strategies, and highlighting successes related to health equity. However, AI/AN data is missing so often that AI/ANs have come to be known as the "Asterisk Nation" – a recognition of how often AI/AN data is withheld and replaced by an asterisk to denote that the sample size was too small or the data was statistically unreliable. Racial misclassification, missing data, and other quality issues continue to impede the representation of AI/ANs in many data sets. With AI/AN people and communities so often missing from the data, this becomes one more form of erasure of AI/ANs – our experiences are not represented, our needs are not heard, and our very existence becomes invisible. Improving data practices – in a way that supports Tribal sovereignty and is meaningful for

AI/AN – is crucially important as a step to undo the centuries of AI/AN erasure contributing to the ongoing health inequities in Tribal communities.

V. Honoring Indigenous Knowledge & Cultural Lifeways

Colonization and the values introduced through colonization have led to devastating health inequities; leaning into traditional values and worldviews opens new pathways forward. We can only achieve health equity for Indian Country when we approach it through a Native lens.

Connection to community and culture is among the most powerful drivers for good health and resilience for AI/AN people. Strengthening connection to community and culture is essential to counter the harmful disconnection that resulted from centuries of historical injustices. For example, AI/ANs currently experience drastic inequities in diabetes rates; this can be traced back to the history of the disruption of traditional food systems through the forced removal of Tribes to reservations and the subsequent forced reliance on commodity foods. Many Tribal communities have prioritized food sovereignty and bringing traditional food systems back to the forefront of daily life, reintroducing balanced nutrition and a stronger connection to community and culture. Tribal communities and public health programs can share many other examples of how this kind of strengthened connection has led to improved health outcomes. CDC programs need to include the flexibility for Tribes to implement culturally appropriate public health initiatives that will support connection to Indigenous identity and community.

Previous government health initiatives have often focused solely on problems and disparities; this can leave the inaccurate, harmful impression that the communities experiencing inequities are somehow inherently deficient. This undercuts these communities' self-determination and sets the stage for government paternalism. Instead, as CDC reorganizes, the agency should strive for an organizational culture that is strengths-based and focuses on cultural humility. A strengths-based perspective recognizes that the answers for achieving health equity for a community lie within that community; the strengths, assets, and resilience of individuals and communities are vital to any effective path to health equity. The federal government is most effective in working towards health equity when it puts its resources behind supporting the leadership of Tribal communities. **Tribes know their people, communities, social and historical context, needs, and strengths best – Tribes are the experts in charting a path to health equity for their people.**

VI. Conclusion

CDC can advance health equity for AI/ANs by ensuring flexibility and Tribal control in public health programs for Indian Country; accepting the federal government's responsibility to ensuring good health and well-being for AI/AN people; conducting meaningful Tribal consultation; implementing equitable funding structures; and recognizing that the answers for health equity lie within our communities. As CDC strengthens the agency's cross-cutting functions through the Moving Forward Initiative, Tribal relations and support should be viewed as a cross-cutting function that is just as important as any other. We look forward to continuing this conversation in the months and years

ahead. Please do not hesitate to contact NIHB if we can be of any further assistance with the Moving Forward Initiative.

