Published in final edited form as:

J Empir Res Hum Res Ethics. 2017 July ; 12(3): 169–179. doi:10.1177/1556264617704542.

Qualitative Research Barriers and Strategies related to Genetic Ancestry Testing in Indigenous Communities

Jessica W. Blanchard, Ph.D.¹, Gloria Tallbull², Chantelle Wolpert³, Jill Powell⁴, Morris W. Foster⁵, and Charmaine Royal⁶

¹Department of Anthropology, University of Oklahoma (USA)

²Center for Applied Social Research, University of Oklahoma (USA)

³Emory & Henry College, School of Health Sciences (USA)

⁴Duke University (USA)

⁵Old Dominion College (USA)

⁶African & African American Studies and Biology, Duke University (USA)

Introduction

Commercial genetic and genomic ancestry tests have been available on the public consumer markets for over fifteen years, and yet there remains little empirical data related to perceptions of these technologies among specific populations. Conducting genetics-related research with populations that may perceive genetic research and technologies as having little direct benefit or even as harmful, including Indigenous and other minority populations in the U.S., poses particular challenges for researchers looking to understand community-based perceptions of genetic technologies such as direct-to-consumer (DTC) genetic ancestry tests (GAT). As part of a larger NIH-funded project focused on public perceptions and experiences with GAT, a team of Indigenous and non-Indigenous researchers from the University of Oklahoma conducted a 3-year project related to perceptions, attitudes, and values associated with genetic ancestry testing among diverse Indigenous communities in Oklahoma¹. The purpose of this article is to identify methodological challenges and strategies for collecting qualitative data related to genetic ancestry testing in practical, ethical and culturally appropriate ways. Specific priority areas addressed in this article include issues related to participant recruitment and tribal advisory boards, the challenges of self-identification as a recruitment mechanism, and the necessity of including Indigenous researchers in all aspects of the research process.

Corresponding Author: Jessica W. Blanchard. 455 West Lindsey Street, Norman, OK 73019. Phone: (405) 325-6936; fax: (405) 325-7386; jessicawalker@ou.edu. Gloria.tallbull@ou.edu.

No disclaimers

¹We use the term “Indigenous” to refer to the original inhabitants to the land base of the continental U.S. who are legally and federally recognized as “American Indian,” and who otherwise utilize a variety of terms to refer to themselves, their communities and other Indigenous peoples of the U.S., including “Native American,” “native,” members of “tribal communities,” or the preferred term that specifically denotes tribal, ceremonial, or community affiliation. We recognize that the term “Indigenous” has broader applications not discussed here, especially when being used in global or transnational contexts to refer to Indigenous peoples worldwide who otherwise use identifiers not mentioned here.

Background

Since the introduction of GAT to the consumer markets in 2000 (Royal et al., 2010; Wagner & Weiss, 2012; Wagner, Cooper, Sterling, & Royal, 2012), over 70 companies now sell DNA ancestry products, packages, and services to consumers looking to access personal genomic information for purposes of discovering ancestral connections (Phillips, 2016; Royal et al. 2010). GAT products are advertised, mostly through popular group-buying sites and social media outlets, as products to “help deliver the richest family stories—and solve the toughest family mysteries” (AncestryDNA), “understand what your DNA says about your health, traits and ancestry” (23andMe), learn the “richest ancestry information available” (Geno 2.0), and discover “even more about your ancestors than the old shaman who appears in five generations of family wedding photos” (AncestrybyDNA). These tests have acquired the moniker of “recreational genetics” (Bolnick et al., 2007; Via et al., 2009), in part because the science of genetics has entered into the private spaces of households where television programs highlight the deeply personal and accessible links between DNA and genealogical records, historical lineages, ancient populations, and even celebrities (Jobling et al., 2016). GAT companies now offer products that bundle ancestral and medical information, blurring the “recreational” and “diagnostic” applications of these technologies. This combination of information now available to consumers reflects “the power of the market to challenge what has been treated as distinct domains of knowledge” (Lee, 2013, p. 551), highlighting the fact that consumers are likely to use these technologies for multiple purposes.

