

MIKE: Hello, everyone. My name is Mike Cherry with the Division of Scientific Education and Professional Development at the Centers for Disease Control. Welcome to the preventive medicine Grand Rounds for November 2nd, 2022. We have a great lecture and presentation today. First, some housekeeping announcements, if you're a presidential management fellow, please type PMF before your name so you can be readily identified for administrative purposes. Also, if you want to change the - - whether it's a gallery view or speaker view in your Zoom settings, you can use the View function in the upper right-hand screen corner. Today we're going to -- our speaker is Abigail Echo-Hawk. She's an enrolled member of the Pawnee Nation of Oklahoma and the Chief Research Officer for the Seattle Indian Health Board, a federally qualified health center serving American Indians and Alaska natives in King County, Washington. She also serves as the Director of the Urban Indian Health Institute, a Tribal Epidemiology Center, whose mission is to support the health and wellbeing of urban Indian communities through information, scientific inquiry, and technology. Ms. Echo-Hawk directs the staff of public health professionals who worked on multiple ongoing research, evaluation and disease surveillance projects to benefit American Indian and Alaska natives in both urban and rural settings. She has concentrated on policy and institutional change to eliminate disparities for women of color locally and nationally, and she focuses on policy advocacy in areas such as maternal and child health, domestic violence, sexual assault, and health disparities. She's received the University of Washington Bothell's Distinguished Alumni Award in 2013 for her dedication to eliminating health disparities, and was also recognized in the 2015 class of the National Center for American Indian Enterprise Development's Native American 40 under 40. And I'll now turn the floor over to Abigail Echo-Hawk for your presentation.

ABIGAIL: Thank you so much for that kind introduction. It is an honor and a privilege to be here to share this space with all of you. And so I'm Abigail Echo-Hawk. I'm a citizen of the Pawnee Nation of Oklahoma, and the -- I am the director of the Urban Indian Health Institute, which is one of 12 Tribal Epidemiology Centers located here in the United States. Their other 11 are focused on the reservation and villages and the federally recognized tribes and their regions split across the United States and the Indian Health Service regions and I highly suggest you go to the tribal epidemiology website if you would like to learn more about the Tribal Epidemiology Centers and the work that we are blessed to do in our tribal communities. The Urban Indian Health Institute, which I direct, is unique in that we are the only ones with a specified national purview, and that is to work and to ensure that we are representing urban-dwelling American Indians and Alaska Natives in data, evaluation and research. And in addition to that, I am actually the executive vice president of the Seattle Indian Health Board. The Seattle Indian Health Board is one of more than 40 urban, funded by the Indian Health Service, urban Indian clinics that are serving American Indians and Alaska natives across urban settings. From New York to Denver, there are urban Indian programs. We serve native people here in the Seattle region, the Puget Sound region, where we have a thriving urban Indian community. It is a blessing to do that, and we also serve anybody else who walked in our doors the native way. It is very -- it is a blessing and also at times a struggle to see the struggles that my relatives, which is what we call our patients, to see the struggles our relatives are experiencing every single day, as they are battling individual, institutional, and structural racism, that is inhibiting their ability to reach their full potential as native people within their urban settings and also in contributing back to their tribal settings. So today, I get to share with you both the struggles within my community and the great strengths and brilliancy that exists, as we think about what is the information that is gathered on American Indians and Alaska Natives? How is it shared? How

is it analyzed? And how can we do that better? How do we look at it from an equity lens? And we're going to do what I call decolonizing data, and I'll define that a little bit more as we go on. If anybody has any questions, I won't be able to address those during the presentation, but please put them in the question-and-answers box, and we will definitely be going through those at the end of my presentation. Be -- as we -- before we start, I kind of want to set the stage. I'm an American Indian and a Alaska Native, but those aren't actually the titles I tell of myself when I'm in my community. I am an enrolled citizen of the Pawnee Nation of Oklahoma on my father's side. We were originally located in Nebraska and Kansas before our forcible removal from our traditional territories, where we are taken to the Oklahoma Territories where there is now the Pawnee reservation, which is two square miles outside of Tulsa, Oklahoma. On my mother's side, I was born and raised in the heart of Alaska amongst the upper Ana Athabaskan people, where I had the incredible privilege of growing up in a very traditional native community where more than 50% of the food currently comes from the land, where our nearest clinic is two -- depending where I was at, either two to four hours away, where our nearest hospital was more than five hours away, where my parents would take me in an all-day trip just to get a well-child checkup, an experience that many native people have in accessing healthcare here in the United States, where many of our reservations and villages are located far away from the facilities that we desperately need to have access to, and the specialty care that many of our relatives need. However, now when I was 18 years old, I was blessed to follow one of my sisters and move to the Seattle region, where I now live as an invited guest on Suquamish, Duwamish, and the Coast Salish tribal communities here in Washington State. And I say invited guests, because many of you, if not all of you, are probably not invited guests on the land that you are on, and it has gotten very popular to do a land acknowledgement. The problem I have with those land acknowledgments is that I was raised in that tradition of acknowledging the land that I'm on, and my responsibility and accountability to the people of that land. So if you were doing land acknowledgments, what I would ask of you instead, instead of doing and saying something token and acknowledge that we used to be there, instead acknowledge that we are still here, and that you as agencies, as organizations, as universities, as individuals, have a responsibility and accountability to undoing the ongoing settler colonialism that exists in this country, that is perpetuating not only health disparities, but socioeconomic disparities. Move beyond the token land acknowledgement, and into what indigenous people have actually always done in acknowledging our accountability and responsibility to the land. So I have been blessed to be put in this position as the executive vice president of the Seattle Indian Health Board, and the director of the Urban Indian Health Institute, but the reason that I'm here is because I am a mother, I am a sister, I am a granddaughter. I hold accountability and responsibility to those next generations, to be a good ancestor to them, and to also look towards the healing of my community, because as an indigenous person, I know that when I heal now, I am doing that for the future generations, but in our cultural and spiritual beliefs, I am actually healing for the generations who came before me. What does that healing look like and what does it mean, when we talk about data, my favorite subject? I want to set the stage before we begin, because I want to talk to you about the difference between equality and equity. I'm going to be saying equity a lot, and I want you all to have an understanding of what I mean when I say that. This cute little cartoon is very often used, and I know I and I've seen all of the incredible, wonderful critiques of it. I've also seen the folks who really believe in this and so, you know, a visual art is one way of disseminating information and engaging people in the message we're trying to share. So when we think about equality, we will often give everybody the exact same thing. That's equality. Everybody gets the exact same thing. In this country in the United States, one that has continuously oppressed and suppressed the vitality and the