Yours in Health,

William Smith, *Valdez Native Tribe*
Chairman
National Indian Health Board

Appendix B: List of Participants— February 9, 2023, Tribal Consultation

First Name	Last Name	Tribal Affiliation / Agency
Cleopatra	Adedeji	CDC
Rasha	Al Rawi	CDC
Jemma	Alarcon	CDC
Noah	Aleshire	CDC
Shoneen	Alexander-Ross	Muscogee (Creek) Nation
Katherine	Allen-Bridson	CDC
Isaac	Ampadu	CDC
Beverly	Anaele	CDC
Tranita	Anderson	CDC
Ty	Anderson	CDC
Alicia	Andrew	Native Village of Karluk / Karluk IRA Tribal Council
Jose	Aponte	CDC
Arielle	Arzu	CDC
Sharon	Attipoe-Dorcoo	CDC
Jed	Augustine	CDC
Margot	Bailowitz	CDC - CSTLTS
Devin	Barich	CDC
Connie	Barker	The Chickasaw Nation
Veronica	Beasley	CDC
Rhonda	Beaver	Muscogee (Creek) Nation
Delores	Becenti	Navajo Nation / Navajo Dept. of Health
James	Beck	CDC
Mitchel	Berger	HHS
Holly	Billie	Navajo/ CDC
Leann	Bing	ATSDR
Carissa	Bishop	Access Care Anywhere
Kelly	Bishop	CDC
April	Blowe	CDC
Randella	Bluehouse	Navajo Nation / CDC Contractor
Kailyn	Bostic	CDC - OTASA
Vickie	Bradley	Eastern Band of Cherokee Indians
Sharunda	Buchanan	CDC
Rebecca	Bunnell	CDC
Tonia	Burk	CDC - ATSDR
Anna Fox	Burnette	CDC - OTASA
Sherry	Burns	Navajo / AMN
Emily	Busta	CDC
Davina	Campbell	Oklahoma Choctaw/ CDC
Hallie	Carde	CDC
Valeria	Carlson	CDC
Justin	Casto	CDC
Annmarie	Chase	CDC

Karla	Checo	CDC
Karen	Cobham-Owens	CDC
Anne-Marie	Coleman	CDC
Elizabeth	Conrey	CDC
Dewayne	Crank	Navajo Nation
Charles	Cuny	Oglala Sioux Tribe / Little Wound School
Scott	Damon	NCEH
Debra	Danforth	Oneida Nation
Laura	Daniel	CDC
Teresa	Daub	CDC
Leslie Ann	Dauphin	CDC
Adina	De Coteau	CDC
Tanni	Deb	CDC
Julie	Deerinwater	Cherokee Nation
Allayna	Dehond	CDC
Devin	Delrow	HHS IEA
Leeann	Denham	ASTR
Miatta	Dennis	CDC
Pasha	Diallo	CDC
Kelly	Dickinson	CDC
Shani	Doss	CDC
Tyler	Dougherty	NIHB
Melanie	Duckworth	CDC
Brianna	Dumas	CDC/DNPAO
Lorna	Elliott-Egan	MDHHS
Jessica	Elm	Oneida Nation / Stockbridge-Munsee Band of the Monhicans
Yvette	Falcon	Koniag / CDC- OTASA
Angela	Falisi	HHS - Office of Budget
Alison	Feise	CDC
Carrie	Field	National Indian Health Board
Sharon	Fields	Cherokee Nation
Rebekah	Frankson	CDC
Herminia	Frias	Pascua Yaqui Tribe
Katie	Fullerton	CDC
Kim	Gadsden-Knowles	CDC
David	Gahn	Cherokee Nation
Sundak	Ganesan	CDC DSLR - Supporting Tribal communities
Anika	Garner	CDC
Colin	Gerber	Council of State and Territorial Epidemiologists
Chebreia	Gibbs	CDC
Candace	Girod	CDC
George	Gover	Northwestern Band of the Shoshone Nation
Melissa	Gower	Cherokee / Chickasaw Nation
Laura	Gravesen	CDC

Donata	Green	CDC
Brenton	Guy	CDC/DOP/Drug-Free Communities Branch
Karen	Hacker	CDC
Miklos	Halmos	CDC
Kat	Hardin	CDC/DOP/DFC
Veda	Harrell	CDC
Zachery	Harris	CDC
Annie	Hatley	CDC
Roberto	Henry	CDC
Jan	Hicks-Thomson	CDC
Cynthia	Hill	CDC
Kimberly	Hoch	CDC
Katherine	Hoffman	CDC
Mary	Holloway	CDC
Meghan	Holst	CDC
Sara	Horak	CDC OTASA
John	Hough	U.S. DHHS CDC National Center for Health Statistics
Robin	Ikeda	CDC
Laurie	Ishak	CDC
Chandra	Jennings	Diversity and Inclusion Recruitment Activity (DIRA)
Billye	Jimerson	Muscogee (Creek) Nation
Kayla	Johnson	CDC
Michelle	Johnson Jones	CDC
Christopher	Jones	CDC
Erica	Jones	CDC
Matt	Josey	CDC-DDID-NCHHSTP-OD
Laurin	Kasehagen	CDC
Jacob	Kerns	CDC
Sophia	Kiselova-Sammons	CDC
Jill	Klosky	CDC
Laura	Kollar	CDC
Jim	Kucik	CDC
Danielle	Lafleur	CDC
Tamara	Lamia	CDC
Karina	Lifschitz	CDC
Geremy	Lloyd	CDC
A.C.	Locklear	Lumbee Tribe / National Indian Health Board
Weston	Lowry	CDC
Marisa	Lubeck	CDC
Jennifer	Lyke	ATSDR
Casey	Lyons	CDC
Goldie	Macdonald	CDC
Taressa	Marchand	Colville Confederated Tribes
Priscilla	Markin	CDC
John	Marr	CDC/ATSDR