DTC ancestry tests incite critical skepticism among various publics and scholars alike, especially with regard to the potential for such tests to perpetuate racial essentialism, to disrupt or subsume personal identities and community histories, to promote unrealistic ideas about the usefulness of test results, and to provide results based on incomplete or limited sample databases (Bolnick, 2008; Fullwiley, 2008; Shriver & Kittles, 2004; Royal et al., 2010). At the same time that these technologies are growing in popularity and expanding their presence on the consumer market (ASHG Ancestry Testing Statement, 2008), there remains “little oversight and few industry guidelines to ensure the quality, validity, and interpretation of information sold” by GAT companies (Lee et al., 2009).

There are limitations to the kinds of information available through GAT and the means for interpreting the findings of GAT; researchers point out the GAT can access only a fraction of one’s entire ancestral lineage and the databases used to infer connections to ancestral populations represent a “woefully incomplete sampling of human genetic diversity” (Royal et al., 2010, p. 668; see also Tallbear, 2007). Further, there are questions about the process whereby individual genetic information is interpreted to either suggest overly unique and individualized genetic relationships that are actually shared by many, or to infer shared ancestral linkages that feed “notions of indigeneity and group membership” by linking individuals to ancient populations (Jobling et al., 2016; see also Lee, 2013). Marketing genetic variance as evidence of ancestral differences, without also highlighting the role of environmental exposures and selection over time, also speaks to a unique cultural interest in using interpretive frameworks like family history and ancestry over, for example, an ecological framework (Fullwiley, 2008). The interpretive process is itself a cultural

phenomenon, so that interpreting single nucleotide polymorphisms (SNPs) primarily as indicators of admixture between groups, without also considering “different kinds of mutation events, gene flow, or environmental exposures and selection over time,” privileges an interpretive framework that explains variations in genetic markers on the basis of “shared ancestry” instead of “similar historical environmental exposure” (Fullwiley, 2008, p. 702).

The accessibility of genetic ancestry testing to the consumer public poses potentially significant implications for many Indigenous and other historically exploited communities who have long been suspicious of the value and goals of genetic exploration (Bowekey & Davis, 2003; Hoyo et al., 2003; Royal et al., 2010; Sankar et al., 2004). Scholars note the potential for GAT to have particularly damaging implications for Indigenous communities in the U.S., including the potential for such tests to invalidate or authenticate specific ancestral identities, paving the way for the possibility that unregulated genetic ancestry products stand to challenge the process whereby federally recognized tribes in the U.S. determine their own conditions for tribal membership (Bardill, 2014; Tallbear, 2000, 2003, 2007 & 2013; Tallbear & Bolnick 2004; Tsosie, 2007). Understanding the implications of GAT for Indigenous communities, both in the U.S. and beyond, is to be understood within the broader context of genetic exploitation impacting these and other populations over time.

Communities that have been historically exploited and underserved by the benefits of genetics and other biomedical research maintain strong mistrust toward genetic technologies, researchers, and the donation of biospecimens for research (Bussey-Jones, 2010; Harry & Kaneche, 2006; Pacheco, 2013). A notable example of intergenerational mistrust that persists as a result of exploitative biomedical research is found among many African American communities as it relates to the atrocities of the Tuskegee experiments (Bates & Harris, 2004; Buseh et al., 2013; Corbie-Smith, 1999; Phillips et al., 2011; Scharff et al., 2010). Another prominent example of mistrust involving genetics research, specifically, derives from the unauthorized use of biospecimens belonging to members of the Havasupai Tribe in Arizona (Dalton, 2004; Drabiak-Syed, 2010; Havasupai Tribe of the Havasupai Reservation v. Arizona Board of Regents, 2008). Researchers from Arizona State University received permission from the Havasupai Tribal Council to collect blood samples for purposes of conducting what tribal members thought would be research related to diabetes. Over the course of the study, signed consent was replaced with oral consent and tribal members were not told of the eventual focus on the genetic basis of schizophrenia, inbreeding, and population migration theories (Drabiak-Syed, 2010). The Havasupai case represents a clear breach of trust on the part of these researchers in at least three important ways: in maximizing the utility of the blood samples for undisclosed purposes, the researchers failed to recognize the cultural and spiritual value of the blood samples to the Havasupai (Drabiak-Syed, 2010), they failed to understand the harmful implications of linking a variety of stigmatized diseases to an easily identifiable population, and they failed to properly and continuously inform tribal members of their research goals.

