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Abstract

American Anthropology has a foundation of using Indigenous people, often Native Americans, as research objects. As a Navajo researcher and anthropologist in the 21st century, I believe that this foundation of literature and research presents an ideal landscape for Indigenous voices to be heard, both *because of* the longstanding history with *and* objectification of Indigenous people. The work I share with you in this dissertation aims to acknowledge unfortunate histories and move those discussions forward in productive ways that benefit Native American people. Anthropology, and knowledge in general, have been used to empower colonialism and displace Native communities; Scientists today must repair colonial relationships by producing knowledge in partnership with study communities.

CHAPTER 1 – Introduction

My story is important, as are the stories of any Navajo or Indigenous person. My journey speaks to a "non-traditional" academic path. I would argue that non-traditional does not equate to an experience that is rare. I often wonder if I had heard a story like mine, or if I had seen people like me growing up, what kind of scholar I might have turned out to be. A story about a Navajo boy who failed at academics, lived a whole other life, returned to school on a whim, and achieved a doctorate would have been a powerful tale to look up towards. Thus, I am sharing this personal history with you now. This dissertation is titled, *Pathways to Elevating Indigenous Voices in Anthropology*. One of those voices is my own. I choose to use this platform to both contribute to academic literature as well as decolonize academic spaces with my voice and the voices of other Indigenous people.

Much of research begins with a problem or a question. A problem that I had in 2009 was that I was stuck in a rut. A lifetime ago, I was a server in a small "mom and pop" Italian restaurant in San Diego, California and I did not appreciate that every semester *my* work schedule changed because the other servers who were students had new class schedules that I had to accommodate. For years, this was my existence. It always seemed that I would just get used to a schedule and establish regular customers and then I would have to start again with a new schedule. This was both frustrating and had an impact on my wages. Ultimately, I did not think it was fair to me.

To many people, this may not seem like a big deal. To me, it was a big deal. I was an excellent server! The amount of effort and time it takes to build a clientele and successful restaurant business is immense. My work meant a lot me and my customers adored me. The other servers benefitted from a happy clientele base, thanks to me, and I was left to build business during unwanted shifts.

Secure in my position with the restaurant, I decided to go back to school and burden my co-workers with the same inconvenience to which I had been subjected. The local community college was San Diego City Community College. The price per credit hour was ridiculously low for residents of San Diego County, $25 per unit. Additionally, students who met certain income requirements often got their tuition costs returned. For the small cost of attending college classes I was able to enjoy the carefree existence of a student. This is all to say, that my petty plan to stick-it to my co-workers and friends is how this dissertation begins.

A year or more into my petty plan, I had nearly completed all my general education requirements to transfer to a university. The pettiness of my plan had long passed. At this time, I embodied being a student and enjoyed learning. With an Associate's of Arts from City College, I envisioned myself being the first in my family to receive a college degree. A Bachelor's degree was still a dream too futuristic to even imagine, but that new dream was beginning to find shape in my mind. I remember struggling to decide on what course I would choose for my physical science requirement. It seems weird now, but back then I thought science was something that was not for me. I

do not know who I thought fit that mold. I now know that these feelings exemplify a lack of Indigenous representation in the sciences and academia in general.

Yá'át'ééh. Shí éí Naakai dine'é nishłí, Bilagáana bashishchiin. Ta'neeszahnii dashicheii, Bilagáana dashinalí. Ákót'éego diné nishłí. All that is to say, I am a Navajo (Diné) man who happens to know his clans. Today, as you read this, I also hold a doctorate in anthropology. I am so very proud of these two parts of my identity, but they often represent two very different and valid ways of engaging the world around me. I am an Indigenous anthropologist.

I had never seen an Indigenous scientist. I had never even seen an Indigenous teacher before I had already achieved a Master's degree. I suppose that explains an odd conversation I had a few years into my undergraduate program at Arizona State University where I was working hard to attain a Bachelor of Science degree. A professor was lecturing to the class and encouraging us about the possibility of graduate programs in our future. After class I had a small chat with my professor about something else inconsequential. She asked me what I thought about the graduate school lecture. I said it was great, but it was not really relevant to me since I was an older student who, many years earlier, had failed out of college.

My statement made perfect sense to me. My logic was that graduate school was for smart people and I my experience as a college drop-out, now labeled a "non-traditional" student, told me that I was most obviously not smart. I surmised that because

I was not able to complete an undergraduate degree until I was the advanced age of 31, that everyone would be able to plainly see how stupid I was. I would most definitely not be the type of person a graduate program would consider. I did not think those exact thoughts, but this was the narrative that informed my position on the subject of graduate school.

My professor looked at me in that moment with a look that confirmed I was stupid. But then she said something I was not prepared for, she said, "If you're not the type of person a graduate program would want, I don't know who is…" She had a very different perception of me than I had of myself. As my professor her opinion meant a lot to me, so I thought twice about what she had to say. She saw me as a man who beat odds to achieve something he never thought he could. It would take me many more years to actually see what she saw. But with those words she set me on the path to find that reality of being a graduation student. Armed with her confidence in me, I reached for graduate school to attempt earn my doctorate degree in anthropology.

Being an anthropologist would not have been my first choice. It wasn't until a professor challenged me to read Bryan Sykes' (2010) book *The Seven Daughters of Eve* that I began to catch feelings for anthropology. The book is written for a wide audience and talks about mitochondrial DNA studies and what they have contributed to human understanding of population migrations and ancestry analyses. I found it all interesting, but I was really fascinated by the book's description of PCR and how it came to be. PCR is the technology that makes genomics possible today (Sanger and Coulson 1975). It all

sounded like laboratory witchcraft! I found that I dreamed of a career tinkering in a lab with all sorts of scientific potions, but I still had little idea what that meant.

As a graduate student studying anthropology, I eventually wanted to know more about what anthropology had to say about my people, the Navajo/Diné. I discovered that Western thought permeated academic interpretations of Navajo histories. By simply referencing Navajo origin stories, a Navajo person would know that the Navajo have been in their homelands for all of time. However, Western literature says that Navajos originating in the Southwest is an impossibility because all humans evolved out of Africa (Templeton 2002). The science behind this is irrefutable and only gains evidence daily. The problem I saw was that anthropologists make few attempts to understand Navajo or Diné origins centered in Diné ways of knowing. Much of how the world's populations understand themselves is through the narratives of the dominant society. Whatever narratives the Navajo have about their histories are only examined enough to see how they might fit into a dominant narrative and then they are cast aside.

From the perspective of a Navajo anthropologist, I can see how both realities can be true and not diminish the value of any knowledge. I do believe that all humans share a single origin and I do believe the Navajo originated in the Southwest. Navajo are not *all humans;* they are a social group. There are unspoken assumptions that muddle interpretations of the Navajo the past. There is a common assumption that Diné and Navajo are terms that are synonymous (Kluckhohn, Leighton et al. 1974, Iverson and Roessel 2002). It is thought that the former is simply what the Navajo call themselves in

their language and the latter is a Spanish term that has remained common since first contact. We assume that all humans abide by a single linear time construct; and we assume that knowledge rigorously obtained will benefit everyone. These assumptions can become reckless and are another reflection of a specific perspective on history. By collapsing these terms for Navajo people, one can inadvertently collapse the histories of these people and lose sight of the individual histories of each category. One way to simplify this understanding could be to say that the Navajo are a Nation of people who claim the histories of the Diné and who are today referred to as Navajo or Diné. That statement only hints at the complex nature of how colonialism shapes and distorts our realities. My position as an anthropologist is that perhaps there are some lost histories that could be elaborated upon if we expanded Navajo thinking about the past in Diné-specific ways.

American Anthropology has a foundation of revealing the stories of Native Americans from the scope of a Western lens. Archaeology, specifically the archaeology that tells the stories of Navajo people, has begun a shift towards interpretations that incorporate Diné perspectives to better align the theoretical orientation and focus of research (Thompson and Towner 2017) to the people being studied. This shift is likely paramount to mending harmful research relationships of the past across all fields that study Indigenous or other marginalized peoples. Aligning genomics research and interpretations to Diné and other Indigenous perspectives is similarly important. Examples of research harms against Indigenous people in the name of genomics have been well publicized and discussed (Garrison 2013, Kowal 2015, Garrison, Hudson et al.

2019, Hiratsuka, Beans et al. 2020, Hudson, Garrison et al. 2020). If and how to move forward will take a specific understanding and accounting of each Indigenous communities' unique history and current needs. Hence, finding new and innovative ways to uplift Indigenous perspectives will foster knowledge production that will benefit those Indigenous people in anthropology and beyond. In the absence of Indigenous voices, the dominant social paradigm that impacts Indigenous people, colonialism, works to oppress and erase Indigenous identities and histories.

I present here 3 chapters that bring forward different Indigenous voices in different ways. These works aim to create a space where Indigenous futures are represented and shaped by those voices. We have reached a time when it is no longer acceptable to narrate the histories of other people. It should be obvious that Indigenous people should be the ones producing and validating knowledge about themselves. That is not to say that this path is not a long journey that will involve much collaboration. Rest assured, non-Native anthropologists will find a lifetime's worth of work, but only in partnership with those who they study. The anthropology of the past has been canceled. The subsequent chapters attempt to advance important dialogues about the Indigenous experience in Indigenous ways.

A note to clarify use of terms. *Native American* is a term that has complex meanings and uses. Native American could refer to any Indigenous peoples throughout North or South America. That is not how I use the term in this manuscript. My use of the term Native American often refers to the people who make up the nearly 600 federally

recognized tribal nations that reside within the boundaries of the US. This definition implies a person is enrolled in one of these Nations, and enrollment is not always the case making this definition problematic in some instances. Generally, the use of the term Native American in this manuscript references the social construct of Native American identity that includes both enrolled and non-enrolled peoples. Similar to Native American, *American Indian/Alaska Native (AI/AN)* (used in chapter 3) references the Indigenous peoples of the US and are terms that are grounded in the US constitution and concepts of tribal sovereignty. *Indigenous*, as I use it, is a very board term to describe the people around the world who have been impacted and maintain a relationship with a colonizing entity. The most ideal terms for Indigenous people are the tribal affiliations they claim or how they reference themselves. Careless use of Native American or Indigenous as identifies can inadvertently delegitimize the specific histories and struggles of a people.

Chapter 2 discusses the complexities inherent in the dichotomization of "Western" science and Indigenous Knowledge. This work, specifically, focuses to create a space within the academy by questioning the structure and the validity of this construct. I argue for empowering the dichotomy in ways that move Indigenous Knowledge into the spaces of "Western" science and engaging Colonial Knowledges from an Indigenous lens.

Chapter 3 is adapted from Blackshar et. al (2021). Chapter 3, also called the "Cross-site" or "methods" paper, explores the work conducted by the Center for the

Ethics of Indigenous Genomics Research (CEIGR) and partners. The paper reflects on a larger set of projects across three American Indian and Alaska Native communities. The CEIGR deliberation team began planning this work in 2017 and completed the projects in 2019. My primary role as a lead research personnel was to develop scenarios in close collaboration with partner sites. The site-specific case scenarios were designed to use appropriate language, to include cultural nuance, and to reflect the locality. The deliberations elicited a sample of three community voices to discuss attitudes and concerns about various types of genomics.

Chapter 4 is a project I took on myself as an independent researcher. The project was conceived because of an unusual experience about direct-to-consumer (DTC) genomics I continued to encounter during science outreach activities and lectures with the public. My odd experience often involved members of the public sharing their personal DTC ancestry results with me and was most directly related to my Indigeneity, I believed. I chose an Indigenous methodology to explore if this experience was common to other Indigenous people. The use of Sharing Circles to understand Indigenous identity and genomics felt like a respectful way to engage the topic with the Native people whose stories were shared.

The conclusion reflects on the power of these voices: my Indigenous anthropologist's voice (Chapter 2) that examines the knowledge entanglement, the Indigenous community voices elicited by the CEIGR deliberation projects (Chapter 3), and the Indigenous student voices shared in the Sharing Circles (Chapter 4) and what

they all might mean for the future of Indigenous anthropology and research. Despite a history of erasure and oppressive practices, we find that these Indigenous people represented here have meaningful contributions toward new and innovative research and science practices.

CHAPTER 2 – Entanglement, Sovereignty and Science*

ABSTRACT

Science has been colonized. Indigenous Knowledge and practice remain entangled in colonial and racial logistics that fosters a binary of "Western" science and Indigenous Knowledges. Here we explore this entanglement. We argue that scientific methods should be disappropriated from the perceived "Western" paradigm, to foster bidirectional exchange of information between knowledges resulting in reduced bias in the type of hypotheses raised and investigated. We argue against views that would promote Indigenous Knowledge as rigid, nonadaptive and antique, revealing flaws in the perception of non-western knowledges and the connection to investigative practices that today would be deemed science. The investigation of nature is inherent to much of human reasoning. This process is timeless and near-universal, with no rights to ownership of any entity or group. Indigenous Knowledge, Western Knowledge, Colonial Knowledge, or any local and regional knowledge is distinct from science, but not mutually exclusive. This reality permits an acceptance of an entanglement and a path to make scientific efforts wiser and empowering and encourages Native American sovereignty - self-determination.

INTRODUCTION

Federally recognized tribes in the United States of America (US) are sovereign nations, this status represents a formal nation-to-nation relationship between specific Native American communities and the US government. There are nearly 600 such nations today. Sovereignty, as it has been generally understood, describes the rights of a people to rule themselves, in their place, in their way (Lyons 2010). But by virtue of existing within a settler state, tribal sovereignty in the US has historically been challenged by a structure looking to undermine a tribe's right to oversee and govern their own land, economy, health policies, data, or any other valued resource. Scholarship on the dynamic nature of Native American sovereignty has described it as "nested" within the colonial regime (Simpson 2014) or even "interdependent" (Cattelino 2008) on the colonizer. This is because of an ongoing and incomplete colonial process which has caused Native American sovereignty to be negotiated in various ways through, and with, the US, as well as with other international governments independently (Cobb 2005). Today, sovereignty is understood as the maintenance of complex networks of political, economic, and social relationships (Cobb 2005, Cattelino 2008). However, tribal sovereignty is unique within the settler state model of existence because these relationships are rooted in the history of the colonization of North America. The unbalanced nation-to-nation relationship has fostered well known disparities among Native American people, including impoverished living conditions, lowered socioeconomic statuses, and poor health with limited healthcare options. For Native Americans, a mutually beneficial form of sovereignty is far from fruition given the colonial legacy, which levied heavy burdens and continues to

attempt to subordinate Native American tribal governments. The subordination of Indian Country is pervasive and ultimately harmful.