Latisha	Marshall	CDC
Ashton	Martin	Sappony / USET SPF
Jay	Matthews	CDC
Anna-Catherine	McCrary	CDC
Leslie	McCrdd	CDC - CSTLTS
Donna	McCree	CDC
Candice	McKee	CDC
Eva	McLanahan	ASPR
Mary	McQuilkin	Employee of tribal health organization (Nurse Practitioner)
Sarah	Meehan	CDC
Lisa	Meissner	HHS/OS/IEA
Will	Micklin	Central Council of Tlingit and Haida Indian Tribes of Alaska
Claudia	Miron	SNS is a federal tribal partner / ASPR/Strategic National Stockpile
Cedar	Mitchell	CDC
Georgia Ann	Moore	CDC
Mitch	Morris	CDC
Jill	Moses	CDC
Ashleigh	Murriel	CDC
Stephanie	Neitzel	CDC
Jennifer	Nelson	CDC
My	Nguyen	CDC
Kelsey	Nies	CDC
Melissa	Nuthals	Oneida Nation
Kevin	O'Callaghan	CDC
Meghan	Oconnell	Cherokee / GPTLHB
Joanne	Odenkirchen	CDC
Ekwutosi	Okoroh	CDC
Stacey	Parker	CDC
Sara	Patterson	CDC
Chandra	Pendergraft	CDC
Bianca	Perri	CDC
Geraldine	Perry	ASRT/CDC
Lori	Phillips	CDC
Lisa	Pivec	Cherokee Nation
Sarah	Pol	CDC
Beth	Pollak	CDC
Alex	Poniatowski	CDC
Dr. Nakki	Price	CDC
Victoria	Ramirez	CDC
Bryce	Redgrave	Northern Cheyenne / HIS
Julianna	Reece	Navajo Nation / CDC Contractor
David	Reede	San Carlos Apache Tribe / Department of Health and Human Services

Jovanni	Reyes	CDC
April	Rodgers	Viejas Band of Kumeyaay Indians / Yaytaanak Wellness Center
Steven	Rodgers	CDC
Ahniwake	Rose	Cherokee Nation / National Indian Health Board
Zoe	Rothberg	CDC
Kameron	Runnels	Santee Sioux Nation
Charity	Sabido-Hodges	Cowlitz Indian Tribe
Melinda	Salmon	CDC
Terisa	Sanchez	Morongo Band of Mission Indians
Delight	Satter	Confederated Tribes of Grand Ronde / CDC
Michelle	Sauve	Mohawk / HHS
Sam	Sears	National Council of Urban Indian Health
Dean	Seneca	Seneca / Seneca Scientific Solutions+
Shari	Shanklin	CDC
Katie	Sives	CDC
Richard	Sneed	Eastern Band of Cherokee Indians
Neeka	Somday	Confederated Tribes of the Colville Reservation
Alisa	Spieckerman	CDC
Yuri	Springer	CDC
Sharon	Stanphill	Cow Creek
Melody	Stevens	CDC
Pollyanna	Stewart	State of Alaska/Department of Health
Jon	Streater	Centers for Disease Control and Prevention
Gregory	Sunshine	CDC
Marissa	Taylor	CDC
Jt	Theofilos	CDC
Sally	Thigpen	CDC
Lauren	Tonti	CDC CSTLTS
Tina	Tourtillott	Menominee / Haskell Indian Nations University
Nate	Tyler	Makah Tribe / Tribal Councilman Makah Tribe
Monique	Vondall-Rieke	Koniag / CDC
Nicole	Wachter	CDC
Rochelle	Walensky	CDC
Henry	Walke	CDC
Bryan	Warner	Cherokee Nation
Victoria	Warren-Mears	NPAIHB
Carolina	Wasinger	Delaware, Cherokee / National Congress of American Indians
Alleen	Weathers	CDC
Angela	Webb	CDC
Jennifer	Webster	Oneida Nation
Seh	Welch	CDC
Isabelle	Welsh	Keweenaw Bay Indian Community / Michigan Dept Health and Human Services