The Havasupai case is just one example in a legacy of biocolonialism perpetrated against Indigenous peoples- including but not limited to the distribution of smallpox-infected blankets into Indigenous populations (Christopher et. al., 1997; Riedel, 2004), the unauthorized sterilization of thousands of Indigenous women in the 1960s and 1970s

(Lawrence, 2000), and the legacy of chronic illness resulting from the destruction of traditional foodways and the introduction of processed foods and government regulated ration systems (Weidman 2012); genetic research and bioprospecting are extensions of this historical legacy of biocolonialism that continues to shape ethical standards and perceptions of biomedical and genetics-related research across Indigenous communities today (Di Chiro, 2007; Harry et al., 1998).

Methods

The work at the center of this article was one part of a 3-year, NIH-funded project designed to broaden current understandings of public perspectives of genetic ancestry testing using a combination of ethnographic knowledge, surveys, in-depth interviews, and focus groups. The goal of this mixed methods approach was to assemble a rich resource of quantitative and qualitative findings about public perspectives of GAT at individual, community, and national levels. This article addresses only the methodological and ethical challenges associated with the process of conducting the community level phase of the project, with detailed findings from all phases of the project being prepared for publication elsewhere. The community level phase of the project involved three years of ongoing community engagement with Indigenous peoples living in diverse tribal communities across eastern and central Oklahoma, which produced a total of thirteen focus groups with 128 participants and 6 in-depth, semi-structured interviews with community leaders. This particular phase was led by a team of both Indigenous and non-Indigenous researchers at the University of Oklahoma, both with prior knowledge and experience working in tribal communities across Oklahoma.

The community phase of the project involved the collection of individual interviews and focus group data related to perceived risks, benefits, and personal experiences with genetic ancestry testing products among self-reported “Native American” individuals in Oklahoma. The original research design called for participant recruitment to be limited to enrolled citizens of five specific federally recognized tribes in Oklahoma, identified by researchers both for their geographic proximity to one another and their unique cultural and political histories related to issues of race, ancestry and citizenship². Ahead of any formal data collection, researchers conducted informal outreach activities in these select tribal communities over a two-year period to share information about project goals and assess levels of interest in future phases of the project. The original research design included community outreach activities as a foundation to build rapport, establish partnerships, and revise project goals according to community feedback. Outreach activities included informative meetings between researchers and select tribal departments and officials, informal conversations with tribal citizens to address initial concerns and plan project goals, presentations at tribal community meetings, and advertisement of the proposed project in select tribal offices, organizations, and tribal media outlets.

Outreach efforts in specific tribal communities revealed tremendous interest among individual community members in the topic of GAT, but we were unsuccessful in securing

²We have chosen not to identify these specific tribal groups by name here because the final research design recruited persons self-identified as “Native American” without membership in any one tribe as a requisite for participation. Our decision to broaden the recruitment of participants in such a way that privileged self-identification over tribal enrollment is discussed further in the article.

all of the formal tribal governmental permissions needed to continue working in the pre-identified tribal nations. Standard practice requires formal tribal government support for research that either identifies specific tribal nations or communities, recruits participants on the basis of their citizenship in any one tribal nation, or that utilizes the services, facilities, employees or programs of a specific tribal nation for research purposes. It was clear through our two years of outreach efforts that individuals across diverse tribal communities and a number of existing tribal programs were interested in talking about and supporting research related to genetic ancestry testing, but recruiting participants on the basis of tribal enrollment was not an option without formal permissions from the respective tribal nations. The lack of formal tribal support, in spite of the interest expressed by individuals or even small communities within tribal nations, prompted a fairly significant methodological reworking of the entire project; our original approach to participant recruitment broadened from a tribally specific approach (i.e. Participant recruitment includes individuals who are enrolled citizens of ___X___ Tribe or Nation) to instead recruit participants on the basis of self-identification as “Native American” without membership in any one tribe as a requisite for participation.