The lasting impacts of colonialization cannot be overstated. The hegemony of the colonial legacy has attempted to dictate, today and into the past, where Native people live, how they are defined, and even what knowledges they may claim. The most obvious legacies of colonialism are seen in places like Native American reservations - the now adopted homelands of the US' Indigenous populations, and concepts like blood quantum – the embodied biological measure of race still used by many Native American nations today to define citizenship. More complex legacies of these events present in differences in socioeconomic and health statuses between Native Americans and non-Natives. Regardless of the rubric, life is categorically changed for Native American people today and these changes are defined within a framework of colonial rule. At its core, the act of colonization institutionalizes an ideology of conquest and domination, and that ideology persists in many forms.

Decolonizing and indigenizing movements in academia aim to mitigate this history of trauma and oppression that can manifest in unequal representation both in people, and ideas, in leading professional fields and at the point of knowledge production. Those scholarships aim to create spaces within the academic institution for Indigenous perspectives and growth (Archibald 2008, Kovach 2010, Smith 2013). Decolonizing and indigenizing of the academy works to destabilize inherent power dynamics that amount to epistemic violence (Parker, Smith et al. 2017), while also being poised towards

reevaluating and re-envisioning the standards of information quality, collection, and curation. The ultimate objective is to offset the Eurocentric imbalance imposed by and within academic institutions, where knowledge is not only produced but legitimized. Qualitative fields, largely the humanities and social sciences, have led much of these movements in academics for Indigenous people. Going forward, to advance Indigenous inquiry both qualitative and quantitative forms of research must be represented. We argue that science has been colonized, and that Indigenous Knowledges and practices have become entangled in a problematic colonial understanding of what constitutes sound investigative practices. This entanglement encourages the use of colonial and racial logics and only through recognition of the fallacy of these embedded logics can these knowledges mature. In this paper, we focus on this entanglement to attempt to highlight where subtle intersections and disruptions can be explored and exploited to continue to benefit Native Americans and tribal sovereignty.

Entanglements, as used here, can be understood as a way to explore the complex processes of social identity negotiation where individual and national identities are understood within a colonial context. The imposed divide between the perceived "Western" science and Indigenous Knowledges provides an opportunity to explore how Native American identities are shaped within this binary. Entanglements are incidental attachments, affinities, antagonisms, and animosities that bring people, concepts, and in this case knowledges, together into each other's orbits (Nuttall 2009, Dennison 2012, Nading 2014, Dennison 2017). The categories of science and Indigenous Knowledges are defined in opposition to one another. As with many settler-colonial binaries, they are

defined as diametrically different. Our concern is in how these colonial dichotomies diminish possibilities for Native American and other Indigenous futures. The entanglement of Indigenous knowing is deeply intertwined with a racial understanding of what is perceived to be Native and what is not. Because indigeneity is often defined through colonization, Indigenous Knowledge, too, is positioned to be colonized, erased, or assimilated per colonial logics (and power mechanisms).

A STATEMENT OF OUR POSITIONS

Author JRL

I am Diné of the Navajo Nation from Ganado, Arizona. I am Naakai dine'é, born for the Bilagáana; **ákót'éego diné nishłį**. Additionally, I am an anthropologist and research scientist for the Center for the Ethics of Indigenous Genomics Research (CEIGR), an NIH funded Center of Excellence in ELSI Research. My research and work explore the intersection of genomics, Indigeneity, and bioethics with the specific aim of elevating the Indigenous perspective and voice to ultimately empower Indigenous forms of sovereignty.

Perhaps it is cliché to say that I often feel as if I must balance two worlds—perhaps it isn't. When I was a graduate student, I struggled to reconcile my Indigenous identity, my research interests, and the academy. I continually questioned if anthropology or genomics could ever truly be decolonized or indigenized. American anthropology was founded through the use of ancestors as willing and unwilling study subjects; and genomics is only a stone's throw away from its predecessor, eugenics. My concerns

about those realities fueled the uncertainty I felt of my own place within the practice of molecular anthropology, but more generally, within Science.

For me, the discussion below highlights both the unstable nature of colonizer knowledge dichotomies and also the power of a recognized knowledge reserve. The future of Indigenous science, Indigenous genomics, and even Indigenous anthropology may find power from being seen today. Unequal benefits from research and research practices only contribute to the long-standing tradition of marginalizing Indigenous people and appropriating their valuable knowledge and resources. I believe confronting these truths can be fruitful and mitigate the potential of future harm and marginalization. In a perfect world, these words will encourage some other knowledge seeker that there is space for everyone.

Author CML

I am non-Native, largely European descent American citizen born in Zeist, the Netherlands. Additionally, I am an anthropologist, tenured professor, with involvement in two research centers, the aforementioned CEIGR and the Laboratories of Molecular Anthropology and Microbiome Research. My research has largely focused on inclusion of underrepresented communities in human biological research, with particular interest in the last 15 years on the human microbiome.

I am an anti-racist, but I am also embedded in structures that have promoted racist thinking. I promote equity in the authority of research, yet much of my outward

character produces an unearned, unequal, power – I am white, straight, and male. By being in a position of power, I contribute to the statistics of inequity; yet, while my presence contributes negatively, I hope my actions contribute positively. I identify, with great passion, as a scientist, but I recognize the great load that term bears. I see that I am entangled, and in confronting this entanglement, I hope to grow. Hindsight has giving me much understanding in my failed attempts at being progressive in ethical approaches, but I remain determined to improve. Much like climate, science has and will continue to change, and much like biological evolution, that change will be at the whim of stochastic and selective forces. As an anti-racist, I am a contributor to a selective force on science.

My motivation to co-author this paper is driven by my desire for personal growth and a desire to be more engaged with equity over inclusion. Equity, in who is making the decisions of science, who is leading the questions, who is performing that science, is a much harder goal than inclusion, and equity in who decides what **is** science, even more so. The personal growth, the new understanding, I achieved during the many discussions leading this perspective is the discovery of the extraordinary degree to which science is impeded from being colonize, diminishing rigor, innovation, and relevance.

INDIGENOUS KNOWLEGDGES & COLONIAL KNOWLEDGE - SCIENCE, PRACTICE, AND POLITICS

It is important to first acknowledge two underlying, yet framing, issues that contribute to the problem at hand. The first issue is the grandness attached to a phrase like “Indigenous Knowledges.” It should be recognized that the phrase encompasses a massive array of tribally specific histories and ways of knowing that are not intended to be seen as the same. The effort here is not meant to lump all Indigenous groups together but rather to attempt to properly position Indigenous Knowledges within the global amalgamation of knowledge systems.

“Science” also bears a grandness. The word “science” often carries with it the assumption of all things rigorously testable. It implies a superiority in knowledge, with exclusive membership. Yet, humans have been documenting and building upon testable knowledge as a defining character of our species long before the term “science” became popular. More contemporary, science, as a cultural practice, has been a way of organizing knowledge to build generalizations (sometimes called laws) and test and develop explanations (sometimes called theories) of the universe (Wilson 1999). Science is a way of conducting an investigation, and under this identity, has made unprecedented achievements. Yet, this practice does not exclude Indigenous forms of testable knowledge, yet Indigenous Knowledge is often commonly defined as something that cannot be credible science.

One could define Indigenous Knowledges as those cultural knowledges collected, used, and reproduced by Native people to aid in understanding the universe. Indigenous Knowledges may model everyday living, from guiding one on how best to interact with their environment to understanding the causes and treatments for illnesses. Often, as part of this knowledge process, recollections of times and events were interrogated and reconfigured to provide meaningful answers to present questions or problems. These observations are collected using the entire body of human senses in direct participation with nature (Cajete and Bear 2000). This understanding takes note of not just the relationships in nature, but also the observer's relationship to what is being observed. Nature is viewed as a narrative waiting to be revealed (Kimmerer 2013). Indigenous wisdom contextualizes the natural world in an intimate and personal way so that the practitioner also understands his or her role and place within the structure attempting to be understood. These types of knowledge systems have been used successfully for the entirety of human history. Additionally, Indigenous Knowledges and inquiry are guided by a research paradigm that often represents differences in the practitioners' place, beliefs, and values concerning the natural world *and* recognizes the Indigenous role in a colonial society. Undeniably, if we define units by place, there is a treasure trove of European Knowledges, Asian Knowledges, African Knowledges, and multitudes of subdivisions, fissions and fusions of knowledges that bear distinction, yet not exclusion, from scientific knowledges. Yet, Indigenous Knowledges rarely have such acceptance.

Indigenous Knowledges, as a singular category, are often defined in opposition to "Western" science. This binary contrast is deceiving. The label of "West" has been used

to mark the occident from the orient (Said 1985). In other words, to define that which is familiar against that which is foreign. This unfortunate colloquialism represents a number of colonial dichotomies that are pervasive and only bring to the present a long history of European imperialism and colonization.

Upon definition, "Indigenous Knowledge" is a racialized category of knowledges that continues to suffer, and be governed, by racial logics. The world's Indigenous populations have been defined in opposition to their colonizing counterparts. Presently, indigeneity must navigate this social mine field. As a result of racial logics, similar to Native American sovereignty, Indigenous Knowledges are at best "interdependent" or even "nested" within the perceived hierarchy of knowledges. At worst, Indigenous Knowledges are perceived as the cultural knowledges of Native Americans that cannot be legitimized. Undoubtedly, these concepts are defined within a colonial framework that lends support to the colonial ideology of dominance and erasure over indigeneity. Through this ideology, it is dictated what knowledges are rationalized as useful in contrast to what knowledges are merely expressions of identity. Indigenous advancement becomes equated to Western assimilation rather than Indigenous innovation. The logics of domination, assimilation, and erasure are embedded within this dichotomy and must be dismantled to foster sovereignty of tribal intellectualism and data.

Many contributions from Indigenous Knowledge have been added to the global canon without much credit to their originating community. Governments in partnership with powerful global corporations use intellectual property rights policies to establish

ownership over specific forms of knowledge and Indigenous people are often at a disadvantage in these types of political and economic dealings (Jackson 2010). One example, the appropriation of corn knowledge has happened historically, but it is maintained presently through patent and intellectual property rights and policies that only serve the colonial ideology and continue to mask Indigenous ingenuity. Meanwhile, corn represents a staple in global foodways and production while not providing any economic benefits back to the people displaced from their lands only a few centuries ago from whom the technology was stolen. Knowledge is a powerful and valuable resource and must not continue to be appropriated. If Indigenous Knowledge is truly dynamic, which it is, knowledge produced by Indigenous people today and into the future should so be credited as such. This is not only important but ethically logical. Nations are producing valuable scientific products and Native nations are seemingly removed from this process.

Scientific knowledge has been less bound by borders and has been well adaptive to new rationalized approaches to investigation. The seemingly rigorous standards of quantitative work are presumed to create a rigid framework where the perceived subjectivity of other human knowledges has no place. This subjugates work outside the current paradigm, creating a fallacy that any data derived outside of this framework must be less "objective," and therefore, in conflict with the rigorous investigative practice that is thought to define science. The result is an unbalanced, self-defining dichotomy that positions Science above all other knowledge forms virtually creating what could be defined as Colonial Knowledge. The colonial logic of acquisition of resources is only

inadvertently embedded in scientific discourse in that advancing science is expensive, and in a capitalist global society, the politics of science play out monetarily.

The communities of scientists contributing to that knowledge system include members of all major nations today and into the past. Scientific Knowledge represents something distinct from Indigenous Knowledges, yet not required to be mutually exclusive. Indigenous Knowledges are cultural and local, and thus, Indigenous Knowledges are perceived to be only useful to local Native people. Science has become defined as systematic and structured, and its knowledge products are legitimized through a network of agreement between likeminded academics. As a result, Native understandings and Indigenous intellectual goals are often at risk of being perceived and dismissed as a silo of thought, while the academy and scientific practice continue to be legitimized as global, even when its product represents a clear western, colonial, bias. The question then arises: can Indigenous Knowledges be science with equivalent information quality, adaptable, and legitimized by a panel of peers?

Science, as it is practiced daily, is an investigation of nature, using an array of ever-changing investigative tools and approaches. There is a general acceptance that bias in any investigation needs to be recognized to avoid mischaracterization. In that spirit then, it must be recognized that the fields and structure of "Science" today are defined by and within a colonial legacy. This bias needs to be recognized. The concept that Indigenous Knowledge is fundamentally distinct from Scientific Knowledge lacks a recognition that much of the now rejected "scientific" knowledge was fostered by a

colonial world view, a Colonial Knowledge, including concepts such as the now rejected view that the Earth is the center of the solar system, which required the scientific investigation beyond any tyrannical culture to move beyond a deeply embedded "Western" cultural bias. Colonial Knowledge follows colonizing logics, acquire and assimilate. In the same vein, Indigenous Knowledges falls victim to racial logics. By uncritically racializing knowledge systems, we have all participated in the continued colonization of knowledge. Not to mention, we have inadvertently diminished the possibilities for a dynamic Indigenous Knowledge, and similarly Native American sovereignty - self-determination and advancement are so too diminished.

Science is cultural, and much of the direction of science includes an organic and deeply cultural process. That said, we do not want to jeopardize that aspect of the science identity that fosters and innovates critical investigative methods, otherwise we enable the pseudo-science narratives that perpetuates racism, climate change denial, anti-vaccination, and religious and national revisions of facts. We also want to celebrate and share that which the science identity has fostered. Scientists have cured countless diseases, landed what is essentially dune buggies on mars, and have harnessed the power of the atom. They have saved countless lives and provided great improvements to our quality of life, in transportation, in communication, in medicine, in all aspect of our physical experience. At the time of this writing, vastly more people today live longer, in less pain, than any other time in history, and much of that can be attributed to science. Very few today would choose a lifestyle where they abandon the tools made from science, including Native people. Indeed, fostered by the cultural construct of science, the

level of sophistication in investigations of nature has brought countless rewards. And yet disparities related to health, quality of life, and life expectancy continue to mount for Native American communities. With this understanding, it is paramount that we reposition knowledges outside of the logics of a racialized colonial lens.

Science indeed empowers, and throughout history and today, has empowered colonialism. Because science is a construct, and a powerful tool, the disappropriation of science from colonialism is not only logically valid, but rewarding, both for the empowerment of Native nations and in the improvement of the wisdom of those practicing science. No culture can claim ownership to science and "Science" does not equal "the West." Yet, society continues to define knowledges in these ways. The national and the political nature of "Western" science has been well documented (Agrawal 1995, Harding 2008, Agrawal 2014, Harding 2015, Marks 2017). In the US, the government funds the majority of academic science for its own national recognition, as much as if not more so, than for human enlightenment. Scientific advancements in the US have been made for the benefit of the US. This type of national recognition is not unique. All the world's most powerful nations participate in this scientific arms race. The entangled definition of science would assume that science is all knowledge, known or unknown. When in fact, science is an investigative practice influenced by politics and policies of the time. As sovereign entities, Native nations should too be participating and benefiting by producing intellectual achievements that reflect their national and cultural identities.