Rachel	West	CDC
Zoe	Whidden	CSTLTS
Jessica	Wiens	CDC
Andrea	Williams	CDC
Stacey	Willocks	CDC
Brandon	Wisneski	Oneida Nation
Madeline	Woodruff	CDC
Sophie	Yarosh	Tribal Health Associate at MDH / CDC
Debbie	Yembra	CDC
Rebecca	Young	CDC
Taylor	Yutan	CDC

In addition to the participants identified above, one person called in and did not identify themselves; for protection of their privacy, we have listed only the area code and not the entire phone number:

1- 949-XXX-XXXX

Appendix C: Current CDC/ATSDR Tribal Consultation Policy (dated 2020)

Category: General Administration
Policy #: CDC-GA-2005-16 (Formerly CDC-115)
Date of Issue: 10/18/2005, Updated 01/08/2013, Updated 11/12/2013, Updated 02/28/2020[1]
Proponent: Center for State, Tribal, Local, and Territorial Support (CSTLTS)
Application: All Locations, Domestic and International
Applicable Staff: CDC Employees

CDC/ATSDR TRIBAL CONSULTATION POLICY

Sections:

1. PURPOSE AND SCOPE

This policy provides direction regarding consultation between the Centers for Disease Control and Prevention (CDC)[2] and Indian Tribes. This policy applies to all CDC employees[3] at all locations, domestic and international, and to all Centers, Institute, and Offices (CIOs), Staff Offices, and Business Services Offices, which are hereafter called "CDC Components"[4] unless otherwise noted.

CDC and Indian Tribes share the goal of establishing clear policies that further the government-to-government relationship between the U.S. Federal Government and Indian Tribes. True and effective consultation shall result in information exchange, mutual understanding, and informed decision-making on behalf of the Tribal governments and the Federal Government. The importance of consultation with Indian Tribes was affirmed through Presidential Memoranda in 1994, 2004 and 2009, and Executive Order (EO) 13175 in 2000.

The goals of this policy include, but are not limited to, assisting in eliminating the health disparities faced by Indian Tribes; ensuring that access to critical health and human services and public health services is maximized to advance or enhance the social, physical, and economic status of Indians; and promoting health equity for all Indian people and communities. To achieve these shared goals, it is essential that Indian Tribal governments and CDC engage in open, continuous, and meaningful consultation.

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[1] This update is a non-substantive update limited to copy editing, revising the policy's format (such as moving or re-phrasing content to fit the template), changing nomenclature, and updating website addresses.
[2] References to CDC also include the Agency for Toxic Substances and Disease Registry (ATSDR).
[3] For the purposes of this policy, the term "employees" consists of members of the civil service, Commissioned Corps officers, and locally employed staff. For more information on these categories, refer to "Employee Categories (Updated July 2018)," available at: http://intranet.cdc.gov/ocio/docs/systems-tools/EmployeeCategoryHelp_July_2018.pdf.
[4] More information on CDC organizational nomenclature is available at: https://sbi.cdc.gov/DOA/pdf/orgnom.pdf.

The U.S. Department of Health and Human Services (HHS) Tribal Consultation Policy requires that all operating divisions of the department develop and implement Tribal consultation policies that are in compliance with the HHS Tribal Consultation Policy, effective December 14, 2010.

2. BACKGROUND

Founded in 1946, CDC is the leading public health agency in the United States. The CDC collaborates with stakeholders and partners to (1) develop expertise, information, and tools to promote healthy people and (2) communicate on topics such as health promotion, prevention of disease, injury and disability, and preparedness for new and emerging health threats. CDC seeks to accomplish its mission by working with partners to monitor health; detect and investigate health problems; conduct research to enhance prevention; develop and advocate sound public health policies; implement prevention strategies; promote healthy behaviors; foster safe and healthful environments; and provide leadership and training. These functions are the backbone of CDC′s mission. Each CDC Center, Institute, and Office (CIO) undertakes these activities to conduct CDC's specific programs. The steps that are needed to accomplish this mission are based on scientific excellence and require well-trained public health practitioners and leaders dedicated to high standards of quality and ethical practice.