brilliance of communities of color and other communities, we know that there are some communities as a result of that continual oppression, if we think about health, that are experiencing health disparities. So if we gave every single community in the United States the exact same resources, those that have been continually affected by this oppression, are not going to be able to be -- get the resources that they need to overcome these continual structural barriers that have been put in their way. So this first little picture under equality shows if you give everybody the same thing, it doesn't allow everybody in this picture to see over the fence to look at the game. So when we talk about equity, it's about acknowledging the fact that there are, in this, you know, this metaphor, continuous health disparities that many communities have been affected by, and that some communities need more as a result of this continual oppression that their community is experiencing, the structural barriers in accessing healthcare, discrimination within healthcare, all of the things that are inhibiting their health, is that we need to give them more in order to overcome those barriers, and this is really how Western based equity has been set up. It has -- you know, we have this movement towards equity, which really started in the 1960s with the civil rights movement. We saw our incredible black brothers and sisters pushing for and demanding justice. We saw that spread out across other communities, and in the 1970s, we saw the rise of the American Indian movement, and native communities, again, also pushing for the rights that we have as tribal people, as sovereign nations, and we saw this movement towards equity. We've been in this for more than 30-plus years. What's working. In actuality, when we look at the equity movement and the push towards undoing health disparities within tribal communities, we have seen little to absolutely no change, and in fact, we have actually seen health disparities widen. We have seen them widen in infant mortality, in maternal mortality, in cardiovascular disease, in suicide, in suicidality, and cancer. I could go on and on and on. Why aren't our efforts towards equity working? Today, I want to offer you my thoughts as an individual who has spent her life dedicated to addressing the health within my community, to how to reclaim our cultural and traditional ways, to express the vitality and brilliance that exists within our communities, and I'm going to challenge this idea of equity, Western-based equity, where we just give everybody a little bit more so they can see over the fence. When I looked at this some years ago, I thought, "I'm really struggling with some of this, because why are we behind the fence? Why are we always pictured as smaller, as less than? Why are we never included in the grandstands with everybody else?" And then I realized there was something that was bothering me even more. Why are we looking at the same game? Why are we looking at the same health? The health of a Pawnee Athabaskan woman like myself, is not the same health or what is needed for an Oglala woman from South Dakota, from a Lenape woman in New York. The health of our communities is grounded in our cultures, traditions, our ways of knowledge and knowing, and the way that we reach that is going to have to be different for each one of those, let alone our health should not be based on the standards of what white people have reached in this country. And in fact, when I look at those standards, and they say and they compare American Indians and Alaska Natives in data, as compared to non-Hispanic whites, I often think, you know, "Oh, we want to get to 80% vaccination levels." It was like 80%. That's like the bare minimum. My expectation for my people is 100%. Why are we set within the same standard of health equity as every other population group? And how is that standard? Part of what institutional and structural racism looks like, definitions of equity for us, not with us, in which we are measured by and then blamed for not reaching the standards that were set for us. And in fact, why are we giving everybody the same box? What worked in the Hispanic Latinx community is not going to be the same of what works in the native community. What worked in inner-city Chicago with the black community is not going to work in Seattle, Washington with the native community. And we are often

handed evidence-based practices that have none of our evidence, none of our evidence, but it is yet what we are given and what we are expected to adapt to make work in our communities. Why do we always have to make something not for us work for us? That is what structural racism could look like, and in fact, in my perspective, does look like. So if we are actually going to reach equity, if we are actually going to address the ongoing discrimination, institutional and structural racism, the ongoing settler colonialism, oppression, and suppression of people of color, and specifically -- and what I'm going to talk to you about for American Indians [inaudible] presentation. I told [inaudible] I'm [inaudible] and putting it on a slide, so as you all are sitting there, and you will be able to walk away and say, "Great presentation." Whereas, I'm going to turn off my computer and I am going to get to work to ensure that the elders program that is located about 100 feet from me get food for the next days. I'm going to have to make sure that our relatives who are coming into the clinic that I'm currently sitting in, are going to get the services they need, and services that are free of discrimination, where they feel comfortable, loved and cared for. In order to reach equity, we have to walk through truth because for American Indians, Alaska Natives, the care that we provide at the Seattle Indian Health Board and is being provided by Indian healthcare providers across the United States, is not what they get in other systems. To reach equity, when we're walking through truth, we have to acknowledge that the land that you are all on in the United States is the blood-soaked land of my ancestors, the stolen blood-soaked land of my ancestors, that the wealth of this country, whether it be from the federal government, to foundations, to organizations, was built off the enslavement of the black community here in this country, and that we have seen that wealth not be redistributed in a way that addresses the reparations that are necessary and needed, but instead held and doled out in small pieces to us under the guise of equity and frameworks that were never meant for us, and were not created by us, but now in this time, as we saw in COVID-19, it can no longer be ignored what has been happening not only in our communities, but in other communities of color. Indigenous equity is different, and it has to be. When we look at where and how the health disparities in this country grew, I told you about the removal of my people. In the early 1830s, the Pawnee Nation, my father's people, we were estimated at 38,000 by the US military. By the census of 1910, we had less than 600 tribal members left. I am directly descended for number 534 of those census rolls, who we call the Old Man Echo-Hawk. I am a tangible manifestation of my ancestors' resiliency, and its ability to survive so that me and my children could thrive in this world that we currently exist in. My ancestors and many other tribal ancestors were not only ripped from their land, we were placed on reservations where we were given commodity foods that directly resulted in obesity, diabetes. We are not actually allowed to leave the reservations, and in fact, if you ever hear the phrase, which you will if you listen, I hear it at least once a week on TV, radio, whatever it is, this phrase that is called don't -- you know, don't leave the reservation, don't go off the reservation. That is actually a phrase that emanates from they could shoot and kill native people if they left the reservation. They were basically prisons for us. We weren't even allowed to leave, and so many of our people survived off of our commodity foods, which in the very beginnings of that program, were corn syrup, flour, and we saw things like fry bread, which is now seen as a traditional food in native communities, emanate from that, but it was a survival food, and out of that, we saw our health disparities grow. We saw the lack of true medical care, both Western medical care, and then the outlying of our traditional ways of knowledge of medicine and of science. We saw the outlying of our -- outline of our languages, and in fact, they began to even take our children. They removed our children from their homes and placed them into boarding schools for no other reason than that they were native. And in those schools, we saw rampant sexual abuse, physical abuse, emotional abuse and spiritual abuse that directly resulted in

severe mental health and behavioral health disparities that exists to this day because my uncles were in those boarding schools, and in fact, the last of those schools didn't close down until the mid-1990s. Many of you were probably born before then. And in fact, the elders program I mentioned, more than 40% of the elders just 100 feet away from me right now, 40% of them were part of these boarding schools where they were taken from their families, and when they came back, they didn't even speak the language of their mother anymore. That is the experience of my community, and the resulting rampant health disparities that didn't exist 500 years ago, but I know we're built and continue to be built right now by the treatment of our people, not only by the federal government, but by the places surrounding where they live, work, breathe. And in fact, I'm going to dispel a myth right now. Most people like to think of American Indians and Alaska natives as living predominantly within reservations and villages, when in fact, today, more than 70% of all native people live in metropolitan areas across the United States, and almost 80% live off-reservation, and we have folks who live in other rural areas, whether surrounding the reservations or just in rural areas across the United States, but more than 70% are living in large cities across the United States. And when you look at data related to health disparities, and you think about more than 70% of that, on average, is coming from urban areas, you would expect, if you were to think that everybody is equal, you would expect that a person in Seattle, Washington, a person in New York City, a person, a native person, in Denver, Colorado, would have access to quality healthcare, would have access to quality, education, housing, etc., but what we should all know, and I hope you all do, is that a result, again, of the institutional structural racism within this country, people of color have not had access, and in fact, have been in areas that are rampant with environmental racism, areas where food is very scarce, where people may have here in Seattle, Washington, take a WIC check, Women, Infants and Children's check, which gives them access to food, a federal program, but they have to ride two buses in order to get it. These health disparities continue to exist and actually grew as native people were relocated, forcibly, some of them, into large urban settings across the United States. And then, in these urban settings, there were already tribes, there were already people, and so we saw these rampant health disparities grow, and in fact, the stories that I know from my community, I know them because I've seen them. I've seen the impact of the individuals who come into my clinic, but as an individual who directs a Tribal Epidemiology Center working nationwide to represent our folks in the data, I often don't see them in the data, because we saw across data that we are not free of the institutional structural racism, and while I do talk about individual -- or institutional structural racism, I want to acknowledge that native people, other people of color, are experiencing individual level acts of racism every single day. When I talk about structural racism, I am talking about organization, structures that have embedded policies and procedures, both embedded in policy, and then those are just a way that things have always been done, that were based on racism, and for many of us, we didn't even know that we were carrying them out. And so today, as I talk about data, I'm going to talk about how data has been absolutely one of the ways and one of the structures in which institutional and structural racism has directly impacted American Indians and Alaska Natives, and to do that, and to tell that kind of truth, I can only do it through an indigenous equity lens. And so when I saw this picture, I thought, "You know? I don't want to look at that game." And instead, we're going to break apart this fence and you'll see in the corner, it's a native woman, and on her back is her child, and her child is wrapped in a traditional cradleboard, one of those things that was taken from us, our traditional practices that was torn from us. In this cradleboard, the baby is on its back, it is tight, it is swaddled, it is secure, it is loved, and in fact, that cradleboard meets every single recommendation of the Academy of Pediatrics for infants' safe sleep, but yet it was one of the traditional practices that was taken from us. This was one that was built