MATURING SCIENCE WITHIN ENTANGLEMENTS

Returning to our question, can Indigenous Knowledges be science with equivalent information quality, adaptable, and legitimized by a panel of peers? In terms of what constitutes a critical investigation of nature, a subset of Indigenous Knowledge has always been science, and similarly, only a subset of Western Knowledge meets even a most generous definition of science. Identifying and acknowledging the politics of indigeneity, and of knowledge production, has thus far been the issue with a legitimized Indigenous Knowledge. Indigenous Knowledges are by definition inextricably tied to ideas of race and thus follow racial logics. Native Americans, their culture, and their identities suffer from the racial "logic of elimination" (Wolfe 2006). This logic describes how settler-colonies require the eventual absence of the previous inhabitants to maintain authority over the acquired land, resources, and knowledge. Because Indigenous Knowledge cannot be legitimized in the same way that Science is, it serves this logic's purpose. The category of Indigenous Knowledge, as less legitimate than science, reinforces a perception of Native American inferiority and justifies subordination. By categorizing knowledge systems around ethnic boundaries, we have fallen into centuries old racist ideological traps. Thus, maturing science requires Indigenous Knowledge to be recognized and no more distinct from science than Western Knowledge, Eastern Knowledge, or any other knowledge that implies a cultural connection, and broader scope of knowing, than those investigations that define science.

The knowledge dichotomy is defining of the concept of nativism, a subset of racism, in that by way of these categories the boundaries of acceptable and unacceptable

are set. Briefly, nativism can signify that which is out-of-bounds; nativist topics are typically relatively neutral, it is societal discourse, as well as, point of view that make a phenomenon more or less nativist (Bosniak 1997). As with the neutral topic of knowledge, it is not until we define the racial boundaries of knowledges that racialized discourses are invoked. Additionally, nativism describes a perceived threat by the ethnic identity of another group (Bosniak 1997). Colonialism perceives Indigenous goals as a threat; subordinating Indigenous Knowledge manages that threat and maintains colonial authority. Most concerning about nativism is the way in which, like racism, it can make use of dubious and ideologically loaded categories (Mbembe 2001). The category of Indigenous Knowledge, as inferior to science, continues to explain and define Natives as inferior to others. Here, nativism amounts to the "whitewashing" (Dennison 2014) of science, where certain ontologies are positioned as normative and those ontologies are used to continue colonialization of the Americans and further oppression of Native Americans.

What is ignored in the dichotomy between Colonial Knowledge vs Indigenous Knowledge is the extraordinary magnitude of Indigenous innovation. A globally impactful tradition that includes domesticated plants and animals to a deep history of monumental engineering, all of which required critical investigation, that if placed properly in the Western worldview, would be, undoubtable, described as historical scientific accomplishments and be proof of the legitimacy of traditional forms of thought. This structure assumes that, prior to the institutionalization of the "Sciences" as fields of study, that "scientific facts," as defined today, were unknown. The innovations of Native

prehistory, by all evidence, rejects this idea. Moreover, the innovations of ancient peoples, globally, rejects this idea. The institutionalization and global structure of current sciences today was achieved by standing on the shoulders of clever ancestors, those ancient peoples, on a global scale. Pervasive in our media is the rejection of these accomplishments, consider how popular it has become to attribute feats of Native engineering to extraterrestrials over brilliant ancestors, a shameful example of erasure that is still deemed acceptable to mainstream programming.

The topic of Colonial Knowledge and data has primarily been focused on interrogating the past. Colonial Knowledge has been defined as the reports, ethnographies, statistics, censuses, revenue assessments, personal memoirs, novels, scientific texts, paintings and other types of materials that were produced and used as part of the administration of colonial rule (Roque and Wagner 2012). Similar to other scholars (Roque and Wagner 2012), we find "colonial" to be a productive starting point rather than a negative positioning. Through recognition of the coloniality of certain knowledges we can: (Roque and Wagner 2012)

- accurately place knowledges as objects of research and discussion
- acknowledge the historical relationships and epistemologies of these data
- begin to understand that science does not constitute a single hegemonic discourse
- recognize historical relationships between European and Indigenous people and ideas, while

- elevating Indigenous voices from being lost as the voices of Indigenous informants

These reading strategies disappropriate science via exploring colonial culture. This definition of "colonial" allows for discussions of Colonial Knowledge to be as an epistemic practice that can inform and articulate ideas and specific histories of the past. In our work, we hope to further this conversation by acknowledging that current scientific discourse, from the Indigenous perspective, is burdened by Colonial Knowledge in practice.

The same reading strategies that have been used to engage historic Colonial Knowledge (Roque and Wagner 2012) can be adapted to suit the needs of engaging Colonial Knowledge in current practice to provide a much richer collection of data. These strategies are often practiced in pursuit of indigenizing scientific discourse; however, they are not often stated. First, scientific discourse must be interrogated for colonial voices. These voices attempt to shape and define the boundaries of indigeneity from a clearly non-Indigenous lens. It is this voice that ignores tribal relationships and histories, culture, and sovereignty. Second, the "against the grain" strategy requires that scientific methods be disappropriated from this unhealthy paradigm so that Indigenous voices are heard with the same legitimize power as any other voice. Indigenous voices creating Indigenous science will begin to dismantle inequity of information. Third, and finally, this strategy recognizes the relationships that must be fostered for the benefit of everyone, Native and non-Native alike.

Indigenous Knowledge is said to be different from "Western" science in specific ways: substantively, methodological and epistemologically, and contextually (Agrawal 2014). Future disruptions of the knowledge paradigm should expand upon these differences. Admittedly, the dichotomy is false in our framework; science, as we define it, belongs to everyone. However, the racial divide and social consequences of that divide are real. By engaging Colonial Knowledge productively and empowering Indigenous Knowledge in the ways that are noted distinctive, we will begin to bridge the divide between epistemologies and people, as well as support Native American self-determination and sovereignty.

There are benefits to a knowledge entanglement. Indigenous Knowledge is an Indigenous *space*, a political space. Inadvertently, the category of Indigenous Knowledge has provided Native people a clandestine space. Indigenous Knowledge is a space that by definition excludes white and non-Native others. While not trying to be an exclusionary place, its position as inferior to other forms of knowledges discourages others from venturing. As a result, there are few, if any, colonial authorities policing the significance of the knowledge products created and maintained within this space. Indigenous identities find a safe haven in this space; it is a space where distinct types of nativeness and indigeneity can openly be explored and reproduced. Indigenous Knowledge is a type of *knowledge-reserve*. Much in the same way that land-reservations were instituted for Native American control but have since allowed for a land-base from which to assert sovereignty and a national identity, a knowledge-reservation could be and is wielded in the same manner. As these knowledge-reserves mature, also these contextual perspectives

of scientific inquiry mature science, encouraging investigations that are more relevant to the needs of such spaces, and when relevant, partnership outside these spaces provides a mechanism by which a larger community of sciences gains fresh perspective, disrupting stifled ideas that burden a monoculture.

Examples of the productive use of Colonial Knowledge and the usefulness of engagement strategies are becoming more available to the public. Demonstrating the first engagement strategy, one recent report on the study of the Diné of the Navajo Nation (Begay, Nanibaa'A et al. 2020), explored 92 years of genetics research done on Navajo citizens. The report explores the colonial voices for valuable information that could potentially be used for future research directions and national policies that will be outlined by the Navajo Nation.

Bringing Indigenous voices to the forefront of scientific discourse is happening. In the past, identifying the research priorities of Native people was not a consideration. In engaging “against the grain”, the goal is to insert the Indigenous voice where it has been lost. Native and non-Native researchers have been working together to elevate the voices of specific Native American communities in regard to their perceptions and concerns of genetics research (Blanchard, Outram et al. 2019, Hiratsuka, Beans et al. 2020, Reedy, Blanchard et al. 2020). This work represents a beginning of an understanding on how research and cultural beliefs and practices can work together for the future of Native people.

In February 2020, Wayne State University Press and the journal *Human Biology* published manuscripts exemplifying "Indigenous Science." The editors state a goal to present and elevate interdisciplinary research that incorporates Indigenous traditional approaches and worldviews in the sciences (Tsosie and Claw 2020). This special edition includes peer review by Indigenous scholars and researchers. Initiatives, such as this, represent active disruptions to the dominant paradigm. The current entanglement of knowledges would insist that this work is merely charming or endearing, if not altogether romanticized. However, "elevating" this work to the status of peer reviewed science disrupts that type of colonial nostalgia. Not only has the work been presented in a biological scientific journal, but the work has been legitimized by Native American peers. With the rise of more Native American scholars in academia, more disruptions such as this can be expected.

Recognizing and nurturing beneficial relationships is gaining momentum. For some time now, Indigenous scholars have been working towards equity in research. Indigenous scientists have created guides on best practices when conducting research *with* Māori people in New Zealand and *with* Aboriginal and Torres Strait Islander peoples in Australia (Neumayer 2013, Hudson, Beaton et al. 2016, QIMR Berghofer, Pratt et al. 2019) so that the science produced about these people and places reflects the long histories of the people who have lived there. Guides for specific Native communities in the US are underway, but general ethical practices in the US have been outlined (Claw, Anderson et al. 2018). Partnerships between academic institutions, Native nations, and communities are exploring various ways of working together to address Native disparities

(Blanchard, Hiratsuka et al. 2020, Hiratsuka, Beans et al. 2020). These practices incorporate and outline Indigenous values, ways of collaboration, and the importance of relevance and transparency into research conducted with these Indigenous communities. For each community, these guidelines will be different and reflect that community.

As big data continues to become a significant resource so too will Indigenous forms of big data. What will be required are Indigenous curation practices to be envisioned and explored. Everywhere that Indigenous people exist today the discussion of best practices and Indigenous values is being had (Garrison, Hudson et al. 2019). For example, using Indigenous genetics guidelines and Indigenous-led research protocols, First Nations peoples of Canada are finding success with the Silent Genomes Project, a biorepository designed to lessen the health disparity that exists for the various First Nations people (Caron, Chongo et al. 2020). This is exciting for US Native Americans as these discussions continue to advance (Reardon 2017, Hiratsuka, Beans et al. 2020, Reedy, Blanchard et al. 2020). Disappropriating scientific methods from the Colonial Knowledge dichotomy is the direction this work will take.

DISCUSSION

Time has entwined and entangled much of our collective experiences together in ways we cannot immediately change. With the knowledge that Indigenous people do not remain stagnant nor intend to disappear, we can move forward with equitable ideals to base our collective future goals. Part of this understanding begins with evaluating our tool sets and capabilities and shaping them to the needs of the people. The aim of this paper is that it

serves to help mitigate the problematic nature of the dichotomy, but also that it serves to identify where benefit of this structure may be wielded to assert sovereignty. It was Native American anthropologist Gladys Tantaquidgeon that once said, “Remember to take the best of what the white man has to offer… and use it to still be Indian” (Bruchac 2018). With culturally-minded goals in hand, robust and tested methods of experimentation, and the free space to explore pertinent questions, Indigenous Knowledge will mature the overall practice of science and improve the possibilities for Native American futures.

The subordination of Native American nations is built into the structure of US tribal policy. Indigenous erasure is a key component of the structure of settler societies. Working together, subordination and erasure guide and shape our misconception of the past and future of Indigenous Knowledge. Colonial knowledge has been curated from all useful knowledge products it has encountered. The power of these knowledge products has built the world around us. Science has been defined ever since through a colonial lens, preferencing it and its knowledge products above all others, falling in line with a colonial ideology of dominance and oppression over indigeneity. Exploring this entanglement allows for more deliberate and critical goal towards decolonizing and indigenizing efforts at the point of knowledge production, a place where Indigenous people are typically excluded. Even when the initial acts of colonialism are behind us, the legacies of those acts continue to influence our societies in detrimental ways. Our examination shows that knowledge production happens as part of complex relationships of power, authority, as well as colonial oppression. Thus, maturing science, making the

practice of science wiser, requires that those oppressed, subordinated, become science knowledge producers, throughout the reach of science, and in doing so, science becomes more relevant.

Native identity and ways of knowing expressed through the practicing of science will only enhance human knowledges and support Indigenous forms of sovereignty. It is essential that scientific methods be *disappropriated* from the colonial paradigm. To disappropriate, scientific methods must be released from the ownership of the "West" and reclaimed by humanity; we must all move forward with an understanding that growth in knowledge belongs to everyone. There will continue to be rewards from legitimized Indigenous science that integrates knowledge from the colonizer, but in this practice, must recognize the historical legacies that work toward the colonial goal of Indigenous erasure. To heal the harmful past, Native identity and ingenuity must be explored and reproduced in *public* spaces by Native people. In maturing science, Native people should be empowered to openly and actively use available tools to explore Native issues and concerns, scientifically or otherwise.

To say that Science is truly objective would be to deny that politics play a role in what is supported to be studied and how data are interpreted. The COVID-19 crisis of 2020 exemplifies how politics influence the practice and conclusions of communicated science. Response to the pathogen differed greatly around the globe. The year 2020 has also reminded us that the racial tensions of the past are still as prominent today as ever. It would be difficult to argue the fact that human knowledge is neither static nor is it the

property of any group; yet there is this perception that attempts to delineate between science and Indigenous Knowledge. Maturing science requires recognition that the very structure of this dichotomy is political and flawed in that it assumes knowledge, and the investigative approaches, can be property, and that the system of a particular people must be static.

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CHAPTER 3 – Deliberations with American Indian and Alaska Native People about the Ethics of Genomics: An Adapted Model of Deliberations Used with Three Tribal Communities in the United States*

INTRODUCTION

Genomic research with American Indian and Alaska Native (AI/AN) peoples is an ethically and politically complicated proposition. A long history of mistreatment by the United States (US) government and federally funded researchers has sown ample mistrust among AI/AN communities and the risks of participation remain serious (Harry and Dukepoo 1998, Greely 1999, Bowekaty and Davis 2003, Strickland 2006, Di Chiro 2007, Christopher, Saha et al. 2011, Harding, Harper et al. 2012, Hodge 2012, Kelley, Belcourt-Dittloff et al. 2013, Morton, Proudfit et al. 2013, Dillard, Caindec et al. 2018). The small size of some AI/AN tribes, and in some cases their unique genetic profile, increases the prospects that such research may identify and stigmatize communities (Goins, Garroutte et al. 2011). Additionally, the path from research to tribal health benefit is often long and unclear, and research may seem superfluous, given that limited access to basic medical services among some AI/AN communities and chronic underfunding of the Indian Health Service contribute fundamentally to AI/AN health disparities (Rhoades and Rhoades 2014, Warne and Frizzell 2014). Finally, tribal sovereignty, rights, and values have implications for study review and approval, recruitment and consent, return of results, and data stewardship that fail to align with current US federal policy and American individualism (Hull and Wilson 2017).