CDC shares its focus on health protection with its sister agency ATSDR. First organized in 1985, ATSDR was created by the Comprehensive Environmental Response, Compensation, and Liability Act (CERCLA) of 1980, more commonly known as the Superfund law. In 1986, Congress passed the Superfund Amendments and Reauthorization Act (SARA). The agency's mission is to serve the public through responsive public health actions to promote healthy and safe environments and prevent harmful exposures.

3. POLICY

A. Core Principles

Tribal consultation between CDC and Indian Tribes is built on two core principles, which are summarized below. Each of these principles supports the unique circumstances for who is engaged, why the engagement is significant, and guidance for how to engage. This relationship is derived from the unique political and legal relationship that Indian Tribes have with the Federal Government and is not based on race or ethnicity.

Tribal Sovereignty

Since the formation of the Union, the United States has recognized Indian Tribes as sovereign nations. As sovereign nations, Indian Tribes exercise inherent sovereign powers over their members, territory, and lands. CDC recognizes that each Indian Tribe sets its own priorities and goals, including those that establish a safe and healthy environment for its members and territory.

Government-to-Government Relationship

A unique government-to-government relationship exists between Indian Tribes and the Federal Government. This relationship is grounded in the U.S. Constitution, numerous treaties, statutes, Supreme Court decisions, and Executive Orders that establish and define a Federal trust relationship with Indian Tribes. This relationship is derived from the political and legal relationship that Indian Tribes have with the Federal Government and is not based upon race.

CDC is committed to continuing to work with Federally recognized Tribal governments on a government-to-government basis and strongly supports and respects Tribal sovereignty and self-determination in the United States.

This special relationship between the Federal Government and Indian Tribes is affirmed in statutes and various Presidential Executive Orders including, but not limited to the following:

- Older Americans Act, P.L. 89-73, as amended
- Indian Self-Determination and Education Assistance Act, P.L. 93-638, as amended
- Native American Programs Act, P.L. 93-644, as amended
- Indian Health Care Improvement Act, P.L. 94-437, as amended
- Personal Responsibility and Work Opportunity Reconciliation Act of 1996, P.L.104-193
- Presidential Executive Memorandum to the Heads of Executive Departments dated April 29, 1994
- Presidential Executive Order 13175, Consultation and Coordination with Indian Tribal Governments, November 6, 2000
- Presidential Memorandum, Government-to-Government Relationship with Tribal Governments, September 23, 2004
- Presidential Memorandum, Tribal Consultation, November 5, 2009
- American Recovery and Reinvestment Act of 2009, P.L. 111-5, 123 Stat. 115 (Feb. 17, 2009)
- Children's Health Insurance Program Reauthorization Act of 2009, P.L. 111-3, 123 Stat. 8 (Feb. 4, 2009)
- Patient Protection and Affordable Care Act of 2010, P.L. 111-148, 124 Stat. 119 (Mar. 23, 2010)

As a Federal Government entity, CDC will comply, to the extent practicable and permitted by law, with all provisions in the HHS Tribal Consultation Policy to ensure meaningful consultation and timely input from Indian Tribes before actions are taken that will significantly affect Indian Tribes.

B. Philosophy

Indian Tribes have an inalienable and inherent right to self-government. Self-government means government in which decisions are made by the people who are most directly affected by the decisions. As sovereign nations, Indian Tribes exercise inherent sovereign powers over their members, territory, and lands. As a Federal organization, CDC recognizes its special commitment and unique relationship with Indian Tribes and is committed to fulfilling their critical role in promoting the health and safety of Indian Tribes.

C. General Requirements

CDC policy on Tribal consultation will adhere to all provisions in the HHS Tribal Consultation Policy.

CDC will honor the sovereignty of Indian Tribal governments, respect the inherent rights of Indian Tribal self-governance, and continue to work on a government-to-government basis. Government-to-government consultation will be conducted with elected Indian Tribal Leaders or their designated representatives, to the extent practicable and permitted by law, before CDC takes any action that will significantly affect Indian Tribe(s).