This new approach was far broader in its focus, precluding the ability to situate participant responses in a specific cultural, historical, or tribal context. There were additional concerns with this new approach, including the inherent problems with self-identification and questions about individual versus community consent, to be addressed more fully later in this article. Ultimately, specific tribal enrollment information was not a requisite for participation for individual participants. An ethnographically informed approach, supplemented with informed and snowball sampling, was used to identify public locations and community events with high attendance by members of Indigenous communities for the recruitment of self-identified “Native American” participants. Thus, we ultimately worked with intertribal church groups, organizations serving Indigenous populations, intertribal civic groups and artist networks, tribal educational groups, and local community boards in high-density tribal communities throughout Eastern and Central Oklahoma. This ethnographically informed approach provided an added check on self-identification, thereby ensuring that participation was defined not only according to self-reported racial or ethnic classifications, but also according to longstanding ancestral identities and community affiliations. This new approach was not without problems, and these are addressed more fully in the sections that follow.

Results

The two-year period of engagement and subsequent year of formal data collection underscored the prevailing perception that Indigenous populations view genetics-related research as harmful or inconsistent with community values, at the same time that many participants expressed hopefulness about the potential benefits of genetic innovations for their communities. Manuscript preparation reporting specific findings related to attitudes and perceptions about genetic ancestry testing are underway, but discussion about the collection of this qualitative data presents clear opportunities to improve the process of conducting genetics-related research in culturally and methodologically appropriate ways. Specifically, we identified the following priority areas for improving qualitative research

related to genetic ancestry testing: a.) issues related to participant recruitment and tribal advisory boards, b.) the challenges of using self-identification as a recruitment mechanism, and c.) the necessity and value of utilizing Indigenous researchers at all stages of the research process.

Participant Recruitment and Tribal Advisory Boards

Our decision to recruit self-identified “Native American” individuals meant that participants were residing, affiliating, and participating in multiple and diverse tribal and non-tribal contexts. The tribally heterogeneous nature of participants on this project did not fall within the jurisdiction of any one tribal review board; thus, it became increasingly difficult to ascertain the most appropriate mechanisms for establishing community consent. Not all of the tribal communities initially approached about participation in this project operate formal tribal IRBs or advisory boards. However, three of the tribes approached during the initial outreach phase of the project did operate a type of Tribal Advisory Board³ from which formal permission is required to recruit research participants on the basis of their citizenship in these specific tribal nations⁴. The appropriate tribal representatives were contacted, and presentations about the project were made both in person and through email. Attempts to obtain formal tribal support and approval from these tribal advisory boards were ultimately unsuccessful; two of the tribal advisory boards denied formal support for the project, and no prolonged communication about the study could be established with the third.

There was seemingly strong support and discernable levels of interest in the project among tribal departments and tribal members with whom we informally spoke; assurances were made both in person and through written communication that formal approval of the project would be likely. Ultimately, however, permission was denied with little explanation. The decision of the tribal advisory boards to withhold formal support of the project was not wholly unexpected, given the politically and culturally sensitive subject of genetics research in Indigenous communities. Concurrent with our outreach efforts to garner support for the project was steady media attention to controversial stories, including the “Baby Veronica” custody case and the Supreme Court case involving Freedmen, both evoking strong sentiments about ancestry, citizenship and infringement on tribal rights⁵. The commitment of any one tribe to participate in a study about GAT had the potential to reveal, and even amplify, internal tribal schisms related to issues of race and citizenship. The political nature of the research topic should not be overstated without also considering the possibility that

³We use the term Tribal Advisory Board to refer to the mechanism of approval operated by each tribe. While some of the tribes approached over the course of our outreach phase do operate formal Institutional Review Boards, others maintain less formalized boards and processes for granting community approvals for research. There are not very many tribal nations in Oklahoma that currently operate an Institutional Review Board; because we are not identifying the specific tribes with whom we worked and with whom we did not work, we have opted to use the less specific language of Tribal Advisory Board when discussing our outreach efforts.

⁴This project was approved by the University of Oklahoma Institutional Review Board.