off indigenous science, knowledge that we knew how to care for our babies to ensure their survival, and now American Indians and Alaska Natives have one of the highest rates of infant and maternal mortality. Those practices were taken from us and this idea of indigenous equity, we are grounded in our culture and tradition and this woman's eyes are on the mountains, her face to the water, her feet to the land, knowing that her cultural ways, indigenous knowledge and traditions is not only how we'll heal, but where the survival and thriving of our community comes from. Her baby though in that cradleboard, I see that as the cradle board built from the pieces of that fence, the best of Western science because there is beauty in Western science, the best of Western science, but it's not what we're grounded in. It's not what we shape our equity efforts in, but we use the lessons there to supplement and support our indigenous knowledge systems. Unfortunately, in the work I've done for more than 20 years, when I walk into a room, I always have to challenge the Western ideas, because they don't want to listen to the indigenous ways and the indigenous knowledge and the science and say that it's valid. So today, as I talk about data, while I do talk about and I understand and I am and have worked as a qualitative researcher, the stories of communities, the gathering of those stories is very important. When we've talked about decolonizing data and going back to traditional ways of data, very often, we're set into this side that says, "Oh, that only applies to qualitative work. It only applies to qualitative science." It doesn't, and in fact, our tribal communities have been gathering this kind of data for more than decades, more than generations. We have been doing it since time immemorial. We have gathered data that was both qualitative and quantitative, everything from the Lakota winter counts, where they actually had hides that had counts of food and resources that they knew they needed to ensure that they had to make it through the winter, to the stories of my uncle in my Mentasta Lake, where we would count the number of beavers, little creatures running around the lake, so that we knew in spring how many we can hunt to ensure that they would be there again in the winter, and they knew how many we could hunt based on how cold the winter was because they also measured that. We were gathering quantitative and qualitative data since time began, and in fact, much of western science is based on our indigenous science, but too often as a result of structural racism, they don't like to think about native people and people of color in general, as always having been quantitative scientists, but we always have been. And so today, we're going to talk about that reclamation, the eyes on the water, the feet to the land, taking the best of Western science, and applying that within an indigenous context, and it's going to get uncomfortable, but working towards equity has to be uncomfortable, and much of western equity, I think we've gotten too used to being okay with the way that it's done, but if we are not uncomfortable in the way that we are working towards equity, you're not doing it right. You're not challenging the status quo. Equity is uncomfortable. I am uncomfortable every single day because I live in a nation that has been trying to kill me, my children and my ancestors for more than 500 years. I am uncomfortable every single day except for when I walk into the Seattle Indian Health Board, a place of safety, of wellness, of being whole and recognized for what I am and who I am as an indigenous person, and the data that we gather here reflects that strength, that community. We are going to have to challenge ourselves, and for folks, as I talk about specific actions that you may have been participating in, well, I don't want you to take it as a personal attack. I want you to know that that is the structures that we work in, and that we personally become complicit in when we just allow them to continue, so you personally have an ability to break down these systems of oppression, and move towards what justice, wholeness, and healing can look like for indigenous peoples and use these lessons to be applied for not only for native people, for other people of color. And I want to start with a story. During COVID-19, the Tribal Epidemiology Centers were working both with the tribes in which the other 11 were specifically

mandated to serve and we were looking at the urban Indian community. As COVID-19 hit our communities, we knew that we had higher risk factors, not because there's anything wrong with us as native people, but again, we have been living in a country that has been trying to kill us for more than 500 years, and as a result of the built health disparities, we had higher risk factors and our people were more at risk for both infection, hospitalizations, and deaths. We began to hear the stories coming from our communities of incredible rates of infections and deaths, but we weren't seeing it represented in the data and we weren't getting access to that data. As a Tribal Epidemiology Center, under the 2010 Affordable Health Care Act, we are tribal public health authorities, and every tribal nation, federally recognized tribal nation, is a tribal public health authority. That means a structure like the CDC, like a county, like a state, is supposed to treat us like another county. And they're supposed to be sharing information with us, public health information and for Tribal Epidemiology Centers, very specifically, data for us to be able to make the informed decisions for and get information to our tribal leaders so that we can ensure that our relatives, our people made it through this pandemic, and we can make the right decisions with our scarce resources, but we couldn't get the data, very specifically, from the CDC. And we began to work with our CDC partners, and I must say, we had individuals within the CDC system who were doing everything they could to get us the data, and then we had others who were like, "You know what? We just can't get this to you," for a variety of different reasons. We had folks who told my team and I that we didn't have the experience, nor did we have the, you know, wouldn't know the method, correct methodologies to ensure that we were suppressing data that could possibly identify communities. We had folks who said, "It's just within our policies that we can't share this unless you sign these specific data sharing agreements like a normal researcher, and agree to have folks take a look at your analysis before publishing them." We had a variety of different excuses, and those excuses were set within the policies and procedures within the CDC that we're not recognizing us as tribal public health authorities, and as a result of not getting that data, people were dying. As a result of not getting that data, our tribal leaders were struggling with making the decisions that they needed to make in order to ensure our scarce resources were allocated appropriately. And so the tribes, along with the Tribal Epidemiology Centers, we got to work. There were congressional hearings. There was a letter from 26 members of congress, and finally, finally, after way too long, we got access to that data, but what did we find? In the CDC data that was had been reported by the states, we found that American Indians and Alaska Natives were very rarely reported within that data. What we found is what I call a data genocide, and I'm going to define what data genocide means. When I use that word genocide, some people are going to be like, "Oh, my God. That's such a harsh word." It is a harsh word, and I'm using it for a very specific reason. A genocide is happening through data. We are being eliminated than the data. We are not being reported in the data, and if our data is there, it is very often not disaggregated in a way that allows for our tribal leaders to get the information that they need in order for the federal government to get the information that they need in order to fulfill our treaty rights. Our healthcare is in our treaties. It is a prepaid benefit. The federal government has a very specific responsibility, and they use data to determine how many tribal members or how many members of tribal nations within -- our folks who identify as American Indian within a specific region or a specific tribe, and they use those numbers to allocate resources. So when we are eliminated in the data, that means that the federal government does not comply with and is eliminating their responsibility within our treaties to give us the resources for all of the lands you are sitting on today. This genocide through data is eliminating us in a way that is inhibiting the ability of our tribes, our tribal organizations and our urban Indian organizations to get the resources that we have a legal right to. And this is often done