CDC will employ a process to ensure meaningful and timely input by CDC and Indian Tribes in the development of policies that have Tribal implications. This Tribal consultation policy does not waive any Tribal governmental rights, including treaty rights, sovereign immunities or jurisdiction; and nothing in this policy waives the U.S. Federal Government's deliberative process privilege. Nothing in this policy may be interpreted as diminishing or eliminating the rights of American Indians or Alaska Natives (AI/ANs) or entities under U.S. Federal law, contained in treaties, agreements and other constructive arrangements.

D. Tribal Consultation Process

An effective consultation between CDC and Indian Tribes requires information exchange, mutual understanding, full and equitable participation, and building and maintaining trust between all parties, which is an indispensable element in establishing an effective consultative relationship. CDC will adhere to the consultation process as outlined in Section 8 of the HHS Tribal Consultation Policy. Upon identification of an action (i.e., policy; funding/budget development; and program services, functions, and activities) significantly affecting Indian Tribes, CDC will initiate consultation regarding the event through communication methods as outlined in the HHS Tribal Consultation Policy.

The CDC Tribal consultative process shall consist of direct communications with Indian Tribes and Indian organizations as applicable, in various ways as provided in Section 9 on Consultation Procedures and Responsibilities of the HHS Tribal Consultation Policy.

E. Consultation Participants and Roles

The government-to-government relationship between the U.S. and Federally recognized Indian Tribes dictates that the principal focus for consultation by CDC is with Indian Tribes, individually or collectively. Consultation parties include:

- Indian Tribes represented by the Tribal President, Tribal Chair, or Tribal Governor, or an elected or appointed Tribal Leader, or their authorized representative(s)
- CDC Director, ATSDR Administrator, CDC Deputy Director for State, Tribal, Local and Territorial Support, or their designee(s)

CDC/ATSDR may gather information from Indian organizations in accordance with the Federal Advisory Committee Act (FACA), 5 U.S.C. App. 2, or with the "Unfunded Mandates Reform Act Exemption" to FACA found in the Unfunded Mandates Reform Act, P.L. 104-4, Section 204. The government does not participate in government-to- government consultation with these entities; rather the government communicates with these organizations in the interests of Indian Tribes and Indian People. CDC may also communicate with Native-serving organizations, including urban and rural Indian organizations, in the interests of Indian communities and Indian people. Government-to-government consultation at CDC will occur as outlined in the HHS Tribal Consultation Policy.

F. Budget Formulation

HHS conducts annual Department-wide Tribal budget and policy consultation sessions to give Indian Tribes the opportunity to present their budget recommendations to the Department to

ensure Tribal priorities are addressed. CDC will comply with Section 11 on Budget Formulation of the HHS Tribal Consultation Policy.

G. Performance Measures and Accountability

CDC will utilize the HHS and CDC Tribal Consultation Policies to address CDC's missions and performance objectives with respect to: assisting in eliminating the health disparities faced by Indian Tribes; ensuring that access to critical health and human services and public health services is maximized to advance or enhance the social, physical, and economic status of Indians; and helping promote health equity for all Indian people and communities. CDC will measure and report results and outcomes of the Tribal consultation performance and will follow the goals and objectives of the seated Secretary and Administration according to Section 12 on Tribal Consultation Performance and Accountability in the HHS Tribal Consultation Policy.

H. Evaluation and Reporting

The consultation process and activities conducted according to the policy should result in meaningful outcomes for CDC and for the affected Indian Tribes. To effectively evaluate the results of consultation activity and CDC's ability to incorporate Indian Tribes' consultation input, CDC will measure the level of satisfaction of Indian Tribes on an annual basis as outlined in Sections 12 (Tribal Consultation Performance and Accountability) and Section 13 (Evaluation, Recording of Meetings, and Reporting) of the HHS Tribal Consultation Policy.

I. Conflict Resolution

The intent of this policy is to promote partnerships with Indian Tribes that enhance CDC's ability to address issues, needs and problem resolution. CDC shall consult with Indian Tribes to establish a clearly defined conflict resolution process under which Indian Tribes bring forward concerns that have a substantial direct effect. However, Indian Tribes and CDC may not always agree, and inherent in the government-to-government relationship is the ability for Indian Tribes to elevate an issue of importance to a higher or separate decision-making authority.