⁵The political implications of genetic ancestry testing for some tribal communities was reaching a fever pitch at this time as a national conversation was being had about two major news stories out of Oklahoma, including the “Baby Veronica” case (Adoptive Couple v. Baby Girl, 6/25/13) and a number of ongoing cases involving Freedmen, including Cherokee Nation v. Nash (Cherokee Nation v. Nash, Case No. 11-CV-648-TCK-TLW (N.D. Okla. Mar. 15, 2013). Both of these cases became national sounding boards for reifying problematic notions about blood quantum, race, and tribal self-determination, and they reinforced the potential for genetic ancestry testing to have significant political impact for tribal citizens and non-citizens alike.

the advisory boards may simply have viewed the proposed research itself as unviable, impractical, or not aligned with their interests.

There are other possibilities to consider as to why we were unable to obtain formal tribal permissions for this project. All tribal governments are organized and operate differently, and all tribes have different processes for granting research approval. It is reasonable to assume that we approached the wrong individual, office, or program for research approvals among select tribes. At least one of the tribal nations approached for this project prefers that researchers partner with existing tribal programs and initiatives identified by tribal representatives, so that attempts to identify individual contacts or liaisons without formal assistance from tribal departments are, as it turns out, time consuming and difficult. This particular tribe encouraged our project staff to work alongside their genealogical division, but attempts to partner with this specific department proved unsuccessful given the lack of perceived compatibility between their ongoing initiatives and our project goals. The lack of compatibility with the identified department, in turn, meant that formal tribal permissions would not be possible. Even if we felt that partnering with other departments in the tribe would have been better suited to our project, deference to the tribe's recommendations occasionally led to an impasse at the administrative level.

This process of seeking permissions underscored the complex dynamics inherent in conducting research that has implications for individuals, communities and entire tribal nations. It is imperative that research involving tribal communities be evaluated by locally sanctioned mechanisms designed to assess the risks and benefits of research at the community level. As mentioned earlier, the call for more responsible research practices in tribal communities stems from a history of irresponsible and harmful research practices against Indigenous communities (Bowekey & Davis, 2003; Burhansstipanov et al., 2002; Christopher et al., 2011; Harding et al., 2012; Kelley et al., 2013; Morton et al., 2013; Strickland, 2006). The challenge is that local mechanisms of community review do not always coincide with prevailing models of institutional review recognized by many Universities and federal funding agencies that privilege individual consent over community risk (Champagne & Goldberg, 2005; Foster & Sharp, 2000). The primacy of the individual in the standard research process (e.g. study size defined by number of participating *individuals*, human subjects consenting *as individuals*, etc.) can undermine the authority of long held community mechanisms, whether they are informal collective decision making processes at the local level or formal review boards overseeing research at the tribal level.

Tribal review boards and community-based approaches assert the importance of community review in the research process, and yet securing tribal permissions for research often requires approval from a designated board or governing body that undermines the relationship between “the individual” and “the community.” Research that privileges the individual stands to disregard a tribe's sovereign right to determine the conditions of research among its own citizens (Harding et al., 2012; Tsosie, 2007), but “equally hazardous is substituting the individual judgments of select, and often arbitrary, community representatives for the collective decision-making processes recognized by the participating community” (Foster & Sharp, 2000). The jurisdiction of most tribal IRBs is based on tribal citizenship and geographic boundaries, and yet the nature of community life is such that the

composition of tribal communities across Oklahoma traverses tribal, geographic, and governmental boundaries in dynamic ways that extend beyond individual citizenship. We ultimately felt that our approach to community engagement and participant recruitment within intertribal organizations, social networks, and areas representing heterogeneous Indigenous populations was more appropriate than the prospect of pursuing support from a tribal-specific mechanism that did not necessarily represent the interests and decision-making processes of the diverse populations with whom we ultimately worked. Further, predetermining study populations on the basis of unique cultural and political histories related to issues of race, ancestry and citizenship introduced a bias with regard to perspectives on GAT, in so much as one might expect citizens of these specific nations to hold particularly charged ideas about genetics research.