Yet, the promise of genomic research to improve individual and community health and healthcare have led to calls for cautious movement forward (Pacheco, Daley et al. 2013, Claw, Anderson et al. 2018). Although the capacity for genomic research and medicine to reduce health disparities among minority and underserved populations is often overstated, these approaches may lead to more personalized predictions of disease risk, optimized clinical therapies, and improved health in some populations, including AI/AN people (Bayer and Galea 2015, West, Blacksher et al. 2017, Burke, Trinidad et al. 2019). But, because less than 4 percent of research participants come from people of North American Indigenous, African, and Latin American ancestry, clinical tests and treatments may not be as effective in these patient populations as they are in patients of European ancestry, who comprise the overwhelming majority (more than 80 percent) of genomic research participants (Popejoy and Fullerton 2016, Mills and Rahal 2019).

In this context of peril and promise, tribal communities need opportunities for sustained and substantive deliberation about whether and, if so, how they can participate in genomic research in ways that comport with tribal values and protect tribal peoples. That aim is foundational to the Center for the Ethics of Indigenous Genomic Research (CEIGR), a National Institutes of Health Center of Excellence in Ethical, Legal, and Social Implications (ELSI) Research and its three tribal partners: Chickasaw Nation Department of Health's Division of Research and Public Health (CNDRPH), in Ada, Oklahoma; Southcentral Foundation (SCF), an AN tribal health organization based in Anchorage, Alaska; and Missouri Breaks Industries Research, Incorporated (MBIRI), an

AI-owned private research organization based in Eagle Butte, South Dakota. In its first phase, CEIGR created the conditions in which members of each of these tribal communities could come together to learn about, discuss and debate, and weigh in on pressing ethical questions raised by genomic research and identify the values that may be in conflict by forgoing or pursuing participation in it. This paper describes the design of three deliberative forums and reports on key evaluation outcomes. The substantive results of each deliberation are reported elsewhere (Hiratsuka, Beans et al. 2020, Reedy, Blanchard et al. 2020) or in preparation.

The deliberation design and evaluative outcomes may interest ELSI and deliberation scholars alike for two reasons. First, the use of public deliberation to convene exclusively Indigenous people is novel. Public deliberation, sometimes referred to as democratic deliberation, is an approach to stakeholder engagement that convenes diverse members of the public to provide well-informed, carefully considered input on value-laden issues of collective concern (Burkhalter, Gastil et al. 2002, Gastil and Levine 2005, Kim, Wall et al. 2009, Blacksher, Diebel et al. 2012, Curato 2012, Abelson, Blacksher et al. 2013). Researchers have used other approaches (e.g., interviews, surveys) to gather input from AI/AN and Indigenous peoples on issues of genomic research (Bennett and Smith 2007, Garrison 2013, Sahota 2014, Hudson, Mead et al. 2019) and deliberative methods have been used to gather input about genomic research in several nations, including in Canada where Indigenous people were included as participants (Avard, Bucci et al. 2009, O'Doherty and Burgess 2009, Lemke, Halverson et al. 2012, Dry, Garrett et al. 2017). Researchers have also used deliberative methods to gather input

from other marginalized communities (i.e., African American) on ethical issues in genetics policy (Bonham, Citrin et al. 2009). Finally, deliberative polling has been used to gather input from Indigenous and non-Indigenous people on matters of reconciliation in Australia (Fishkin 2011). We know of only one other US effort to date that has used democratic deliberative engagement to convene exclusively AI/AN people to consider ELSI issues in genomic research (under review).

Second, proponents and opponents of democratic deliberation have raised concerns about its use with diverse communities and those subject to structural inequities. Critics worry that, in conditions of significant background injustice, deliberation's emphasis on reason-giving, argumentation, and consensus may discount cultural differences and silence the voices of minority and socioeconomically marginalized populations (Sanders 1997, Young 2001, Chambers 2003, Fung 2005, Min 2014). Given concerns about diversity and inequity and the lack of a precedent for designing deliberations exclusively with and for tribal communities, we drew on frameworks of "enclave deliberation" and of community-based participatory research (CBPR) to guide our work.

Enclave Deliberation and CBPR

Enclave deliberation and CBPR share egalitarian values that served as guideposts for our work. Enclave deliberation convenes people who share a collective history or social experience of disempowerment and resistance, as is the case for Indigenous peoples, in order to create space for them to talk together, separately from others

(Karpowitz and Raphael 2014, Raisio and Carson 2014, Abdullah, Karpowitz et al. 2016). The potential benefits of enclave deliberation are several. It can facilitate candor and conversation among those who share structural and cultural experiences and reference points. It can help to cultivate relationships and rapport among participants and identify areas of agreement and disagreement in a context of underlying solidarity. Finally, enclave deliberation can acquaint people with deliberative practices that may differ from their own (e.g., disagreeing in public, disagreeing with an Elder) and build capacity for and potential interest in participation in future deliberative democratic forums (Karpowitz and Raphael 2014, Raisio and Carson 2014, Abdullah, Karpowitz et al. 2016).

Similarly, CBPR is an approach to collaborating with communities subject to social, material, and environmental conditions that compromise their health that aims to engage and incorporate their priorities and views throughout the research process (Jones and Wells 2007, Horowitz, Robinson et al. 2009). CBPR recognizes communities as cultural and social entities with resources, knowledge, and capacities that are integral to research processes and outcomes (Israel, Schulz et al. 1998). Both CBPR and enclave deliberation seek to empower participants and redress structural inequities by addressing power imbalances and ensuring that voices often sidelined or silenced are heard.

Close, ongoing collaboration with tribal leadership and commitments to shared power and resources, mutual learning, and co-capacity building animated our work at every step of deliberation planning, design, and implementation. Everyone had a lot to

learn from each other, beginning with what deliberation is and how it might be appropriately used in and adapted for these unique tribal contexts. Although all the site teams were interested in and committed to using public deliberation, they were not familiar with it as a style of community engagement. In response, a training in deliberative democracy for key investigators and site leadership took place in August 2017. Monthly calls followed the training, which eventually overturned CEIGR's original assumption that all sites would take up the same deliberative question(s). Addressing issues related to return of results, for example, did not make sense for partners not working within health care delivery systems. Each site would instead take up a distinct deliberative question(s) that reflected site-specific concerns about and relationship to genomic research (see Table 3-1).

A second in-person planning meeting sought to translate democratic deliberative theory into practice and helped to (1) clarify what deliberation might look in these tribal settings (e.g., framing of questions, approaches to educational materials, use of experts and case scenarios, facilitation style) and (2) forge agreement on a subset of pre- and post-deliberation survey questions. Importantly, this meeting identified three cultural adaptations that would be needed, the first of which concerned facilitation. Deliberations often involve a facilitator to ensure respectful discussion and equal speaking opportunities (Black and Wiederhold 2014). Recognizing that the engagement approach, specific deliberative activities (e.g., ranking exercises), and facilitation style would be largely unfamiliar to participants, we opted to use a co-facilitation model. One facilitator would be from and familiar to the community ("community-placed" facilitator) while the

second facilitator would be experienced in deliberation design and facilitation and consistent across all three deliberations ("deliberation facilitator"). Greater detail about this approach and its utility is described, respectively, in the Deliberation Design and Methods and Discussion sections.

A second cultural adaptation was reserving space at the beginning and end of the deliberative events for customary and culturally appropriate oratory expressions at Indigenous gatherings. All agreed that each deliberation should open and close with prayer and blessing led by an Elder from each community. This long-held tradition in these particular tribal communities would, everyone agreed, help normalize a new experience for the deliberants as well as orient them to the importance, potential sensitivities, and responsibilities involved in the deliberations.

This in-person planning meeting also identified cultural differences among the sites, which led to a third adaptation and a new approach to planning. First, all case scenarios would need to be developed in close collaboration with local site teams to ensure appropriate language, cultural nuance, and locality, about which we say more in the Deliberation Design and Methods and Discussion sections. Second, moving forward, each site would work independently with the core deliberation team to design its event.

Importantly, these community-driven processes were enabled by a consortium grounded in CBPR values. From its inception, CEIGR worked intentionally to create a trusting environment and positive working relationships. To those ends, the consortium

provided resources (e.g., people, time, money) to overcome initial wariness of a new research method, enabling investigators (academic and community-based) considerable planning time to learn about deliberation and how to adapt it for use in these tribal communities. The strategic use of in-person meetings when introducing or incorporating new members of the team and forging agreement on key considerations helped investigators learn about and trust one another. Solid working relationships formed well before the deliberative events took place. Flexibility at the leadership level and deference to tribal site leadership to formulate distinctive deliberative questions suited to their respective communities was imperative.

CEIGR's 4-year funding timeline was also an essential ingredient in helping to create trustworthy relationships and processes. Research timeframes are an oft-cited challenge to building trustworthy partnerships (Minkler, Blackwell et al. 2003). The good working relationships and adequate timeline also enabled the sites to learn from one another. Planned sequentially, each successive event benefitted from the lessons learned from the planning and execution of the previous deliberation(s). All team members involved in their planning were encouraged to share candidly about what worked well and what did not. The timeline enabled us to learn from one another and grow as investigators *together*.

None of the deliberation planning and design work began, however, until tribal leadership and Elders at each site approved the use of this unfamiliar form of engagement. In keeping with standards of conducting research with sovereign tribal

nations, community-placed lead investigators sought approval for this project, using site-specific review channels. Once community-level reviews were completed, the research protocol for each deliberation was reviewed and approved by boards at all sites: Alaska Area Institutional Review Board, the Chickasaw Nation Department of Health Institutional Review Board, and the Great Plains Institutional Review Board. The University of Oklahoma Institutional Review Board deferred all decisions to the appropriate tribal institutional review boards.

DELIBERATION DESIGN AND METHODS

Recruitment

Best practices in deliberation suggest that gatherings should endeavor to ensure a balanced pool of deliberants that represents the diversity of the community to which they belong in hopes that a pluralism of perspectives will obtain (Gastil, Knobloch et al. 2013, Knobloch, Gastil et al. 2013). Given the modest size of face-to-face deliberations, achieving a sample representative of a larger population, in the same way a large survey can, is an oft-noted challenge (Collingwood and Reedy 2012, Siu and Stanisevski 2012). Only AI/AN people were recruited and those who participated were not necessarily politically and statistically representative of their tribal communities, due to the relatively small size of the events (15-21 per site). However, sites sought gender balance, and diversity in age, education levels, place of residence, and experience with the health system and research, believing these differences would support a pluralism of perspectives.

Recruitment at each site also faced challenges related to geography, e.g., populations dispersed over large geographical areas, and the potential difficulty of recruiting people who could take part in a day and a half event. Each site used recruitment techniques that had proven effective at their sites in the past and would likely generate a diverse deliberant pool.

Both CNDRPH and SCF employed a convenience sampling frame to recruit AI/AN adults. CNDRPH posted flyers at its healthcare facilities and disseminated an email posting via a secure distribution list to recruit AI individuals enrolled in any federally recognized tribe eligible to receive healthcare services within the Chickasaw Nation (CN) health facilities located across the tribe's 13-county jurisdiction. CNDRPH also targeted community centers in four CN communities in order to oversample for representation of CN citizens living in diverse communities across tribal boundaries. SCF recruited in person in the lobby of its Primary Care Center. SCF limited its recruitment to adults who received services there in the last two years and were able to participate in a day-and-a-half deliberation.

MBIRI employed a two-tiered approach that, given its thirty-plus-years history of recruitment for research studies in the Cheyenne River Sioux Tribe (CRST), sought to minimize repeated sampling of past participants. Similar to CNDRPH and SCF, MBIRI conveniently sampled from tribal health events at each of the six CRST districts, followed by an additional step purposively to select the final deliberants based on screening questionnaire responses to promote maximum variation of backgrounds and

perspectives. Eligibility was restricted to enrolled CRST members, and potential deliberants were stratified according to self-defined descriptors such as district, age, knowledge and interest in genetics.

Deliberation Structure

The deliberations were conducted between September 2018 and September 2019: CNDRPH on September 14-15, 2018; SCF on January 14-15, 2019; and MBIRI on September 13-14, 2019. Given the lack of a blueprint for how to design deliberations adapted to tribal contexts and not knowing in advance whether and to what degree each deliberation might need to vary in response to local interests, customs, and values, a full review of the design elements could only be done post hoc. As it turned out, the only major difference among the forums were the questions addressed and the sites' respective use of their questions for polling; all other design elements were the same (Table 3-1).

Table 3-1. Deliberation Design

Site-Specific Content

CNDRPH – Participation in Genomic Research

- Do the potential benefits outweigh the potential risks of tribal participation in genetic studies, e.g., All of Us?
- Do the potential benefits outweigh the potential risks of tribal participation in biobanks?

SCF – Return of Results

- What are the potential benefits and harms of genetic testing and return of results?
- What are the potential benefits and harms of direct-to-consumer testing?

MBIRI – Data Governance

- What types of data should be protected?
- What form of data governance do we trust?
- What does good tribal data governance look like to us?

Shared Structural Features

- Length of deliberation: 1.5 days with shared meals
- Number of deliberants: 15 to 21 deliberants
- Structure of facilitation: one community-placed facilitator, one deliberation facilitator
- Ground rules for discussion that incorporate culturally familiar practices and language; deliberations opened and closed with prayer led by a traditional leader
- No advance educational materials; experts present balanced plain language information during events
- Agenda: welcome, introductions, ground rules; expert presentation and Q&A; whole group discussion followed by small group discussions with case scenarios; flip charts to track deliberation themes and deliberant "check-ins" to ensure accuracy of themes; polling and voting exercises to assess deliberant views and priorities;
- Pre- and post-deliberation survey;
- All participants paid $25/hr stipend for participating in 1.5 day event
- Deliberation report for deliberants and tribal leadership, with deliberant review and input prior to finalizing
- Consistent deliberation team members to carry out range of activities

Site-specific Content

The core deliberation team worked with key personnel at each site to identify and formulate questions about genomic research that would benefit from community input. All three sites used a small set of questions to frame and structure the deliberations (Table 3-1). CNDRPH and MBIRI polled deliberants only on those questions during the events. SCF developed 18 questions about return of genetic results and polled deliberants on those questions twice during and once after deliberation using a paper survey (Hiratsuka, Beans et al. 2020).

Shared Structural Elements

The design of the deliberations aimed to achieve key deliberative goals (e.g., equal opportunities for speaking, informed and careful consideration of issues) while remaining open to reimagining those commitments to ensure the events suited each tribal setting.