through racial misclassification. And in fact, one study found that in a specific area in the United States, that there is as high as 36% rate of racial misclassification in vital statistics in that area, and we know that in many other areas, we find that exact same rate, and that is because people don't ask our relatives when then they are both born and also when they die of what their race and ethnicity is. And American Indians and Alaska Natives are one of the largest growing multiracial groups in the country, and so there's also a stereotype of what native people look like. We are presenting in every beauty that exists, every skin color that exists, every hair color, every eye color, but when a coroner, a funeral director, a whoever is classifying that death, doesn't ask the family and visually identifies who they think we are, it has created a common saying in Indian country now that we are born native and we die white because that is often how we are racially misclassified. In addition to that, within hospital records that were reported, we found that hospital systems weren't gathering race and ethnicity. I was a co-author on a paper around COVID-19 where we found in the beginning of the pandemic that native people were 3.5 times more likely to be infected with COVID-19, but we could only use data from 23 states in the nation because only 23 states at that time, were reporting at least 70% of the race and ethnicity data, despite it being a federal mandate for the federal dollars they were getting. We saw a lack of enforcement mechanisms to ensure that that data was being reported. In addition to that, because of the lack of investment in public health data infrastructure for states and counties who are trying to transmit race and ethnicity data, their systems often didn't match the systems they were trying to transmit it to, and there was no way for them to appropriately record it, and that, these instances, which are built on institutional and structural racism, where this country benefits from the non-reporting of American Indians and Alaska Native is creating what I have called a data genocide. And you can read this specific report on my website at uiha.org, but I want to say this isn't a new battle. Folks like myself, the other Tribal Epidemiology Centers, numerous indigenous scholars, epidemiologists, academics, we've been shouting this from the rooftop for years, and nobody has ever listened, but now is the time and there is a reckoning towards data equity, and also towards movement towards real equity, and now is the opportunity under the current administration, under the incredible individuals who have recognized where and how systems need change, that we have an opportunity to address structural racism in data. I want to go through some of the specifics, particularly for the epidemiologists, the data science and folks who are currently on the call about the other ways we see structural racism in data. The use of single race, American Indian/Alaska Native, which is very too often done in reporting out health disparities, and also health resiliencies. Single race, what does that mean? That means an individual only marked American Indian/Alaska Native on a on a form, or they marked American Indian/Alaska Native, and put both -- put a primary race, and then other multi-race, and so what happens when they use the single race data is that it excludes the almost-now more than 50% of American Indians and Alaska Natives (we're getting real close to that) who identify as multirace American Indians/Alaska Natives, and it effectively eliminates a huge segment of our population and skews the data to not tell the true story of what's happening in our community. It also shrinks our sample size significantly, and in shrinking that sample size, those numbers are very often what is used at both the federal level to allocate resources to our tribal communities. I recently had a conversation with some folks who are doing a big national survey of youth, and I asked them why are you using single race as, you know, as your denominator? Why are you using single race instead of multi-race? And the answer was is that that's what we've always done. What and how does this benefit? So the use of single race American Indian/Alaska Native is actually a holdover from when the federal government was determining who was native and who was not. They were applying at the time, the one drop rule to the

black community, which means if you were had one drop of black blood, you could be enslaved, and they were doing the opposite for American Indians and Alaska Natives, that if you were intermarried into another race or ethnicity, you are no longer native, and thus, they didn't have to give you your treaty rights and the resources you needed. It became embedded in the systems, in the data systems, and so now we see agencies and we see individuals, we see researchers and academia, using single race when it's meaningless. For American Indian and Alaska Native people, we value all of our people. Our connection to our tribal roots is based on our knowledge of our culture, and the only people who can determine tribal membership is tribes, no one else, and those individual tribes, and this single race category attempts to do that, and attempts to define who is American Indian and who is Alaska Native. It is the absolutely epitome of what structural racism looks like within data, and one action that every data scientist, every epidemiologist, right now listening could change immediately in the way that both are agencies, and they look at data. We see the lack of disaggregation of data, whereas a small population will be included with groups that often don't make sense. Asian Americans, Pacific Islanders, we're all grouped together into a group that is meaningless. It's a trash data category. It means nothing. We have no ability to take a look at that. And what should be happening instead, and what we have found, is that many folks who go through, particularly epidemiologists, when they go through their schooling and training, they are not taught small populations data methodologies. It needs to be required that every epidemiologist going through an academic program, that there should be a required class on small populations data analysis. It's an equity issue, and the reason that my people are considered a small population is because of the genocide that was perpetuated in this country, and if we're going to apply an equity lens, we acknowledge that and move into the healing, which means that we lift up and ensure that these methodologies are happening to ensure the inclusion of American Indians and Alaska Native in data. We see the literal representation of native people actually working in the data. We need to ensure that our educational systems are prioritizing and creating welcoming warm spaces for Native people when in fact, many of our native kids who are going through Western education systems are constantly combating the structural racism that exists, are often being pointed out and almost asked to teach the class because of the only native person in there. We are also seeing across, in particular federal agencies, the reliance on a group of one, a group of four, a group of six small groups of native people to be the ones who are determining and deciding where and how data is both gathered, how it is analyzed, and how it is shared, what papers look like, how native people are written about. There is such a diversity in Indian country, I am just one voice. There are more than 500 federally recognized tribes. There is multimillion native people in this country. You cannot rely on one small group. It needs to be diverse, and it needs to be engaging with the tribal communities in which the data is theirs. As I talked about before, we need to enforce the mandated data collection of race and ethnicity, address the lack of respect of tribal public health authorities in both federal systems, county systems, state systems, and we need to be focused on an understanding what tribal sovereignty is. Tribal sovereignty is tribal nations, like my own, the Pawnee Nation of Oklahoma, we are domestic nations within a nation, and with that comes responsibilities. My tribal president has the same standing as President Biden and should be treated as such. There are laws and regulations that are in place that we need to be working towards and ensuring that as we work in data, we are acknowledging them. The tribal nations are grounded in that knowledge and understanding of where and how to not only gather data, but how to analyze it appropriately for their populations, what should be released, what shouldn't and under tribal sovereignty is tribal data sovereignty. Tribal data sovereignty is the inherent right through their tribal sovereignty of tribal nations to own, regulate, and govern all data gathered on their

people, and there are some incredible scholars who have written about this Dr. Desi Rodriguez, Dr. Stephanie O'Carroll, some folks in New Zealand. It is one of the areas where we are really pushing for and ensuring that our tribes have access to their data. That is a cultural value, and for our people, where this data, because of the embedded structural racism, where very often how we are representing the data was meaningless to our community. So I'm going to share with you what decolonized data could look like. So when I say decolonization, the decolonization aspect is by the tribal nations, is by tribal people. Decolonization is not a metaphor. Decolonization cannot happen, since I'm talking to the CDC, decolonization can't happen in the CDC because it's an institution that was built to oppress me. You can't decolonize an institution that was built to oppress, but what you can do is apply an equity lens, a justice lens to identify structural barriers, institutional structural racism, and begin to work towards eliminating those to ensure that tribal nations, tribal people, can decolonize data. That means myself as an individual, I am applying my cultural teachings, the cultural understandings, the advice of my elders, ancestors and community, and bringing back the cultural values of not only gathering data, but using it for one reason only, the good and the wellbeing of our people. So I'm going to share with you this study is on our website uiha.org. It was a study of sexual violence specifically on American Indian and Alaska Native women in the city of Seattle. It was the very first of its kind, looking at sexual violence on urban Indian dwelling women. When I came into this organization, the Urban Indian Health Institute, this study had already been done, but it had not been released, and the decision to make -- to not release it was one that was embedded in both patriarchy and structural racism. Decisions were made about native people and native women without insulting them, and they decided to not release the data because they thought it could stigmatize American Indian and Alaska Native women in our experiences with sexual violence. That was the wrong decision. And when I came into this organization, we worked towards, and it took us about a year and a half to do the work that we needed to do with the community to release this data. And we did that, and we gathered the community first. We gathered them, we shared with them, and they told us how we needed to both move forward in releasing the data, and also what steps needed to be taken in order to undo this ongoing violence against our urban Indian women, and I can talk about that, you know, for hours, but what I want to share with you instead is how we brought this data forward, and so I had this graphic created. I did it in consultation with the folks who had been part of the study, and my elders in my community. When I shared this with some of my federal partners, because I wanted to get both their feedback because I respect their knowledge, and I also wanted to be -- we wanted to disseminate this really widely, and so one of the feedback that I got, and I actually got it several times, was this looks really great, beautiful graphic, you know, you've written this up really well, but they're like, "You know, there's like one weird way with how you're presenting the data. You know, data science tells us, we need to redo that from ascending to descending order or descending to ascending order. And, you know, the evidence says that that's how people absorb it better. They're going to really relate to it more." My answer to them was, I didn't create this for you. It's not always about you. I did a successful dissemination rodeo. It was used for powwows and community gatherings. It was the wallpaper on people's phones, because the way we presented the data was very culturally specific. The feedback was and our knowledge is that this is a ribbon skirt. In our traditional teachings, each ribbon is a prayer, and we wanted to hold this very hard data in prayer, and the hardest part about it was the 94%, who had been sexually assaulted or coerced into sex in their lifetime, they wanted it by her hand to know that she was held, and they're -- that they were held in prayer in their trauma. The bottom of the skirt is historical trauma. We had a measure of historical trauma, questions like did you ever go to boarding school? Do you feel a loss of land? It's a validated