Nothing in this Policy creates a right of action against the CDC or HHS for failure to comply with this Policy.

J. Tribal Waiver

CDC will fully comply with Section 15 of the HHS Tribal Consultation Policy on Tribal waivers and process all requests routinely received for waivers under existing program authorities with the statutorily set timeframes.

K. Effective Date

This policy is effective on the date of the signature by the CDC Director/ATSDR Administrator. This policy updates the Tribal Consultation Policy signed on October 18, 2005.

4. RESPONSIBILITIES

A. Center for State, Tribal, Local, and Territorial Support (CSTLTS)

- Designates, through the Deputy Director for State, Tribal, Local and Territorial Support, the Tribal Support Unit with the responsibility for implementation, coordination, and agency-wide adherence to CDC/ATSDR and HHS Tribal Consultation Policies

B. CDC/ATSDR Tribal Advisory Committee (TAC)

- Serves as an advisory committee to CDC/ATSDR providing input, guidance, and advice on policies, guidelines, and programmatic issues affecting the health of Indian Tribe(s)
- Complies with the requirements of the FACA, 5 U.S.C. App. 2, or with the "Unfunded Mandates Reform Act Exemption" to FACA found in the Unfunded Mandates Reform Act, P.L. 104-4, Section 204

5. REFERENCES

A. HHS. *Department Tribal Consultation Policy*, dated December 14, 2010, https://www.hhs.gov/sites/default/files/iea/tribal/tribalconsultation/hhs-consultation-policy.pdf.

B. Presidential Memorandum for the Heads of Executive Departments and Agencies, "Government-to-Government Relationship with Tribal Governments, Presidential Memorandum," dated September 23, 2004, https://www.govinfo.gov/content/pkg/WCPD-2004-09-27/pdf/WCPD-2004-09-27-Pg2106.pdf.

C. Exec. Order No. 13,175, 65 Fed. Reg. 67,249 (Nov. 9, 2000) – Consultation and Coordination with Indian Tribal Governments

6. ACRONYMS or ABBREVIATIONS

AIAN – American Indian and Alaska Native
ATSDR – Agency for Toxic Substances and Disease Registry
CDC – Centers for Disease Control and Prevention
CERCLA – Comprehensive Environmental Response, Compensation, and Liability Act
CIO – Centers, Institutes and Offices
EO – Executive Order
HHS – U.S. Department of Health and Human Services
SARA – Superfund Amendments and Reauthorization Act
U.S. – United States
USC – United States Code

7. DEFINITIONS

Agency – Any authority of the United States that is an "agency" under 44 USC § 3502(1) other than those considered to be independent regulatory agencies, as defined in 44 USC § 3502(5)

CDC Components – Organizational entities of CDC that are comprised of CIOs, Staff Offices, and Business Services Offices, as outlined in Organizational Nomenclature Used in Delegations of Authority

Communication – The exchange of ideas, messages, or information, by speech, signals, writing, or other means

Consultation – An enhanced form of communication, which emphasizes trust, respect and shared responsibility; is an open and free exchange of information and opinion among parties that leads to mutual understanding and comprehension; and is integral to a deliberative process that results in effective collaboration and informed decision making with the ultimate goal of reaching consensus on issues

Deliberative Process Privilege – Is a privilege exempting the government from disclosure of government agency materials containing opinions, recommendations, and other communications that are part of the decision-making process within the agency

Executive Order – An order issued by the Government's executive on the basis of authority specifically granted to the executive branch (as by the U.S. Constitution or a Congressional Act)

Federally Recognized Tribal governments – Indian Tribes with whom the Federal Government maintains an official government-to-government relationship, usually established by a Federal treaty, statute, executive order, court order, or a Federal Administrative Action
NOTE: The Bureau of Indian Affairs (BIA) maintains and regularly publishes the list of Federally recognized Indian Tribes.

Indian – Indian means a person who is a member of an Indian tribe as defined in 25 U.S.C. § 5129
NOTE: Throughout this policy, Indian is synonymous with American Indian or Alaska Native.

Indian Organizations – 1) Those Federally recognized Tribally constituted entities that have been designated by their governing body to facilitate HHS communications and consultation activities, or 2) any regional or national organizations whose board is comprised of Federally recognized Indian Tribes and elected/appointed Tribal leaders
NOTE: The government does not participate in government-to-government consultation with these entities; rather these organizations represent the interests of Tribes when authorized by those Tribes.