Duration. Deliberative methods vary considerably in length from 2.5 hours to multiple hours or days over several weeks (Carman, Mallery et al. 2015). These 1.5 day (10 hours total) deliberations sought to promote learning, discussion and exchange, and careful consideration of the issues, key features of quality deliberation (Burkhalter, Gastil et al. 2002, Blacksher, Diebel et al. 2012), as well as be practicable in these communities and manageable for budgets. Convening the deliberation over two days enabled overnight reflection, rapport building, and the use of varied discussion and value elicitation techniques (e.g., small group discussions grounded in case scenarios and polling exercises in which participants could stand up, move around, and interact while casting

ballots or ranking priorities), which supported varied learning and discursive styles. These techniques and the 1.5-day duration sought to enhance inclusiveness and deepen deliberants' understanding of their own and others' perspectives.

Size. The number of participants in a face-to-face deliberation can vary, with anywhere between 12 and 25 participants being common (Carman, Maurer et al. 2014). These deliberations ranged from 15 to 21 participants, a number small enough to enable opportunities for all to speak, yet large enough that variation in perspectives is likely to obtain.

Co-Facilitation Structure. The co-facilitation model—a "community-placed" and a "deliberation" facilitator—created continuity between the community and local customs while also building a bridge to this new form of engagement and set of researchers. The community-placed facilitator at all three sites delivered the opening (welcome, purpose of and ground rules for deliberation) and closing remarks, integrating local customs, language, and communication styles with norms of deliberative practice. For example, deliberants were reminded to be mindful that all should have the opportunity to speak and to listen when others are talking. The deliberative facilitator introduced the deliberative questions and initial probing and led deliberants in voting or ranking activities. Other activities were split between them.

Information Base and Role of Experts. Deliberations aim to be grounded in an information base that is sufficient to support knowledge gain but does not overwhelm

deliberants and is factual and neutral, informing reasoning without unduly influencing the outcomes of deliberants' reasoning (Goold, Biddle et al. 2005, Gastil 2008, MacLean and Burgess 2010). It is common to send printed briefing packets about topics to be discussed and the purpose of deliberation in advance; experts may also present on the subject matter during the event. All three sites agreed that the best strategy for delivering content to their respective communities was to have experts present educational content in person during the event. Individuals with active affiliations and relationships in each community were chosen with the goal of engendering a trustful atmosphere. In-person interactions lay the foundation for transparent research practices and are an expectation in many AI/AN contexts (Weaver 1997, Christopher, Watts et al. 2008, Beans, Hiratsuka et al. 2018, Claw, Anderson et al. 2018, Tuhiwai Smith 2020). The format of the experts' presentations differed across sites, based on each site's assessment of appropriate methods for presenting information to their respective communities (e.g., presentations with PowerPoint slides at two sites, an oral presentation without slides at one site).

Once experts and formats were chosen, the core deliberation team devoted considerable time discussing the expert role and working with experts to develop the content of each presentation to ensure it provided an adequate information base for the deliberative questions and was neutral in its framing (Friedman 2007). Although questions varied across sites, some informational elements were common to all three (i.e., what genomic research entails). To ensure neutral framing, presentations of what genomic research is included not only a plain language discussion of the science involved, but a balanced representation of widely recognized potential benefits and risks

of genomic research. The team reviewed presentation language with an eye to not overstating either the promises or perils of genomic research for AI/AN communities. Additionally, in prepping the experts for their role, the core deliberation team emphasized that they were there to supply information, not to weigh in on the deliberations. Experts were also prepared for the possibility that deliberants might ask them to do so and were offered approaches for how to respond to such requests in such instances.

Case Scenarios. Case scenarios were used across all sites to ground small group discussions. While varied to reflect each site's specific content, the scenarios depicted potential concerns and benefits of genomic research specific to AI/AN communities.

A member of the deliberation team, who is himself AI and a doctoral student in Anthropology, worked closely with the local site teams to draft the scenarios and ensure cultural nuance and locality in their content. Iterative discussions and drafts sought to develop language relevant to the topic that was also respectful and, when possible, familiar to local participants. For example, the scenarios referenced familiar institutions and social activities relevant to each site. One scenario presented at two sites, for example, had a situation in which an individual had attended a doctor's visit. Because the healthcare delivery systems differed at each site and the participants would be familiar with those differences, site-specific terminology was used to describe these systems. The social event of the powwow was referenced in a scenario at one site but not the other two, because this type of social event is common to some but not all AI/AN communities. Additionally, we chose scientific verbiage carefully and used plain language explanations

to avoid confusion or misunderstanding, resulting in scenarios with a reading and comprehension level that was accessible to all participants in attendance.

Finally, the case scenarios foregrounded real-world issues meaningful to the AI/AN participants. Issues addressed ranged from concerns around genomics and individual health, genomics and community privacy, the impact of genomics on Native American identity to the potential of big data to address community concerns. For example, one scenario challenged the participants to discuss the potential of genomics to assist in the recovery of murdered and missing Indigenous women. Because perspectives on the potential usefulness of genomic research and data vary widely in AI/AN communities, the scenarios were tailored to encourage wide ranging and rich discussions.

Evaluation. We took a global (versus cross-site comparative) approach to evaluation to determine whether an adapted approach to deliberation that incorporated culturally appropriate norms and customs of engagement would also meet standard deliberative criteria. It did, as we show and elaborate on, respectively, in the Results and Discussion sections. This global approach was appropriate given that little to nothing is yet known about how best to adapt and use deliberative approaches to convene exclusively tribal community members and our fundamental question was whether what we did would meet established criteria for deliberation. Future manuscripts may explore site differences in a comparative approach, grappling at that time with issues of the measurement of deliberative quality across cultures more explicitly.

We used two approaches to assessing deliberative quality (Appendix). Pre- and post-deliberation surveys with an identical core set of questions were completed by deliberants at each site. A pre-deliberation survey captured demographic information to assess deliberant diversity; the post-deliberation survey posed 15 questions to gauge deliberants' perceptions of the quality of the deliberations. The post-deliberation measures are widely used criteria of deliberative quality, such as whether deliberants felt the information presented was clear, they had an equal opportunity to speak, their opinions were respected even when others disagreed, deliberation impacted their views, and whether they valued participating (Bonham, Citrin et al. 2009, Goold, Neblo et al. 2012).

A second form of evaluation assessed social and analytic components of deliberation based on prior theoretical and empirical analysis (Gastil 2008, Knobloch, Gastil et al. 2013), and was conducted by an observer experienced at evaluating deliberations using well-established deliberative criteria reflected in a rubric; see Table 3-2 (Gastil, Reedy et al. 2016, Reedy and Anderson 2019). This analysis involved the observer monitoring each deliberative event in its entirety and taking detailed field notes about the proceedings from the perspective of deliberative quality, as well as using a real-time observation scheme for noting the prominence of several important components of robust deliberation (described in more detail below). In addition, the observer discussed his observations with other members of the research team present to develop a shared sense of the performance of the process (Knobloch et al. 2013). The observer, based on field notes from and observations of the process, rated the deliberative process on several

social process markers of good deliberation, such as equal opportunities for participants to speak, apparent respect between participants, mutual comprehension of others' comments, and consideration of others' ideas and arguments; and on several analytic process markers of good deliberation, including the building of a strong base of information about the topic, analysis of the underlying values related to the topic, consideration of pros and cons of various policy choices, and evaluation of potential solutions. In addition, several markers of a good approach by the deliberation organizers were also analyzed by the observer, such as unbiased framing of issues, representation of diversity within the community (either through the diversity of participants or views shared and represented in their comments), clearly defined tasks for the deliberants, and opportunities for the deliberants to give feedback about the process and the topic. Each of these indicators for a robust deliberation were scored on their prominence or reoccurrence in each major segment of the event (i.e., Friday evening, Saturday morning, and Saturday afternoon), with scores ranging from zero (meaning they never occurred or were not found in that segment) to five (meaning they were often/always occurring); see Table 3-2. Those markers that did not apply in a particular segment (e.g., potential solutions were not introduced until day two) were noted with N/A.

We also reviewed key segments of the transcripts for evidence of participants' views of the deliberative process. The second day of the deliberations all began with a "morning debrief" and closed with "concluding thoughts," during which participants were invited to share any observations about the deliberations and about the process itself, including what could have been done differently or better. We did not conduct a

formal qualitative analysis of these relatively brief stretches of discussion. Instead, three members of the research team reviewed these portions of the transcript separately to identify comments that captured indicators of good deliberation, after which we discussed and decided as a team which quotes best illustrated key indicators of good deliberation.

RESULTS

Demographics

A total of 52 individuals participated in the deliberations across all three sites. CNDRPH had 16; SCF, 21; and MBIRI, 15. Deliberants at all sites reported being of AI/AN heritage alone or in combination with another race and 94% reported not being of Spanish, Hispanic or Latino ethnicity. Participant age ranged from 22-74. At all sites, the majority (65%) of participants self-identified as female. Participants ranged in their self-reported highest completed education level from some high school to post-baccalaureate degree completion, with 75% of participants across all sites reporting completing some college or a 2-year degree. At all sites, almost a third of all participants reported speaking a language other than English at home.

Post-Deliberation Survey: Deliberant Perceptions of Deliberative Quality

At the conclusion of each deliberation, participants completed a 15-item survey on perceptions and impact of the deliberation event. Deliberants across all three sites reported feeling interested during group discussion; that even when people disagreed, they respected each other's opinion; that information was presented in a manner that was clear and easy to understand; that facilitators made sure all opinions were considered; and

that the event was well organized. Overall, deliberants at all sites reported feeling like their opinion was respected by other deliberants with only one participant at one site strongly disagreeing. Nearly all of the deliberation participants across the sites reported that they spoke as much as they wanted during the deliberation (97%), felt that the purpose was clear (94%); and thought there was enough time to fully discuss all the relevant issues (96%). In agreement with the qualitative data and the polling questions, the majority (73%) agreed that the discussion led them to change some of their opinions and nearly all (97%) thought the group discussion affected their opinions. The impact of educational presentations on deliberant opinions varied across sites, from "not at all" to "a lot." Finally, the majority of participants across all sites felt strongly that deliberative forums should be used to gather community members' views.

Social and Analytic Elements: Observer Evaluation of Deliberative Quality

All three events performed very well on the criteria for deliberation rated by the observer, indicating that all three represented robust, well-executed deliberative forums (Table 3-2). The events had segments in which certain criteria were not applicable due to the design of those portions of the events; however, those criteria were addressed at some point during the 1.5-day event (e.g., waiting until Day 2 to discuss potential solutions and policy outcomes). All three events performed very well on the social components of deliberation, such as expressing mutual respect, authentically participating, sharing personal knowledge and experience, and considering other ideas.

Table 3-2. Deliberation Assessment*

				"A"			"B"			"C"
		Day 1PM	Day 2 AM	Day 2PM	Day 1PM	Day 2 AM	Day 2PM	Day 1PM	Day 2 AM	Day 2PM
Analytic	Information base: Participants	4	4	4	3	5	5	3	4	4
	"Information base: Experts"	4	N/A	N/A	3	4	5	5	4	4
	"Info accuracy and support"	4	3	4	4	4	4	4	4	4
	"Prioritize values"	3	5	4	4	5	5	4	4	5
	"Range of solutions"	N/A	N/A	4	4	4	5	N/A	5	5
	"Evaluating evidence"	N/A	3	3	3	3	4	N/A	4	4
	"Weigh pros and cons"	4	5	5	3	4	4	4	4	5
Social	Equal speaking opportunity	5	4	5	5	4	4	5	3	4
	"Sharing personal experience"	5	5	4	5	5	5	4	5	5
	"Sharing personal knowledge"	4	5	4	4	5	5	5	5	5
	"Mutual comprehension"	5	5	4	4	4	4	4	4	4
	"Consider other ideas"	5	5	5	4	4	4	4	4	4
	"Authentic participation"	4	4	5	5	5	5	5	5	4
	"Mutual respect"	5	4	5	5	5	5	5	5	5
Approach	Unbiased framing	4	5	5	3	4	4	5	5	5
	"Representativeness"	5	5	5	3	4	4	5	5	5
	"Clearly defined tasks"	3	4	4	5	5	5	4	4	4
	"Opportunities for feedback"	5	4	5	5	5	5	4	5	4
	"Community/Group identity"	N/A	5	5	5	5	5	5	5	5

*Tribal site names have been anonymized and are not listed in the order the events occurred.

The events also performed very well on the analytic components. All three events had positive contributions to a good information base from the expert presenters, and information shared in the groups was generally very accurate and well-supported. As noted above, there were also times at which a wide range of potential solutions was not addressed in the deliberation, or may have received comparatively less attention, but those were choices of design, and these areas were addressed in later segments of the event.

One criterion in which all three events performed somewhat less well was in evaluating evidence, which was present but observed somewhat less often than other markers of a strong analytic process. However, when information was discussed, the evidence used was very accurate in all the forums, based on the assessments of the

deliberative observer which were then checked against the observations of other research team members present. One factor that may have contributed to the evaluation of evidence being less present in these deliberations is that the information presented—e.g., what genomic research is, tribal research review processes at each site, what a biobank is—did not play a pivotal role in the normative questions posed at each site. Although questions about, for example, whether the potential risks of genomic research outweigh its potential benefits do turn on an understanding of what genomic research entails and what the consequent risks and benefits are or might be, deliberants demonstrated knowledge of those realities and potentialities and focused on what they – as a community – should or should not do about them. These deliberations were arguably less like those focused on whether, for example, a particular chemical should be banned from agricultural use because it poses a health hazard, making the scientific evidence of its relative safety imperative to the normative question at hand (Knobloch et al. 2013). Overall, the forums encouraged deliberants to discuss and understand the issues with respect to their ethical implications for AI/AN peoples.

Participant Experience

The following quotes illustrate the value deliberants placed on the opportunity to learn about an important issue directly relevant to them and to engage in substantive dialog with others in their tribal community. These quotes supply some supplemental evidence that key goals of deliberation and enclave deliberation were achieved. First, the following statements suggest that deliberants gained deeper insight into their own and others' views.

> "I would say I feel more informed about the opinion I did have before. It made me consider things I hadn't thought about before, but it didn't change my mind about it." (CNDRPH deliberant)

> "I think just learning a lot of different perspectives is what I've taken away. Cause there are things that [man's name] has shared from the multiple groups that I never would have thought about in a million years." (SCF deliberant)

> "…hearing everybody's thoughts, it kind of sways you a little bit. But I think in the end it eventually reaffirmed what I initially felt about it. Even though you hear other people's opinions on things." (CNDRPH deliberant)

> "I like coming to research groups and I would like to be part of more. It's very eye opening. I knew just a little bit about genomics but seeing everybody on a different level of where they [are] versus where I was … you know, not everybody is going to be on my same page and that's great because then it gives you more insight and more information. It's great." (SCF deliberant)

Second, the following quote is representative of comments we heard during and often after the deliberations suggesting that participants especially appreciated the collective experience of talking together with members of their tribe.