measure of historical trauma. From a cultural perspective in these ribbon skirts, when your skirt brushes the ground, healing flows from Mother Earth, and so this recognized the cultural teaching, and as a result of it being grounded in this decolonized data, information only known to the tribal communities should be used by tribal communities and presented in a way that challenge Western ideas of data science and evidence-based practice on showing data, and it has been so incredibly effective, that it's now in textbooks and being taught in communications classes. When you work with the community, you can move this kind of thing forward. You can apply these standards and these teachings. You can address the fact that too often, we've been being talked about and not talked to. And now when I think about all the COVID-19 money that has been flowing into our communities, I've been working with communities nationwide, and this has been a constant struggle with the dollars that have been flowing in our communities to address these rampant health disparities is that we often get these evaluation plans, again, not created with us or for us, and I began to struggle with that, because I thought, "You know what? It is so weird and unethical. It's truthfully, just unethical for these institutions, which have been part of not only oppressing, but suppressing the vitality of our communities and been part of building these health disparities, is they're telling us how to measure undoing their racism." That makes no sense. We need a restructure of how evaluation systems across agencies from federal, state, county, foundation, philanthropic, whoever it is, it needs to be done with community, because how are you going to tell us how to measure undoing your racism? You're going to get a bunch of measures that mean nothing to us, that isn't going to help us create better programs for our communities, and instead, you may be, and probably are, perpetuating ongoing health disparities instead. One way to do this is what's going on right now. Actually, this just ended a couple of days ago. As a result of the Tribal Epidemiology Centers not getting data, there was a Government Office of Accountability report that was issued, and HHS had issued, as a result of the findings of that, which found all of the things that I said, that there wasn't an upholding of tribal trust/responsibility, that they were not respecting tribal public health authorities, and that there needed to be plans for sharing data, HHS issued what we call a "Dear Tribal Leaders" letter, and it's an issue to tribal consultation. A tribal consultation is that respect of individual tribal nations with the federal government, and it is a two-way, government-to-government dialogue on the specific chain of programs, in this instance, creating a program to ensure that data sharing, and what is it the need to do in order to get the appropriate data sharing in place for tribes and Tribal Epidemiology Centers? And so in making those changes, they just can't do that. They'll do that through a formal tribal consultation, and there is a really great definition and more in-depth information on this on the website bia.gov, The Bureau of Indian Affairs dot gov, where you can hear more about tribal consultation. A similar kind of consultation, but it's a little bit different, is done by the Indian Health Service in what we call an urban confer. An urban confer recognizes that we're not living on federally defined tribal lands, that little sovereign nation, but we have native people who, because I stepped off the reservation, doesn't mean that my treaty rights went away, and the urban confer works with the urban Indian organizations that provide healthcare, and ensures that they get their input on changes to policies and programs. Any significant changes to policy and programs that impact one or more tribal nations should go through a tribal consultation, or at the very least, issuing a tribal letter asking if they should go through tribal consultation. So HHS has done this right now. We'll expect to see some changes happening as a direct result of that. And this idea of consulting and sharing information, and coming into these formal spaces is something tribes have been doing for, again, not decades, not centuries, but since time began. We have always sat down with our tribes, one to one and shared information. We have always respected all of our people, regardless of their race or ethnicity, if they

held a connection to a specific tribal nation, regardless. We always counted our loved ones, and we did this gathering of data, not because we think there was something wrong with our people. That's not why we gather data. We'd gather that data because we know there's everything right with our people. So we also have to shift within data and epidemiology specifically, focusing on deficits only. Instead, we need to understand the strengths. As I said, I come from number 534 on this Pawnee census rolls. He's survived. I'm a tangible manifestation of his resiliency. He survived so that I could thrive. Where and how did he do that? And what are the protective factors, the lessons learned, the traditional knowledge, because it wasn't Western knowledge. They were trying to kill him. Where and how are the protective factors that exist within our communities and how do we highlight that vitality and that strength within our data? And what have we thought about every time we've looked at a dataset? I can't wait to see where the strengths of a community lies, when in fact, we're taught within epidemiology instead, to look for the deficits. We have to change that. That is a face-forward into justice, and this is a picture of my grandmother, teaching my nephew how to twine birch bark, and in his hands is a little birch canoe. She taught him not only about balance, about the science of a canoe, the engineering of it, where and how to twine this birch, she could survive off the land because of her deep knowledge of science. And in fact, I grew up chewing on a little piece of bark. Come to find out when I was in college, that the bark of that birch tree is actually where the enzyme that is the basis of aspirin comes from. That is the knowledge that my community has always had, and that we gathered not only qualitatively, but in a quantitative way, but what we have found too often is that when we look at data comparison groups, (and I want to make this really specific), is there's a lot of conversation right now within data about using non-Hispanic whites as a comparison group for people of color. There have been good arguments and I would agree with them that very often it centers whiteness, that we are compared to white people because they are the standard. That's not true. I am not comparing the outcomes of my community because white people are the standard. I'm not comparing it because they're the majority population. I'm not comparing them to -- I'm not comparing us to non-Hispanic white people because they're better than native people or that I even want their help. Why am I comparing? And in fact, as of three months ago, my organization, as we compare American Indians and Alaska natives on all of our data, we will compare them to non-Hispanic whites because they are beneficiaries of structural racism, no matter how poor they grew up, no matter where they live in the country, they have benefited from the theft of indigenous land, the enslavement of black people, and the other benefits that exist through individual and structural racism that continue to marginalize people of color. So we compare American Indians and Alaska natives health outcomes to non-Hispanic whites, but we focus on instead that they are beneficiaries of structural racism. We have to be blatant in what we are doing if we are going to reach equity, and yes, it is uncomfortable, because I'm sure many of you identify as non-Hispanic whites, and maybe you've never thought about yourself as a beneficiary of structural racism, but you are. And when we do this, and we blatantly call it out, we shift the data conversation. I'm not saying native people are worse off, but we have not had these benefits that other people in this country have had, but what's possible. Where and how can we move forward? It starts with this. Quit looking at people of color as a problem to solve. Data looks at people of color as a problem to solve, and we are not. We are in fact, every single one of the answers. When consulted, when and how we are able to use our decolonized data practices, when tribal sovereignty is respected, when indigenous sovereignty is respected, when Tribal Epidemiology Centers and tribal public health authorities are respected and we receive the resources we have a legal right to through our treaties, we are not the problem to solve, and in fact, the systems are the problem to solve. We are the answers that are needed, and those answers are in way