Indian Tribe – An Indian or Alaska Native tribe, band, nation, pueblo, village, or community that the Secretary of the Interior acknowledges to exist as an Indian tribe pursuant to the Federally Recognized Indian Tribe List Act of 1994,
25 U.S.C. § 5129.

Policies with Tribal Implications – Refers to regulations, statutes, legislation, and other policy statements or actions that have substantial direct effects on one or more Indian Tribes, on the relationship between the Federal Government and Indian Tribes, or on the distribution of power and responsibilities between the Federal Government and Indian Tribes

Self-Government – Government in which the people who are most directly affected by the decisions make decisions

Sovereignty – The ultimate source of political power from which all specific political powers are derived

Treaty – A legally binding and written agreement that affirms the government-to-government relationship between two or more nations

Tribal Government – An American Indian or Alaska Native Tribe, Band, Nation, Pueblo, Village or Community that the Secretary of the Interior acknowledges to exist as an Indian Tribe pursuant to the Federally Recognized Indian Tribe List Act of 1994, 25 U.S.C. § 5129

Tribal Officials – Elected or duly appointed officials of Indian Tribes or authorized inter- Tribal organizations

Tribal Organization – The recognized governing body of any Indian Tribe; any legally established organization of Indians which is controlled, sanctioned, or chartered by such governing body or which is democratically elected by the adult members of the Indian community to be served by such organization and which includes the maximum participation of Indians in all phases of its activities, provided that in any case where a contract is let or grant made to an organization to perform services benefiting more than one Indian Tribe, the approval of each such Indian Tribe shall be a prerequisite to the letting or making of such contract or grant

Tribal Self-Governance – The governmental actions of Indian Tribes exercising self-government and self-determination

Appendix D: Dear Tribal Leader Letter for CDC/ATSDR February 9, 2023, Tribal Consultation

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

December 15, 2022

Dear Tribal Leader:

The Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) announce an upcoming consultation that will convene leaders from tribal nations, CDC, and ATSDR:

CDC/ATSDR Tribal Consultation
February 9, 2023, 4:00–5:00 pm (EST)

The consultation will occur virtually via Zoom after the commencement of the 25th Biannual CDC/ATSDR Tribal Advisory Committee Meeting. To register, please use the registration form to generate a unique personalized ID needed to access the meeting. The agenda will be available on the CDC Tribal Health website in early January 2023 at www.cdc.gov/tribal.

This tribal consultation will provide opportunities for leaders from tribal nations, CDC, and ATSDR to have a government-to-government discussion to advance CDC/ATSDR support for and collaboration with AI/AN tribal nations and to improve the health of AI/AN communities. Tribal nations, CDC, and ATSDR share many goals for AI/AN health, including assisting in eliminating the health disparities faced by AI/AN tribal nations; ensuring that access to critical health and human services and public health services is maximized to advance or enhance the social, physical, and economic status of AI/AN people; and promoting health equity for all Indian people and communities. To further advance these goals, CDC/ASTDR is conducting tribal consultation to receive input and guidance on strengthening relationships during the implementation of the CDC Moving Forward Initiative.

Your input is very important to us as we work to improve CDC and ATSDR public health capacity, programs, and services and to strengthen partnerships with tribes and AI/AN community organizations. CDC and ATSDR remain committed to respecting tribal sovereignty while working together to leverage capacity, expertise, and resources to achieve the greatest impact on the health issues affecting AI/AN communities.

Elected tribal officials are encouraged to submit written tribal testimony by **5:00 pm (EST) on February 24, 2023**, by email to CDC's Tribal Support mailbox, tribalsupport@cdc.gov, or by mail at the following address:

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

Office of Tribal Affairs and Strategic Alliances
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We look forward to the consultation and hope you will be able to participate.

Sincerely,

Celeste Philip, MD, MPH
Acting Director, Center for State, Tribal, Local, and Territorial Support
Deputy Director for Non-Infectious Diseases (DDNID)
Centers for Disease Control and Prevention

Appendix E: Federal Register Notice for CDC/ATSDR December 13,2022, Tribal Consultation