> "But even just sitting in or taking part in this discussion, I'm kind of glad I know more about what other people think just because, I don't know, it just feels good to know …. I feel like part of the group." (SCF deliberant)

Finally, deliberants strongly endorsed this approach to gathering input in their communities and expressed an interest in participating in future deliberations.

> "I feel privileged to be able to come here to be able to participate in this. I got to meet really cool people…but I got more of an understanding about this, so I just feel really lucky to be able to be here. I just appreciate it. Thank you. And I want to participate in more if there is some." (SCF deliberant)

> "I couldn't quit thinking. Couldn't go to sleep and then got up at 3:00 thinking…" (CNDRPH deliberant) (this prompted others in the room to recount the conversations they had with one another during their car rides home and back again the second day)

Deliberation Report

A two-page deliberation report was prepared and draft versions of which were sent to deliberants for input. Final reports were sent to the deliberants and to tribal leadership within 6 weeks of the events as a formal record of the event and its outcomes. These local deliberative reports have enabled tribal leadership to reflect on their members' views and values about complex ethical issues in genomic research that are not well described in any population, let alone small tribal populations that participated in the three deliberations.

DISCUSSION

This research project is, to our knowledge, the first to design and implement deliberative public engagement exclusively for and with tribal citizens on ethical issues in genomic research. Our results suggest not only that deliberative approaches can be culturally adapted for use in tribal communities with good outcomes, but also that the processes used to plan these events and the deliberation design implemented in all three sites have broad applicability and transferability to research seeking input from AI/AN peoples on complex, value-laden questions. We attribute the relative success of these forums to several factors, the first of which we have already described in some detail—the community-centered values that guided CEIGR leadership in the daily operations of the consortium.

Cultural adaptations also played pivotal roles. The co-facilitator model and development of culturally nuanced case scenarios also proved especially important. The community-placed facilitator set the tone early in the deliberation, welcoming people, explaining the purpose of the research project, and ground rules for deliberation, the latter of which was infused with local nuance. The community-placed facilitators' familiarity with the context and people helped break the ice, with appropriate moments of humor, in preparation for undertaking what to many may have seemed daunting—a day and a half "deliberation." The ground rules for deliberation incorporated both deliberative and community norms, often drawing on familiar language, family relations, and colloquialisms. For example, community facilitators introduced themselves by situating their stories in relation to specific familial, geographic, and tribal histories, thereby establishing familiar ways of relating to one another based on specific community customs. All three community facilitators also used humour effectively to mitigate tension and lighten the mood (Johansen 2003, Garrett, Garrett et al. 2005, Kongerslev 2020). One community-placed facilitator, for example, noted the importance of starting on time after breaks and asked deliberants to not "run on Indian time," which brought a burst of collective laughter. Community-placed facilitators also encouraged the practice of taking home leftover food. This customary practice is a subtle but poignant indicator of familiarity that establishes a sense of communal hospitality.

The community-placed facilitators also successfully navigated their dual roles as research team members and community members. For example, as discussion on the end

of day 1 began to conclude at one site, the community-placed facilitator acknowledged the powerful contributions of those present and remarked, “This (process) makes me proud to be from here.”

The value-added of site-specific case scenarios—reflecting distinct relationships to genomic research, exposures to research harms, among other salient social and cultural variations—was borne out in the deliberations. Observers of the small group discussions noted rich discussions in which participants from any background were able to speak about a range of topics and to express deeply held values. The scenarios were particularly effective in motivating participation from those who spoke up less in large group discussions. At no point during any of the small group discussions was there a shortage of conversation among deliberants; instead, responses to the scenarios prompted lively and sometimes deeply personal commentary that often spilled over into the plenary discussions.

Finally, we believe the relative success of the forums is attributable to what deliberation is in the base case and the inclusion of only AI/AN people (“enclave deliberations”). To the first point, sound public deliberation creates conditions in which all participants can learn and talk together with mutual respect (Carpini, Cook et al. 2004, Goold, Biddle et al. 2005, Gastil, Bacci et al. 2010, Abelson, Blacksher et al. 2013, Carman, Mallery et al. 2015, Wang, Gold et al. 2015). Deliberants are situated as experts in their own right; their views and values are being solicited on a topic of direct relevance to their well-being and that of their communities. These goals and values stand in stark

contrast to a history of mistreatment of AI/AN people by the US federal government, as well as a history of exploitation by some in the research enterprise, and that contrast may help explain deliberants' positive appraisals of these events.

The opportunity to deliberate candidly with only AI/AN community members seemed to be reflected in comments where deliberants talked freely about their comfort or discomfort with non-AI/AN researchers and companies, as reflected in the following exchange about biobanks. For example:

> Participant 1 asks Participant 2: "Say we [the tribe] hired somebody…would you be more comfortable going with a non-Indian firm or entity or another tribe? Or would it even be a factor?"
> Participant 2: "I never thought about that. I like that option."
> Participant 3: Can I add to that? (Participant 3 went on expressed the view that "Natives working native is more comforting." (MBIRI deliberants)

There is some evidence that members of minority and marginalized groups may find deliberation a particularly valuable experience (Wang, Gold et al. 2015). Although the grounds for these findings are not established, it stands to reason that social groups that have been or are mistreated, ignored, or otherwise marginalized from a society's mainstream deliberative processes, which is the case for AI/AN peoples, might find it especially meaningful to participate in a carefully designed event that solicits input for purposes of informing tribal leadership and, ultimately, leadership at the National Institutes of Health. These deliberative events may, then, have represented a rare opportunity to weigh in on a topic of special concern to AI/AN communities: the ethical conduct of genomic research with AI/AN peoples. In this and other ways already described, public deliberation's central goal to create the conditions in which all

participants are heard and respected, even in the context of disagreement, may be especially appreciated by people who too frequently have been ignored or disrespected by majority powers. Such deliberations may also bring more accountability, legitimacy, and transparency to decision-making and governance structures in an era of genomic research and medicine (Button and Ryfe 2005, O'Doherty, Hawkins et al. 2012).

Beyond the evaluative results from the post-deliberation surveys, the expert observer datasets, and direct comments, deliberants seemed to signal their appreciation of the events in other ways. At one site, a deliberant brought traditional food to the event on the second day, despite provision of ample food and snacks served at the event. During lunches, designated as 'no work' times, many deliberants joined investigators who were often eating lunch at a separate table or invited investigators to take short walks with them on breaks. A couple of deliberants at one event invited the research team to attend community events at later dates, and others introduced investigators to their family and friends who came to transport deliberants. At all events, spontaneous hugging occurred at the end of the deliberation event between the deliberants and the deliberation team, all of whom were new to the community. These activities no doubt reflected the hospitality and good will of the deliberants, but they may also speak to their appreciation of the deliberation events.

There may, however, be another explanation for deliberants' generally favorable views of this deliberative approach. While distinct in practice and social organization, some Indigenous nations have historically governed themselves in communal ways that

valued kinship, reciprocity, and consensus decision-making (Korovkin 2001, Lee 2013, Johansen, Ka Hon et al. 2016). Thus, a deliberative approach wherein community members are the experts and decision-makers may be culturally consistent. The culturally adapted design allowed for social dynamics and oratory customs in the discussion and created a space for everyone to participate in ways that were perceived as egalitarian and respectful. For example, at one site deliberants appeared to engage in a practice of deferring extra time and respect for Elders to speak on matters of cultural knowledge and traditions, while the Elders were careful to then acknowledge the specific expertise and experiences of other deliberants.

Limitations of this approach need also to be noted. As with other research methods, deliberants were individuals who could willingly participate in the research, and, in the case of these deliberations, offer a minimum of a day and a half of their time, and more for those who had considerable travel time. The nature of self-selected volunteers lends itself to a type of response bias in that individuals who are more willing to engage in research may also have more positive perspectives than non-participants. Also, the expert presenters were intentionally chosen because of their familiarity to the deliberants' community in hopes of cultivating a trustful atmosphere. While this approach seemed successful in generating trust, in retrospect, we do not know whether this design choice had unintended and unmeasurable effects (i.e., deliberants overly trusted a familiar source or were reluctant to ask uncomfortable questions) and whether similar effects would be seen if this technique were applied in a different community or context.

CONCLUSION

In summary, participant perceptions and statements, external observer datasets, and direct investigator observations and experiences depict three deliberations that offered intensive conversation experiences in which participants felt connected and respected and had expectations that their views on research conduct are valued and would be heard. The views, observations, and values shared by participants in the deliberations enabled richer, more in-depth insight into participant perspectives than what can be achieved by surveys, interviews, and focus groups. Early worries that the duration of the event and intensity and complexity of topic might burden participants proved not to be the case. Many participants commented that more such events should be held, and they made quick and sophisticated use of the ideas introduced (Hiratsuka, Beans et al. 2020, Reedy, Blanchard et al. 2020).

Designing deliberations for specific tribal contexts requires a purposeful approach to engagement with AI/AN communities. Tailoring deliberations to local contexts centers community structures and leadership (e.g., recruitment techniques, leadership involvement in development of research questions, equity in research process), and the specific communities in which the deliberation will take place. The events confirmed the importance of the meaningful involvement of AI/AN tribes, their staff, and their community members in discussion of policy and practice that impact AI/AN communities. Deliberation as a method of engagement can provide an equitable approach to gathering needed community-level data for policy makers and decision-makers at various levels that otherwise might not be captured.

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We would like to thank those who participated in the deliberations who made this work possible and for reasons of confidentiality remain anonymous. Deliberations are only as good as the people who choose to take time out of their busy lives to come together, listen, talk, and learn from one another. We are grateful for what we learned from each of them.

*See Supplementary Material B for full list of co-authors, affiliations, and funding.

CHAPTER 4 – Eliciting the Perspectives of Native American Young Adults at the University of Oklahoma on Identity and Genomics through Sharing Circles*

ABSTRACT

Native American identity is fluid, complex, and like all identities, socially constructed. Today, social conceptions of Indigeneity are increasingly playing out in genomics discourses. Genomics does not adequately define Native American identity for many reasons, so genomics discourse around this identity is something to critically examine. As Native identity is increasingly asserted by widely accessible genomic technologies, Native Americans continue to have alternatively distinct ways of identifying and belonging. This project discusses with a sample of Native American young people their perspectives on genomics and Native American identity. Sharing Circles, an Indigenous centered approach to understand the stories of Native Americans, were conducted with 18 self-identified Native American students and staff at the University of Oklahoma. Sharing Circles as an alternative to focus groups works to decolonize methodological spaces by being both culturally sensitive and relevant. The Sharing Circles events resulted in rich discussions that convey a sense of identity that is grounded in ties to tribal communities, relationships with other tribal students, and specific conceptions of traditional and modern tribal identities. The grounding of identities in tribal community life and explicit tribal relations- and not genomic technologies- works to decolonize popular understanding of what Native American identity is and is not. Participants expressly challenge genomics as a defining discourse about Indigeneity.

INTRODUCTION

Native American identity is a fluid and complex concept that in recent years has been made to seem very simplistic and static in the eyes of the public by way of genomics technologies. This fallacy is perpetuated within public discourse through any number of direct-to-consumer (DTC) genomics advertisements which often present an actor who now claims a new and undiscovered heritage by simply providing a biological sample to be analyzed for a nominal fee.

In a long standing advertisement for DTC genomic ancestry testing (https://www.ispot.tv/ad/wKqV/ancestrydna-kim), an actor for Ancestry.com states, "I wanted to know who I am and where I came from." She states she chose to do an Ancestry.com test and that "The most shocking result is that I'm 26% Native American. I had no idea." While the actor speaks, the camera captures various styles of Native American pottery all around her. She finishes the commercial by saying, "I absolutely want to know more about my Native American heritage." The commercial context assumes a market for the DTC genomics product from many people like this actress, people who also do not "know who they are" or "where they came from." Set within a settler-state, like the United States, this type of work can be seen as a settler project, a project that works to erase and replace the Indigenous people to this land.

The fourth world status of many Indigenous Nations (Manuel and Posluns 2019) may be at the crux of what problematizes this entire scenario. As the people of the Nations within nations, with various levels of dependance on colonizing authorities

(Tsosie 2001), Indigenous identities are many times inextricably, yet precariously, tied to the land being colonized (Garroutte 2001). Meanwhile, settlers are making attempts to legitimize their claim on the same land. DTC genomics play directly into this structure.

A note to clarify use of terms. *Native American* is a term that has complex meanings and uses. Native American could refer to any Indigenous peoples throughout North or South America. That is not how I use the term in this manuscript. My use of the term Native American often refers to the people who make up the nearly 600 federally recognized tribal nations that reside within the boundaries of the US. This definition implies a person is enrolled in one of these Nations, and that is not always the case. Generally, the use of the term Native American in this manuscript, by myself and the participants, references the social construct of Native American identity that includes both enrolled and non-enrolled peoples. *Indigenous*, as I use it, is a very board term to describe the people around the world who have been impacted and maintain a relationship with a colonizing entity.

Nations, Genes, and Identity

For many tribal Nations, *enrollment* can be assigned solely off a particular blood quantum calculation, an imaged-biological measurement of Native American race based off census rolls created in the early 1900s (TallBear 2003). For some Nations, and their citizens, their idea of belonging is more concerned with living a certain lifestyle, speaking the language, or any number of social or political criteria overlaid in a multitude of ways (Garroutte 2001, Garroutte 2003, Dennison 2012, Simpson 2014). Tribal nations

have been grappling with disentangling colonial conceptions of tribal belonging with more culturally grounded ideals. This intra- and intertribal discussion on tribal identity, enrollment, and belonging has impacts on the allocation of resources, enrollment policies, and has also been heavily influenced by colonial practices of the past that have lasting legacies. Measuring and proving one's Indigeneity is one of those legacies.

DTC genomics offers an essentialist version of Indigeneity to anyone who can afford the price. On one hand, with a simple transaction—a payment and a biological sample—a perceived truth of science simply erases unique histories and struggles of countless Indigenous Nations and adds the new struggle: warding off frivolous claims to enrollment. While on the other hand, Indigenous people who are secure in their tribal identity are often the ones who cannot afford the price of a DTC test and they do not participate in the consumer science, only knowing about it from commercials. The result is a situation where Indigeneity is being defined by powerful technologies for public consumption without Native American people in consultation.