both how you gather data, how you analyze the data, and how you disseminate it. Because we are the answers, I was able to put together that graphic on sexual violence that had the ability to possibly retraumatize people, but because we did it in such a culturally based way, that in fact, it motivated our community to move forward in incredible meaningful change in programming. These opportunities for changes are here. You have to be comfortable with getting uncomfortable. If you are not uncomfortable and challenging the ways that you have always done things, you need to begin to address that within yourself and look at the areas of implicit bias that you have. We all have them. I have them. Where and how are they playing out in your work? And how is it represented in the data? You need to look at every single practice that exists within your organizations, whether you're a nonprofit, philanthropy, federal agency, academia, no matter who you are. How are your data practices and data systems moving forward to address and bring forward justice? And are you collecting what you need to collect in order to combat the data genocide my people are experiencing? I do want to point out that the collection of tribal affiliation should only be done after appropriate tribal consultation, and urban confer if it's being done in an urban setting. You do not collect tribal affiliation, and you do not report it out without the specific approvals by the tribes, because there are opportunities for you to actually create more structural racism, and in fact, motivate people for individual acts of racism as a direct result. We actually saw some of that with the Navajo Nation during the COVID-19 pandemic, where there was an instance where an individual was showing up and had a weapon with them and was saying that they were going to murder Navajo people because they were the ones who were spreading COVID-19. These are the kinds of things that can happen if you are not releasing information appropriately, and that respect for tribal sovereignty is absolutely key. So I've told you a bunch of stories. I'm going to close here with just one thing. In our indigenous communities when you are told a story, it is a way of passing down knowledge and it is a way of passing down accountability and responsibility. When you hear a native person, an indigenous person, an American Indian or Alaska Native, a Pawnee-Athabasca woman tell you a story, I have gifted you responsibility, I have gifted you accountability, and I am challenging you to recognize your own individual responsibility to break apart systems of oppression that you are participating in. And I understand that takes bravery, and in that we need allies and accomplices. I'm tired of doing presentations like this where I get a million little emails that say "Oh, good job. I'm glad you said that in public meetings." But when I did it, and everybody just stared at me and nobody said anything, I didn't see or feel that support, and I'm one of many who do that same thing. Be that support. Don't try to lead this change if you are not part of the indigenous community, but identify where and how you can make changes to support, and I've given you some of those today. Be an ally. Be an accomplice. Take a chance. Take a risk. Let indigenous people lead it, follow their lead and recognize that one native person like myself is not the expert on all, and in fact, the engagement with the communities, whether it be at your local level to your federal level, that is your opportunity, because today, how big is your brave? What is the chance that you will take? What are the actions that you can make to ensure that this data genocide doesn't continue, that we aren't talking only about deficits, that instead we are focusing on the assets, the brilliancy, and recognizing that systems of oppression are not only -- are the root cause, and that Western equity cannot be applied to all and we need to recognize that each individual community knows the path forward? And that will take bravery. So today, I end with how big is your brave? What is the chance that you will take? And what is the change that you will be, because it is together that we will see data equity and indigenous data sovereignty, not just become words that we say, but the every action that we take? Thank you.

MIKE: Thank you. The presentation is now open for questions. I don't know, Abigail, if you want to start reading the questions. There's about six in the chat, if you want to start reading them out.

ABIGAIL: Yeah. So I'll start with the one of the preference not to land acknowledgement, so I would suggest everybody Google a -- it was a an article that was done by Dr. Cheryl Crazy Bull. She is the CEO of the American Indian College Fund, and she writes, and she gives some specific examples, that if you're going to do a land acknowledgement, which I -- you know, when done right, are the appropriate thing to do, but if you're just acknowledging that you're on somebody's land, that's not why we did them. How are you investing in? How are you making structural change in? I just gave you examples of ways, if you're a Data organization or an epidemiologist and you do a land acknowledgement, you could say how you are working towards data equity for indigenous peoples. What are the actions you're taking? Just acknowledging you're on my land doesn't do anything, unless you want to give us a deed for some land back. That's always an option. Did you see anything else, Mike? I'm reading through the rest of them.

MIKE: Yeah, there was questions about analysis, a few questions about how to classify variables for multi-race, and there's different examples that were given.

ABIGAIL: Yeah, I see this one are related to Hispanic. So I am absolutely a proponent of including Hispanic, and along with multi-race and a category that shouldn't even exist, single-race, American Indian and Alaska Native and combining those together. We do have a very large growing Hispanic population, and not only that, the border between the United States and Mexico crossed us, and so we have and I've always been engaged with our indigenous relatives at that border, and so the inclusion. So my children identify as indigenous Mexican, along with American Indian and Alaska Native, and very often in data, because they're multi-race, they don't count it all, or they're included in Hispanic because that's very often where everybody is counted on. So we absolutely -- the recommendations, and you can find very specific data recommendations on my website, uiha.org. I have a document, a publication called Best Practices and Data for American Indians and Alaska Natives, and we absolutely believe that you should be including Hispanic. Again, as we kind of break apart these categories, what and how does that benefit the populations? Not does how does it benefit our analyses, but how does that benefit the populations? And by taking out Hispanic, at the last numbers I looked, I could be a little off, but I believe it was about 23% of American Indians and Alaska Natives in the country were identifying as Hispanic. So again, it shrinks your sample size, and these are other ways to increase your sample size so that we are able to actually get good analysis. I just want to add in another methodology that really should be done is if you have small sample sizes, particularly if you're doing a lot of work in maternal mortality where we're really struggling with getting both states and the feds to release data on maternal mortality that's meaningful, or they'll release it for one year, and we're not included because there wasn't, you know, in my mind, there wasn't enough reported maternal deaths within our communities because of racial misclassification or non-collection of data, but one of the ways to combat that is to combine multi years together, so that you get a large enough sample size, and yes, there are limitations to that, and I understand the limitations, but we have to work with what we have now. That's an immediate answer. And then you need to look at how do you do oversampling? How do you take a look at and mandating

the collection of race and ethnicity? Where and how are your individual states ensuring that, you know, the people who are collecting race and ethnicity and vital statistics actually have some kind of training? That's another problem. Most of the people who are doing vital statistics have no training at all. Funeral directors, no training on how to gather race and ethnicity, and it's directly impacting us. So these are just, you know, a few of the potential methodologies to ensure that we're actually gathering enough data to do a good analyses. I will say that our communities are very small, and my organization actually has a higher standard of suppression than most states, and most states and the federal government, actually. Like we suppress any numbers lower than 10 and, you know, very often we'll find in like CDC, for example, it's lower than five or six. Some of the other Tribal Epidemiology Centers, we all kind of vary based on where our populations are, but we have a higher standard because of the smallness of our communities, and we don't call data, data points. We call them, in my organization, storytellers, and so how we honor those storytellers is really important to us, and we need to make sure as they're telling their story, that we don't identify anybody that could be harmed by the release of that data, so we really think innovatively about the best way for us to grow our sample size to ensure we have enough data to do a good analyses.

MIKE: So we have a question sort of as a follow up to that, asking about small population methodologies, and where is the best place, if they can't go back to school, to learn about that? Where could someone go and epidemiologists who are currently in practice go to learn more about small population methodologies?

ABIGAIL: It is a huge gap, a huge gap. In fact, if there's somebody out there who wants to help me address this, so you have folks like myself, and there are -- I named some of them Dr. Desi Rodriguez at UCLA, Dr. Stephanie O'Carroll, Dr. Don Warne, and others, and we go to universities, we go to organizations. I've worked with states. I've worked with hospital associations. I've worked with everybody that we could possibly get into, to help build education in order to do this. We need to have a more standard opportunity for this. I know that there are certain universities. Emory, for example, does a certificate program that's like a, you know, like a summer certificate program. There are some small opportunities like that, but we need to have a more cohesive way to do that, and I don't have a perfect answer for this, unless there's somebody out there who wants to contact me afterwards, because I would love to build some more of that out specific for the American Indian and Alaska Native community that would be a true curriculum, and I just haven't had the capacity to do that at this point in time. And we just need to push academia. That has to change. I have to retrain almost every single one of our epidemiologists who comes in, and I'm training some folks who are going into epidemiology programs, and the worst part about it is young native people going into epidemiology programs, they end up having to educate the teachers, and that is not the way education is supposed to work. Where and how can we change the standard as a field to ensure that academia shifts to the need and applies an equity-based lens as to what is needed to truly improve the field of epidemiology? We have an opportunity in this field to start doing that.

MIKE: There's a question here about self-identification, and in many surveys, people ask, they want to make sure that they're cognizant of someone's self-identification of where they belong, but also understands that tribal membership and enrollment can be a sensitive topic as well. So could you speak to any best practices for affirming both self-identification, specifically of descendants who are not tribal members, and tribal sovereignty and determining who is part of a tribe in data collection and reporting?

ABIGAIL: Yeah, so I'll start with who determines who's a tribal member, only tribes. And in fact, that can -- should never be done by a state entity, a federal agency. There opportunities to partner with tribes to correct for racial misclassification and to ensure and for them to look at the information related to their own tribal members, and there are some really great papers published by the Northwest Portland Area Indian Health Board who does -- they're just absolutely one of the best in the nation on doing what they -- they do linkage projects where they work with state data for example, and COVID-19 data. They just did a linkage in Washington State's COVID-19 data, and we saw a 40% increase, almost a 40% increase of American Indians and Alaska Natives in that data as a direct result of racial misclassification, so there are those opportunities to partner, but that data in the Portland area, and I can't speak to the work that they do, but they have published some things on that, and I know that they don't always release it, you know? That's for the tribal nations. There is no reason that a federal agency needs that. That is for them to understand and to work through, and so that's the other thing is that within data, and within science, there's this idea that we should all be open and we should all have access. I'm sorry, that's not how it works with tribal nations. They are sovereign nations. They have a right to share data or not share data, and you just need to agree with them. You can offer why it would be meaningful and beneficial, and when they say no, accept it and move on. They will use that data for the good and wellbeing of their people. When it comes to how you should be collecting data, again, unless you have done specific tribal consultation and urban confer, you should not be collecting tribal affiliation, but I highly suggest you do that because it can be so meaningful. So that's an opportunity to trigger an urban confer or a tribal consultation at a -- you can do it at a county level, state level or a federal level. What you should be collecting is tribal affiliation, and people should be able to affiliate with whatever tribes, and they may have more than one that they're -- that they identify with. There is and there has been some questions related to, you know, people who are descendants, and then we also have people who have this, like, my great-great-grandmother was a Cherokee princess. By the way, that is a myth. Cherokee princesses aren't real. That's not a real thing, and it's actually where we see the appropriation of native culture and where people have these stories within their families that there is no evidence of and no ancestors to relate to. And so occasionally, we do know that those folks may identify themselves as native, but it is so small, that it doesn't have a meaningful impact on the data. And when folks can go in and do linkage projects like the Portland area, what they see is they didn't -- we never see the numbers go down. We only ever see the numbers go up, so it -- while, you know, you want to make sure you're asking do you identify as a American Indian or an Alaska Native, and use those verbiage, American Indian and Alaska Native, we use that specifically in data and in peer-reviewed work, because that is the legal language of our treaties, but you'll may have noticed I interspersed indigenous, native, Native American, because we all do identify differently, but whenever you're writing or whenever you're putting it on a data form, it needs to say American Indian and Alaska Native, because that is where our treaty rights come from. That is a way to, again, combat that that data genocide is to use the legal language of our treaties, but always know that we all identify in a variety of different ways, and whenever you can speak to a specific

tribal person, like people should introduce me like was done as a Pawnee woman, as an Athabaskan woman, because that's -- I'm connected to those tribal identities, and they're very different than I'll say a Lenape woman from New York, a Ponca woman from Nebraska. So we need to, again, whenever possible, name folks as their tribal affiliations, and if you're working closely with tribes, when you have good relationships, they will at times let you publish data about their specific tribes, because they're doing such amazing things, that it's good to give them the credit that they so deserve, and as they work towards undoing these disparities for their people. So again, tribal consultation, urban confer, affiliation, do not collect -- do not ask if you are an enrolled member of a federally recognized tribe. And in fact, don't even collect tribal affiliation unless you've done those tribal consultations, but the only people who can say who is a member of their tribe are those tribal nations themselves, and they hold that data very closely as they should, because data has too often been used against us rather than for us, and we really need to work towards rebuilding that trust, and the processes I just talked about can be a part of that.

MIKE: So there's a question about engaging people who are not -- do not acknowledge their gaps in understanding when it comes to race/ethnicity, and do you have any suggestions for people on who are watching that on how to engage in colleagues and clients who aren't acknowledging their gaps?

ABIGAIL: I'm trying to see that question. If you can --

MIKE: Maybe it's up further.

ABIGAIL: I don't quite understand. So and maybe that's just because I'm like, I can't believe anybody wouldn't believe this. So this is how -- if that's the question is --

MIKE: Yeah, I'll read it specifically. It says, "Do you have any examples on how you engage colleagues or clients who do not acknowledge their gaps in understanding when it relates to race/ethnicity, etc.?"

ABIGAIL: Yeah, so and so I have done that quite a bit, and sometimes it's been aggressive, and I'll tell a story. I was -- I had a child who was in one of the largest -- it was at Seattle Children's Hospital. They serve a five-state region. They work with children, and so my son had -- was in there for several weeks, and I realized -- a friend of mine was -- who worked there, looked and she's like, "Oh, my God. You know, your son's classified as white." I said, "What? Nobody ever asked me, this large brown child, if -- you know, I can't believe he's classified as white." So I go to the front desk, and I'm like I -- you know, it's been brought to my attention that my child is classified as white within your data system, and I need that changed to American Indian and Alaska Native. And I proceed to get into an argument with the front desk person who tells me that there is no such category, and that it can't be changed after it has been put into the system, and so I got very aggressive. And I had just actually written a paper with some

folks at that agency where I'd use data, and so I was able to exert amount of privilege that doesn't exist very often in my community. I was able to say, "I know it has." I contacted all the right people. It took me about two days to figure it out, but what I found was not only did we have an individual who did not understand why we don't collect -- or why it was important to collect race and ethnicity. So that's the beginning of it. The presentation I just did, as we talked about what the data genocide does, what happens when you only -- when you don't collect the race and ethnicity, how it's part of -- doesn't give the ability of folks to get our legal rights for resources? That is one way to help move people into an understanding, because they often will be like, "Well, why does it even matter? What impact does this have?" And so that's one way is to do that educational component. The other was, is that this individual who I was working with at the front desk, later on, what -- or it was like a front area, later on, called security on my husband and my child, and what we were experiencing was individual acts of racism, and so we were able to move forward with that hospital system to address those specific acts, and to look at what were the education that was needed for their staff, and what levels of accountability, so you're not always going to be able to win everybody over, and that's okay, but where and how you change the structures and the policies that you can ensure that they have to move forward, regardless of whether or not they believe you, and so that's where I believe, like the both educational process is just as important as the policies and procedures process. And in all of that, needs to be enforcement mechanisms, as we saw within the data, and we're seeing the same with vaccinations right now. You know, just what my sister TEC, the Portland area, did in improving data within Washington state on COVID-19, is -- that's because nobody was enforcing that people collect race and ethnicity correctly, even though it's in the federal mandate for the dollars. There is not an enforcement mechanism, and so in that, I know that there are several members of Congress looking at like, what and how does this look like? I know that different agencies are also looking at where and how do we actually enforce in, you know, ensuring that we're getting the information that we need? So it has to be both, the educational process, and when that doesn't work, you fight. And so I will say that I had great response from Seattle Children's Hospital, and I've actually sat on different panels for them now at this point in time to address institutional and structural racism within their agency, and so it creates also opportunities for meaningful change. I will say that too often, that responsibility is placed on people of color with very little support and very little payment, and so that is an equity issue that also needs to be addressed. Where and how do we build in the systems of accountability that it doesn't rely on somebody like me, somebody like, you know, I've been talking about Portland area, so my -- the other director there, Dr. Warren Mears, others, where and how can this responsibility spread? Where and how are their accomplices and allies in this so that all of the pressure for this doesn't exist on one small group of people?