Academic genomics, with all its prestige, has a shaky relationship with Indian Country. For decades Native American people have been encouraged to not participate in genomics because of harms committed that benefitted researchers without regard to the Indigenous communities being researched (Pullman and Nicholas 2011, Garrison 2013, Hudson, Garrison et al. 2020). Today, bioethical research—research that explores the ethics involved of advancing technologies in biology and medicine—is starting dialogues with Indigenous communities about what genomics might mean for them (Hiratsuka,

Beans et al. 2020, Reedy, Blanchard et al. 2020, Blacksher, Hiratsuka et al. 2021). The dialogues indicate community members from diverse backgrounds and even different nations have valid and complex opinions on the topic and they want their voices considered when outline the future of the genomics in each of their communities. Consumer genomics rarely acknowledges these important dialogues in meaningful ways and continues practices that Indigenous people and their communities are charged to defend against.

Settler race-shifting is a common enough behavior that it has coined its own name. There is no one reason non-Natives are drawn to race-shifting; it is complicated practice that often undermines longstanding political and cultural identities furthering the goals of settler colonialism (Sturm 2011, Leroux 2018). Race-shifting can be accomplished by knowledgably using science jargon to support claims of Indigeneity (for example see Yates and Yates 2014). Consumer genomics is presented in ways that are problematic to Native American identity and sovereignty (TallBear 2007, Schmidt 2011, TallBear 2013, Leroux 2019). One finds that through genetic science human DNA is used to Indigenize non-Native settler populations (TallBear 2013, Leroux 2018). However, most people do not read academic literature for profession or leisure, so much of what is known about the frivolous and even harmful use of genomic information to construct racialized identities is only known by a small group of specialized academics. Many in the public continue to experience the genomics age through television commercials that have the purpose to solicit business, not convey accurate information.

Positioning and Purpose of This Study

I am a Navajo man and academic who studies anthropology, genomics, and Indigeneity. Because of my academic training and as a playful joke, my mother once asked me what I thought her DTC results might be. She had seen the Ancestry.com commercials and found it funny that someone could find out they were Native American so easily. My mother is a full-blood, enrolled Navajo citizen. It says this on her tribal enrollment papers, and she is proud of it. Our family's collection of tribal enrollment documents tells an amazing tale of yearly interactions with federal authorities dating back to the late 1800s. Her understanding of the world is from that position. I exasperatedly explained to her that regardless of what a test like that might say, she is 100% Navajo, biologically or otherwise. I also knew that any DTC test would tell her she was not 100% Navajo. My knowledge told me that even under the best of circumstances a commercial test, such as these, could only possibly tell her that she was, at most, 99% Native American/East Asian and that is not how my mother identifies. I could not understand why anyone would want to take a test that would tell them they were less than they thought they were.

Prior to the Sharing Circles project, I studied how settler colonialism and DTC genomics work together to amount to a type of biocolonialism. Biocolonialisms are situations where biology or medicine is used to achieve the goals of colonization and further the erasure of Indigenous people. That work has yet to be published. However, I found that the topic appealed to many audiences and was a great way to engage students, professionals, and the public about science and anthropology. When I shared this work

professionally or in passing, to a non-Native person, the conversation often turned to a conversation about a specific person's own DTC results.

Many times, I found the person sharing their genetic ancestry results with me to be doing so as a way of trying to make a friendly connection. I began to notice that the person would both be agreeing with me that settler colonialism is bad, and yet in the same breath look for validation of their own "Indigeneity" from the DTC results they shared. I became accustomed to this and ultimately found new ways to engage the topic that worked to better frame the issue. I had to incorporate the use of dog genetics and discuss selective breeding to get my point across. I found it fascinating to see, in real-time, how people could simultaneously believe that settler colonialism has systematically undermined the authority of tribes to govern and determine citizenship of their own people and endorse the use of DTC products to understand Indigeneity in ways that also undermine tribal sovereignty. I found this to be a very passive, but pervasive form of cognitive dissonance.

I do not claim to be the ultimate geneticist with all the genomics answers. Yet, within these encounters my life experience and training were sufficient to address the issue, where perhaps other geneticists may have struggled. The issue was that many people across all these various audiences did not understand what being Indigenous means, specifically belonging to a Tribal Nation (TallBear 2003). Instead, they held a belief in (consumer) science that encouraged them to fill the role of a settler colonizer. The occurrence began happening so often and in such a specific way that my curiosity

was piqued, and this project was conceived. I wondered: do all Indigenous people have these encounters with non-Native people, how do they handle it, and how might it impact their perception of genomic science and identity? I did not have access to all Indigenous people, but I was situated as a graduate student and a researcher at the University of Oklahoma where there is a substantial Native American student population and within proximity to many tribal communities. My study applies Sharing Circles to address, 1) what were the experiences with DTC genomics Native American people might be having, 2) were other Native American people having encounters with non-Natives who share DTC results with them, and 3) did DTC genomics observations and experiences impact Native American people perceived genomic science.

METHODS

Sharing Circles are a culturally appropriate and relevant method for gathering the data (Archibald 2008, Rothe, Ozegovic et al. 2009, Tachine, Bird et al. 2016). Sharing Circles are a time-honored tradition in many Indigenous communities to create space for the stories of Indigenous people to be shared and explored for various purposes including research (Struthers, Hodge et al. 2003, Rothe, Ozegovic et al. 2009, Tachine, Bird et al. 2016, Wilken and Nunn 2017). Sharing Circles as research works to decolonize and Indigenize methodological spaces (Smith 1999, Kovach 2010) in hopes of creating equitable Indigenous futures through knowledge production. Ultimately, Sharing Circles is research of respect – Sharing Circles acknowledge the value of the people and stories shared, but also works towards healing harmful research practices and relations of the past.

The criteria for inclusion as participants was defined as students and staff, 18 years of age or older, of the University of Oklahoma who self-identify as Native American or who had been identified by the university as Native American. There was no upper limit on age to be qualified for the study. The "young adult" sample I achieved was a coincidence. Recruitment flyers were posted in public spaces, especially spaces on campus reserved for use and frequented by many Native American students (i.e., the Native American Studies department and study lounges). Additionally, I partnered with university administrative staff to be permitted to email recruitment information to identified Native American students and staff on campus. These potential participants would be ideal for two reasons: 1) ease of sampling, the University of Oklahoma is home to a large population of Native American students belonging to numerous and diverse tribal communities from across the United States, and 2) these particular individuals may be sharing a similar experience with me, in how we all would be navigating these traditionally White academic spaces, and how it may be impacting an understanding and perception of genomics and identity.

The Sharing Circles to discuss DTC genomics and Indigenous identity were conducted at the University of Oklahoma in November and December 2019 (OU IRB #9193). I designed the Sharing Circles closely modeling the guide of Rothe, Ozegovic, et al. (2009). A total of five Sharing Circles were convened over two months. The sessions ranged from one hour to three hours and from two to five participants each Circle. Eighteen self-identified Native American students participated, both undergraduate and

graduate students. Of the 18 participants, 10 were also university staff members. The participants ranged in age from 20-40 years old.

I served dual roles as both the researcher and the Sharing Circles facilitator. The Sharing Circles were opened and closed with prayer (by a participant? A designated person?). Light food and drinks were provided. Qualified participants received compensation for their time in the form of a Wal-Mart gift card. [you might add: This project was reviewed and approved by the University of Oklahoma Institutional Review Board. All participants were informed of the project goals and consented prior to participation.

The Sharing Circles were audio recorded and electronically transcribed. The transcripts were cleaned for electronic transcription errors and refined to elicit the participant answers to the Circle questions. To avoid caricature of the participants and for ease of reading, excessive "um's" and "like's" were removed from normal speech with no impact on participants statements. The participants were deidentified in the transcripts, though if they mentioned their tribal affiliation, I left the tribe's name in context.

The participants' statements are purposefully reported void of gendered pronouns. I made this decision for two reasons. The first reason is that I believe that everyone is entitled to be referred to by their preferred pronouns as a sign of respect that I feel for that person. When the Sharing Circles were conducted, I did not understand this importance, thus, I did not ask my participants how they might like me to refer to them in this work. I was left with the choice of potentially misgendering people who I respect or removing

gendered pronouns. I understand, removing gendered pronouns is also not ideal. However, gender neutral pronouns also facilitated further deidentification of participants, who happen to come from a relatively small community of people at the University of Oklahoma.

The participants were asked five questions pertaining to their experience with DTC genomics and DTC genomics discourses (Table 4-1). Illustrative examples of responses are shared here.

Table 4-1. Guiding Questions for Sharing Circles

Question 1	What is your experience with direct-to-consumer (DTC) genetics? If you've had an experience with a DTC company, how did your results compare to how you self-identify?
Question 2	Has anyone ever told you they received results from a DTC company that affirmed they were Native American? What was your response?
Question 3	If you were to participate in a DTC genetics company's service and received a result that stated that you were not Native American what would that mean to you?
Question 4	If you took a DTC test, what would you expect your results to be?
Question 5	What is Native American identity?

RESULTS

Question 1. *What is your experience with direct-to-consumer (DTC) genetics? If you've had an experience with a DTC company, how did your results compare to how you self-identify?*

Only one of the 18 participants had any experience with a direct-to-consumer company. Our discussions revealed that the participants felt various levels of trust or mistrust about DTC companies and other colonial authorities. Participant 3 stated,

> "I haven't taken a test. I guess the extent of my experience is just seeing the commercials on TV and I usually think they are pretty funny… there was that one where this woman found out she was Navajo or something like that and I was like, 'No you're not!' … it just kind of gives me the perspective that it's a scam… I don't trust it and I don't believe it."

Participant 6 expressed their mistrust by suggesting a fear of the impact participation might have on their family. They said,

> "I have never taken one of these tests, except my grandpa has. He's the only one in my related, like biological, family who has taken it. He got it as a Christmas gift from one of his employees. Everyone told him not to take it. He ended up taking it. We're like, 'Great now we're all in the system!'"

A similar type of family mistrust was discussed by Participant 10. They said,

> "I've never had a direct experience, but I've talked about wanting to get one before just for fun to my grandma and she shot that down immediately. She thought that the information would be used illegitimately."

Participant 15 expressed mistrust that was rooted in fear. They said,

> "I have no experience and I'm too scared to with them being private companies and holding on to something that's really important. Also, I feel like eugenics is a topic that's coming up again and it's really scary."

In contrast, Participant 4, the only participant to have had an experience with a DTC company, shared some personal experiences with us. Participant 4 was not connected to one of their biological parents and was not seeking Indigenous roots as much as new family connections.

> "I was kind of obsessed with ancestry because I didn't know anything. I just remember having to sneak a look at my birth certificate before it got changed to figure out what my biological father's name was and I've been doing this research on my own… I trusted what I got for the most part… a little bit Spanish, mostly Indigenous."

The participants felt strongly about how knowledge of one's history can impact your engagement with DTC genetics. The discussion about knowledge of one's history began in response to Question 1 and continued in the discussion of other questions. To Question 1, Participant 18 said about herself and why she would not be participating in any DTC genomics, "Knowing my history, knowing my ancestors, that right there is enough for me to know where I identify from." Participant 6 would add the inverse to that understanding,

> "[This] is an outsider's way of trying to become integrated into our space, but it's because they don't know… You have to be minimally knowledgeable about your own cultural history and your genealogy [to want to participate in DTC genomics], and for a lot of Americans that is an issue because of the way… their ancestors immigrated to the United States. There is a lot of mystery around that [for them], so they are all trying to find out who they are."

Three other themes emerged more than once in response to Question 1. Other themes that emerged: ideas about using DTC genomics to reconcile lost family histories. The participants mentioned some "gaps" in the histories of some Indigenous people due to historical and recent colonial practices and adoption and two participants felt DTC genomics could be a potential solution. Cultural appropriation was identified as a potential issue with DTC genomics, and the participants discussed that the practice of

DTC genomics and its consumers were "not normal." The practice was both not normal in regard to how Native American people understand their ethnic, racial, or political identities, nor was it science that could be considered normal or reliable based off of the reality of how they understand their tribal identities.

Question 2. *Has anyone ever told you they received results from a DTC company that affirmed they were Native American? What was your response?*

Eleven participants had this experience. Two students were familiar with someone having this experience or a similar type of experience. Five students had never been approached in this way by anyone. When the participants discussed their responses to these claims, they often speculated about why these people may have chosen to speak to them in this way. The participants many times described situations that spoke of appropriation or requests for validation. They would respond by "testing" the person's Native identity with insider-type questions or by educating them. Their words often indicated being put-off by the experience, even "angry."

Appropriation, defined as a description of someone asking them about acquiring tribal services was brought up by five participants. Participant 2 had worked at their tribe's heritage center and had been approached "many times" with a claim like Question 2 describes. They mentioned one encounter,

> "I remember one time this lady came in—so she [had taken] a test. She was [now] Cherokee and [claimed] her daughter needs new clothes for school. I told her, 'We're not the Nation, you can go to the Nation, but you have to prove it.' She

> was like, 'But I have the test.' I explained to her you have to find your [family] on the roll. She was like, 'But I have this test!'… I guess she got angry and left."

Seeking validation of their Nativeness was what some participants speculated as the reason someone might approach them with this type of personal information. Participant 1 said, "I feel like non-Natives have the need to tell somebody who is Native 'Look, I took the test!' … I know I physically appear [Native], but that does not mean I'm the final person, the final judge to certify you."

When I asked Participant 6 about how they have responded to the "hundreds of people" who have brought this encounter to them, they talked about both appropriation and requests of validation, and they spoke about summing up the situation as best they could in the moment. They said,

> "[How I respond] really depends on what I think they are trying to get out of it. Like are they saying that because they want me to help them with a scholarship then that's different that someone who is just trying to up their legitimacy in a friendship relationship."

Two ways of handling this type of encounter we mentioned a total of five times. One method used for engaging the ignorance expressed was to educate the individual on the participant's understanding of the complex issues. Participant 5 said, "I feel like it is almost my responsibility because how are these non-people of color going to know if nobody tells them?" Participant 15 educated their encounters in this way,

> "[It's] more than just trying to seek our resources… try to understand that Native identity is not just genetics… It takes more than genetics to be Native American. I

> don't want to tell them don't believe it. I don't want to be mean. I want them to learn about tribal sovereignty and stuff like that."

By stating, "It takes more than genetics," Participant 15 seems to suggest that they feel genetics is a player, but not the deciding factor.

The other method was widely acknowledged as common practice, a Native ID test. These tests consist of asking the person approaching them insider questions that only someone from within the community would be able to answer correctly. For example, in my community, a question like, "What are you clans?" can produce results that indicate a person's Navajoness, more or less. A Native ID test might incorporate informal or community-based practices of identity, like clan membership, or more formal mechanisms of identity, like questioning citizenship or enrollment. Participate 3 described her particular Native test and a time she used it,

> "We have three districts that we come from. That's where your family comes from. You can usually tell if someone's culturally Osage, they'll know their district at least, even if they don't participate in dances where we have these three districts, they'll know where their family comes from. So, I asked him, 'What's is your district?' That's my go-to test when people claim Osage because even if you're not culturally there somehow, you'll know your district through family."