MIKE: So obviously, we have a lot of questions, which is great, so we won't be able to get through all of them during the talk, but we've had a couple of questions about specifically 23andMe DNA testing, and people who, whether the test results come back either way, that they are affiliated or not, and how does that affect public health data and how is that utilized?

ABIGAIL: Yeah, so I have worked in this area of genetics and genomics for a while. I actually sit on the All of Us precision medicine tribal advisory, particularly from the ethical, bioethics perspective on tribal

nations. So 23andme, ancestry.com, etc., first of all, the science isn't great right now when it comes to American Indians and Alaska Natives, and in fact, the largest samples that they have of indigenous peoples are actually coming from South America, and so the science isn't good at this point in time. And also, it creates this idea of both appropriation of tribal identity, so there's this 23andMe, I think it is, commercial. And there's this woman walking through and she's got some Pueblo pottery, and she's got like an Alaska Native rug behind her, and she's got some planes, something that she's walking towards, and she's talking about, I had no idea I was 20%, American Indian, or 20% Native American or indigenous. And even in that, that's the example of why those particular kinds of ancestry tests are meaningless for the native community. Who we are is directly tied to our tribal membership, and we both being recognized by our community and our community recognizing us, and that is tied to our knowledge of our cultures, traditions, and practices, and so it is not tied to, you know, have, you know, some misidentified 20% probably coming actually, from bad science truthfully, at this point in time. I'm not going to say that it won't get better, because the more samples they have, the better it gets, but at this point in time, it's really bad science, and it does not, absolutely does not denote that you have any kinds of claims to tribal membership or indigenous identities, and so how you can look into -- because I have to acknowledge as a result of these federal policies that have harmed our people, we had children who were taken and adopted out, never knew their tribal communities. We have children that were removed and never came home from the boarding schools. We have folks who were relocated to urban settings against their will. We have all of these things that happened and there are tribal people who haven't had the opportunity to connect to their tribal roots, and we love them and we care about them and we want to engage with them. There is really good resources to look and to connect your family genealogies. That is what I suggest. Don't use a 23andMe. Don't use an ancestry.com DNA test. Go back and look at your genealogies, and if you are able to trace an ancestor back to -- and this is how tribal memberships are defined -- to tribal rolls, so I talked about the census of the Pawnee people. There was original tribal rolls that I'm directly descended from. That is where and how you can track back. And there's some really great people. I had a friend who they had always had this story in their family. He actually thought it wasn't true, and he traces it back to one ancestor from the early 1700s, and they were able to document where they were not eligible for tribal enrollment, they were eligible and welcomed in the community to begin to learn their tribal cultures, and so that is where and how our tribal identities are tied to, not these DNA tests, and they are in no way used by any tribal nation to determine tribal ancestry. And again, the science right now for indigenous peoples is faulty.

MIKE: So we have a lot of trainees on the phone, and in particular, one person's in their first semester of a PhD program in indigenous health, and do you have any advice for a young indigenous researcher?

ABIGAIL: I assume that that program is probably my friend Don Warne's program at the University of North Dakota or up in there. And my advice to you is to hold on to your tribal identity and roots. You're lucky to be in a program where they are focused on doing that. Know who you are. Know your stories. When it comes to data, I was able to tell you a story that was directly my tribe's story of qualitative and quantitative data collection. What do those stories look like for you? And the other is, is to connect to a deep group of mentors. My work has not been easy. I've done a lot of work, unfortunately, last couple of years, particularly in the work that I do on missing and murdered indigenous women or girls and

sexual violence, death threats happen. I've had several stalkers. I've had all kinds of things. We saw a lot of public health officials had things like that happened during COVID-19. It was kind of a new thing for many public health people, and unfortunately, for people of color, it's been a norm for us to be attacked for us challenging systems. How do you make it through that? You build up a network of folks who are both mentors and peers, and there are many of us who are just waiting for the next brilliant person to come in and take our place, so we want your voice, we need your voice. And in addition to that, identify those allies and accomplices that can come with you, and when and if they're taking advantage of you, move on. Really depend on that group of mentors, people of color. One of the things my organization has done really well is build up solidarity across communities of color to create collective power. That exists also within PhD programs, academic programs. Where and how do we support each other? And one thing for the non-people of color, you know, for non-Hispanic white people, for white people on this call, just because you weren't invited to the group, that's okay. It's okay for us to have places of safety, and we need them. It's not an affront to you. It's not an attack on you. It's us creating a safe place in a country and in a world that is not safe for us, and so when we create those safe spaces just for people of color, support us, sponsor some people, buy us some snacks, and don't feel offended you weren't invited. Again. It's not always about you. It's about addressing systems of oppression.

MIKE: We have a question on data systems that currently exist, so data-sharing systems, maybe between a tribal health center, tribal epi centers. What type of data-sharing systems do you -- what exists already? And then what type of data-sharing systems do you envision that would be needed to end data genocide?

ABIGAIL: The data systems that currently exist are a crumbling infrastructure. I know that one of the things that our tribes were experiencing along with our different states and counties as I was, again, trying to gather data from across the country, is that some of them were sending in PDFs. Some of them were sending in Excel files. Some of them were connected and linked to data systems, but then the fields in which they were gathering data didn't match the fields of the data system that they were sending it to. So what we need to see -- and I know that there has been some congressional efforts. I know the CDC has set up a new center. I know that there has been congressional dollars allocated, and there was actually, for folks to take a look at, I was actually part of this. There was what was called the Data Commission, which was put together by the Robert Wood Johnson Foundation. It included thought-leaders from across the country, predominantly, and people of -- for people of color, and other folks who work in data systems about what are the strategic changes that need to be made, because we need to make data systems that can speak to each other? So I got something from the folks when I started here to use plain language. But so that data systems can talk to each other, and that there's a commonality in where and how data is gathered, that we're gathering data in a consistent way, so that when our data meets in these big data lakes or data pools, as we call them, whatever you want to call it, when it meets, you can actually merge them instead of having to spend -- I know that the CDC along with IHS, have done some really great linkage projects on vital statistics, and they cost like \$4 million because the data systems don't work together. They have to come up with all this technical infrastructure, and then all the cleaning of the data that is necessary in order to link these datasets together. We need to continue to see an investment, not only financial investment in a crumbling public

health infrastructure, data infrastructure, but we need to see champions on the ground from the local all the way to the federal level, pushing as to why this is important, and where and how the change that it will bring when we have a better data system together. So when it goes to tribes, it varied. Some folks had great relationships and knew exactly how to share data with their counties, because they were already doing it. Do you have those relationships? Have you begin to establish those? What does data sharing look like? Have you worked together to create the systems? And if they don't trust you to do it, have you begin to build the trust? And what is necessary to build this trust to build to do that? And then we need to look at again, when we did our data genocide report, and we're talking to different states, they're like, "If we could have reported it, we would have, but we simply didn't have a way to get that information in the format that was needed in order to have it included in the datasets." And so it needs a full -- the data system needs a huge rehab and an influx of dollars. The RWJF Data Commission report gives examples and some solutions for that, in addition to looking at things like workforce investment, policy and other things, so it's a really good resource.

MIKE: Well, it's 3:00. That ends our time for today. We won't be able to get to every question, but I want to thank everyone that's attended. I want to thank Abigail Echo-Hawk for a wonderful presentation, some excellent questions. There'll be a recording posted on CC YouTube, and there was information put in the chat, and there'll be continuing education available with the links in the chat. So I want to thank everyone for this November Preventive Medicine Grand Rounds, and please join us in December for the December Preventive Medicine Grand Rounds. Thank you.

ABIGAIL: Thank you