Question 2 brought up two juxtaposed knowledges about Native Americans that possibly speaks to several issues. One idea was that Natives do not partake in DTC genomics tests. Participant 18 said, "I honestly do not hear too many of my peers that are Native that actually will do [a DTC test]. It's just more [for people] that are not Native." However, Participant 17 described a type of reconciliation that they were aware of

happening in their friend group. They said, "One of my friends that is Choctaw took a DNA test and it was just because her dad is non-Native and she was wanting to kind of find out that lineage." These statements highlight a perceived taboo in the community—ancestry testing, and a problem in the community—lost familial connections, a problem that could be addressed with the taboo.

Question 3. *If you were to participate in a DTC genetics company's service and received a result that stated that you were not Native American what would that mean to you?*

Seventeen of the 18 participants stated that they would understand the results to be wrong if they were told that they were not Native American.

P01: "I think it would only tell me that whoever created this you need more work. Go get your facts straight."

P02: "I'd show them my CDIB. Because I know who I am. I'm proud to be Native and of how I was raised and all that."

P03: "I would not believe it because I did grow up in my community. I'm Osage, I grew up here with my mom in the Osage community. In Osage county!"

P05: "It would not mean one difference to me. I mean, it would only open other curiosities as to how these people actually get their information."

P06: "It wouldn't be anything. … I have family members who are full, lots of them. And some of them are not enrolled and they couldn't get enrolled even if they wanted to because their parents didn't enroll. But we don't treat them any different."

P07: “I know who I am, and at the end of the day, the community that I grew up in is my family. It’s my friends. It’s the people who matter to me and I know they’re going to accept me unconditionally.”

P08: “I know who I am and so even if it said that I wasn’t… I guess it wouldn’t really change anything for me. It’s interesting to think about because—I mean—I don’t know. I guess it wouldn’t change anything.”

P09: “Holy cow! That would blow my mind. I would say you got the wrong guy, sorry.”

P10: “The tests are inaccurate. I know my history enough to know who I am. … That means their algorithms has a mistake somewhere or there’s a void of data that they don’t have and it just put me somewhere that it shouldn’t have.”

P11: “I would think that it was messed up or fake. Because there is no way. There is no way! My family and I live in Tahlequah. I’m from Tahlequah. They stopped in Tahlequah on the Trail of Tears! We know so much of our history.”

P12: “I’d be super sad because I know it’s not true. History…traditions…ceremonies. I feel like that defines your Nativeness.”

P13: “I’d think they were lying because my great-grandma’s full-blood Creek Muskogee and she went to the boarding schools. I look exactly like my grandma and I’m named after my great grandma, so… I’m like no.”

P14: “That it really was a template. They sent me the wrong template.”

P15: “I would probably laugh. And it would confirm how inaccurate these tests are because I know that I am part of a community that is Native, I know my language, I know our customs.”

P16: “Land and territory and spirituality and religion and language and scared history are all interdependent and interrelated and that’s ultimately what contributes to Native identity. I have a connection to all of those and no test can tell me otherwise.”

P17: “My connection to the land, to my family, to my language, and the relationship that we have in and between those things—I feel like that’s what makes me who I am as a Native person and I just don’t really see paper results that are relevant to who I perceive myself to be.”

P18: “I don’t think it would affect me as far as I feel who I am or where I’m from and understanding where I’m from. I’d just laugh at it.”

Participant 4 revealed that they might believe the results and what that might mean. They shared their very personal story:

> “My understanding of what it means to be Native has changed so much even within the last couple of years. I also have the added layer of not being connected to my Comanche family because my biological father and my mom split up when I was really small, like two or three maybe, and so I grew up my whole life without ever meeting him after that. I always had a shadow, like oh you’re not really Native because you don’t know anybody, right? Because none of my immediate family is Native. I probably would be devasted because it’s like an imposter-self-fulfilling prophecy. I’m an enrolled citizen and we’re not just a race we’re a political identity.”

Question 4. *If you took a DTC test, what would you expect your results to be?*

The answer to this question varied widely. Seven participants answered with percentages, often based on their known blood quantum and their understanding of

admixture in their family histories. Six others exclaimed that the results did not amount to anything at all. That last themed group of six discussed genomics' biases towards European populations and associated risks. Below are examples of these discussions.

Participant 3 summed up their ancestry expectations using their knowledge of tribal affiliations and blood quantum. They said,

> "I'm not good at math. I'm dad's full-blooded Apache so I know I'm half Apache. But then also I'm like 1/16th this, this, this, and this. Like there's a bunch of one-sixteenths. But then I've heard of maybe they're being some German in our family. I would expect like maybe around probably 90% Native and then like 10% miscellaneous."

Participant 16 didn't give much thought to their imaginary DTC genomics results. He stated to the group,

> "That's not something that I really thought of because I wouldn't do any tests. … The way that I think about being Native is much more than just your blood. It has to do with how you engage with your community. It wouldn't change how I identify because the way that I engage with my community, the way that I serve my people, the way that I work with my family and my responsibilities—they will still be intact regardless of what any tests says."

The discussions about European biases in genomics and associated risks varied. Participant 4 was "worried about how much White" they were going to be as a result of DTC participation, which was a similar concern of two other participants. Two participants echoed concerns of risks to Native American populations and their sovereignties, one participant even citing a podcast featuring Dr. Kim TallBear discussing her 2013 book, *Native American DNA*.

Question 5. *What is Native American identity?*

Many of the participants described Native American identity in details that were very personal to them. They described Native American identity being more than just enrollment, that it is being active in your community, being claimed by a community, and knowing about tribal culture, struggles, and history.

Some of the participants questioned the validity of the concept "Native American identity." Participant 1 stated,

> "When you're thinking of the term 'Native American' it's kind of what the colonial society wants you to be or claims you to be. It defines you on its own terms by only giving you limited options of what it means to be a Native American. I always like to say I'm Apache. That is who I am."

Participant 1 understood Native American to be their race category, or how one is defined to the larger population. But this participant felt "Apache" to be how they personally identified ethnically and culturally. Participant 1 finished by saying, "We stay away from using 'Native American.'"

Participant 16 felt similarly about Native American identity as a construct. They said that attempting to define this concept gives it "rigidity" and that the construct should not be rigid. "There are 500 plus federally recognized tribes. How do they see themselves? I'm not going to speak for them all [by defining what Native American identity is]." They continued by pointing out how a static definition of Native American

identity contributes to anti-blackness and colorism in tribal communities. “For example, lighter complected Natives are often seen as not Native based on their physical appearance. I feel like defining this would contribute to that type of oppression of our own people.”

CONCLUSION

The Sharing Circles to understand direct-to-consumer genomics and Indigenous identity contributes an interesting voice to the literature that has much to say about the complex reality of the continued objectification and commodification of Indigenous identity by DTC products. The project aimed to explore if a sample of self-identified Native American students may have had similar encounters as I had, where I found myself being approached by many people telling me their direct-to-consumer results. I further wanted to explore the participants’ experiences, in general, with DTC technologies and how it may have impacted their perception of genomic science.

Question 2 (Has anyone ever told you…?) revealed that more than half of the participants, 61%, had an experience where someone approached them with DTC results. The participants discussed that these encounters were often focused on appropriating Native American resources or seeking validation of Indigeneity. The participants shared the two ways of handling these encounters: educating the person or by asking the person insider questions to gauge the person’s connection or belonging. They often expressed that these encounters were uncomfortable for them.

The results of Question 1 and Question 3 (What is your experience with…? If you were to participate…?) show a similar pattern to how participants responded. For Question 1, seventeen out of the eighteen participants had not personally participated in the services of a DTC genomics company, Participant 4 had participated. Similarly, in Question 3, seventeen participants said they would believe results to be wrong if they were not returned results that stated they were Native American. Participant 4, however, said that they would "have been devastated" had they received results stating they were not Native American. It is obviously that the majority group of participants was very comfortable in their identity for a variety of reasons (CDIBs, connection to land, connection to community, etc.) and for those reason they would never believe any test that told them otherwise. The participants have direct evidence in their life experiences to know that this "science" is false. However, for Participant 4, despite their being an enrolled member of a Nation, they would have been deeply impacted by this type of negative result, even as far as feeling their "imposter syndrome" validated by the experience.

Question 4's (If you took a test, what would you expect?) results are a bit puzzling. The participants responded in 3 ways: with speculated percentages of Native DNA they may hold, with an assertion that these tests are false, or with a concern for the ethics of the research and its impacts on tribal sovereignties. Three participants felt they would be returned results that would indicate that they were "100%" Native American, others rationalized more conservative estimates. It is not possible to be 100% anything. Purity is a misguided colonial benchmark of race and is not possible. It would seem the

participants most generally believe in the coloniality of the science, that science more often supports settler projects that aim to erase and replace Indigeneity.

Question 5, about Native American identity, was most surprising. I found many participants give nuance to the question with their answer. As they understood it, they would describe to me the difference between race and ethnicity. I found several participants offended by audacity of the question. Those participants were concerned with the "umbrella" term Native American and its colonial origins. They, too, were describing to me the idea of Native American race in their own words, as a colonial construct that did little to uplift their specific community. Most generally, I got the sense that "Native American" is simply a box that gets checked government forms, while tribal identity is what is embodied and passed down to future generations.

DISCUSSION

Indigenous research harms of the past would have people believe that Native Americans do not participate in DTC genomics. We would believe that only non-Natives use these services to attempt to belong and ultimately undermine tribal sovereignties. To a large extent, the stories of these participants confirm that to be true.

Participant 4's story challenges these mantras. Participant 4 shared a very personal story that revealed a complex identity that could have been revoked, in her mind, by results other than what she received. Reconciliation stories like this must be highlighted, in balance to race-shift narratives. In *The Social Life of DNA,* Alondra

Nelson (2016) explores reconciliation projects that use genomics to "contribute to community cohesion, collective memory, or social transformation" (8). Participant 4's use of genomics was a type of personal reconciliation with a lost family history. Participant 4 was happy with their result. In contrast and from personal experience, enrolled Natives Americans have been known to get results that do not come near to matching their known Native American status. Not to mention that results will vary from one company to another, sometimes wildly! I believe it is time to open the discussion for how DTC genomics can aid Indigenous people, if at all, and what that might look like.

There is a distrust of science by some Native Americans that may be rooted in a misaligned conception of what it means to belong to a Native American community. Within this distrust is a fear for how these powerful tools may be used to further displace and/or eliminate Indigeneity in the US as we know it today. It should be concerning that such a high percentage of this sample believed the "science" to be wrong. Consumer science, academic science, and industry science share a goal to be truthful and objective. In a time when diversity, equity, and inclusion are at the forefront of training and hiring, this particular type of genomics and its discourses would repel certain populations from participation and could potentially sour relationships between academic and industry scientists and minority populations. A more ethical, informed, nuanced, and decolonized praxis of DTC genomics is called for immediately. Possibly this could be envisioned by a Native run DTC genomics service that recognizes the harms of the past, the concerns of the people today, but also, allows Native people to explore their genomes in entertaining and culturally relevant ways.

*See Supplementary Material C for funding.

CHAPTER 5 – Conclusion

The research presented in this dissertation is connected by a need and desire to uplift the voices of Native American and Alaska Native peoples in anthropology, but also in research. The need is necessitated by anthropology's long history of objectifying Native American and Alaska Native subjects. Additionally, this research is connected by exploring Indigenous perceptions of genomics and science. I question the validity and structure of the dominant knowledge production paradigm (Chapter 1), I aid tribal peoples in weighing the benefits and risks of genomics research in their community (Chapter 2), and I convene my peers to explore their specific position in an Indigenized forum.

Chapter 1 – "Entanglement, Sovereignty and Science" aimed to create equitable spaces and outcomes for research, knowledge, and people, specifically Indigenous people. I looked at the colonial legacy and entanglement of Indigenous Knowledge and "western" science and how that impacts the knowledge production process. The unstable dichotomy continues to be defined through a colonial lens, allowing both colonial and racial logics to play. Rather than deconstruct this dichotomy, I outline a framework for empowering it, which includes disappropriating scientific methods from the paradigm as well as crediting Indigenous scholars' research as Indigenous knowledge. Chapter 1 is a theoretically rant that hopes to empower a future Indigenous student of science.

In Chapter 2, we detail the nature of conducting a cross-site deliberations solely in Indigenous communities. The chapter presents 2 years of collaborative work done by me and others as part of the Center for the Ethics of Indigenous Genomics Research (CEIGR) consortium. Here, we showed that deliberation, as an approach to community engagement, effectively facilitates dynamic dialogue about genomics research and how community perspectives are shaped by local political, economic, historical, and social factors. The deliberations proved that tribal citizens maintained diverse perspectives about complex topics, like genomics.

Chapter 3 – "Eliciting the perspectives of Native American young adults at the University of Oklahoma on identity and genomics through Sharing Circles" emphasized an Indigenous centered methodological approach to research, the sharing circle. My goal was to both use and validate an Indigenous method, but also to explore the stories of Native American people and how they engage with direct-to-consumer results in their everyday lives. I learned that these participants believe this specific technology to be inaccurate to how they understand their tribal identities and lived reality. Within this distrust is a fear for how these powerful tools may be used to further displace or eliminate Indigeneity in the US as we know it today.

By the simple act of existing within a settler state, Indigenous voices and perspectives are muted if not all together removed. Within these chapters is an acknowledgment of those types of historical harms and distrustful relationships by the research and his participants. But also, this with this collection of works, I and my

colleagues, work to repair those relationships by restoring these much need perspectives to public understanding. Indigenous people want to define their reality and their experience in their own way.

The approaches used in this dissertation represent innovation in thought and praxis. Genomics technologies are rapidly advancing, and Indigenous test subjects continue to be enticing to researchers. Thus, Indigenous people need to be the ones shaping the ethics of genomics research. To be Indigenous implies a certain relationship with a colonizing authority. That relationship includes disparities, oppressions, and even genocide. The ways questions are asked, how data is collected, and how that data is interpreted are riddled with colonial legacies. The chapters here present research possibilities that aim to empower communities and mend research relationships.

My future research will continue to innovate methods and methodological spaces. In the coming years, Indigenous genomics will flourish by asking questions that align with community values, needs, and curiosities. Today, we are at the forefront of this shift. In my few "short" years as a graduate student, I have witnessed and experienced genomics as it has evolved and grown to include many Indigenous genomics professionals who work for their communities. Having representation in this field has been key to maintaining that forward momentum. I hope that these chapters represent for some young Native American person an open door to the sciences.

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Supplementary Material A

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Supplementary Material B

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Supplementary Material C

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