Also, in obtaining community permissions we sought to employ an ethnographically informed approach as a means to identify appropriate community leaders, understand the underlying social organization of the distinct communities, and situate individual responses within a broader historical and community-specific context. A reliable ethnographic approach relies heavily on extended community engagement, long-term participant observation, and ongoing collaboration with community members. While the research team's previous knowledge of these communities produced outreach efforts that were ethnographically informed- including the ability to identify individuals occupying informal leadership positions- time and personnel constraints did not allow for full ethnographic engagement in all aspects of the communities. We had to rely on the support and influence of select community and local organization leaders to encourage wider participation from their respective group affiliations instead of, for example, establishing our own networks of broad-based community support and trust from which participation would have emerged over time. Ultimately, community engagement and participant recruitment was done in accordance with local practices and established social roles, but these were defined on the basis of select intertribal organizations, religious institutions and civic groups, and not on the basis of citizenship in any one tribal nation. In spite of our unsuccessful efforts to secure governmental support from select tribes, individuals with whom we encountered during the engagement process continued to express interest and even enthusiasm for the project. Many of these individuals encouraged our research team to pursue intertribal social organizations and institutions with whom they were affiliated, such as Native American churches and intertribal civic groups, to recruit participants for our project. Thus, our recruitment strategy was revised to include participants who self-identified as "Native American" without regard for enrollment in any specific tribal nation.

The Challenge of Self-identification

Self-identification allowed us to extend the scope of the project beyond the jurisdiction of tribal boundaries to include a more diverse population of individuals identifying as "Native American." Privileging self-identification over tribal enrollment is not, however, without its own problems, the least of which is the overly broad use of the term "Native American" as an identifier, the contested nature of this term as it relates to citizenry, ancestry and identity, and the problematic notion that self-identification can challenge the sovereign right of tribal nations to determine conditions of tribal membership for themselves. Self-identification is

not verified through documented tribal citizenship or blood quantum, both of which can also be disputed qualifiers; instead, self-identification promotes the use of inconsistent racial and ethnic categories to represent identities that are fluid and often conditional according to a host of unreported factors.

A final concern we had with self-identification was that our efforts to recruit participants without regard to tribal citizenship and without formal tribal support somehow privileged individual consent over a collective decision-making process. Research practices in Indigenous communities that subvert collective decision-making mechanisms, such as tribal IRBs or community advisory boards, have the potential “to disrupt the established social order of their shared community, and places the moral authority of the larger community at risk” (Foster and Sharp 2000). We thought seriously about the implications of pursuing our research project with University IRB permissions but without formal tribal permissions; after all, tribal IRBs are designed to ensure research involving tribal populations is conducted responsibly and according to conditions determined by a representative tribal body. Our challenge was determining the most appropriate representative body to speak on behalf of the tribally heterogeneous individuals that we had come to meet through participation in a wide array of social, cultural, religious and civic networks.

The Role of Indigenous Researcher

Indigenous researchers are severely underrepresented in biomedical research and are less likely to become recipients of biomedical research funding (McGee, Saran & Krulwich, 2012). Indigenous investigators improve the execution and outcomes of health research in Indigenous communities in important ways; thus, the “need for American Indian/Alaska Native’s (AI/AN’s) in the biomedical, behavioral, clinical and social sciences research workforce has never been so pronounced” (Francis, 2016). The sensitive nature of genetics-related research, in particular, benefits from the direction and perspectives of a growing field of Indigenous researchers who can “bring their cultural perspectives to the sciences” (Claw & Garrison, nd). Our decision to expand recruitment beyond the scope of a handful of pre-selected tribal nations to instead include self-identified “Native American” participants greatly expanded the recruitment process in scope and presented unique challenges for a small research team looking to establish trust and generate interest in a project that proved to be controversial for some communities. A non-Indigenous researcher who had worked and maintained positive relationships with Indigenous communities in Oklahoma for many years initially led outreach activities, but it was quickly apparent that even the strongest commitment to the principles of community engagement did not equate to community representation. The perspective of an Indigenous researcher is critical for implementing a more culturally appropriate approach to the design and execution of research involving Indigenous peoples. Our original research design, lacking meaningful Indigenous representation, greatly benefited from the direction of an Indigenous researcher whose commitment to and knowledge about the diversity of tribal communities across Oklahoma was central to the revision of our study design.

An Indigenous researcher was particularly instrumental in the improvement of the data collection processes, noticing that focus group facilitators were initially posing questions

that dictated the content of the discussions to preference a non-Indigenous research agenda instead of allowing participants to proactively address their own concerns. For example, participants were originally asked how they would respond to geneticists doing research in their communities. This question relies upon the presumption that Indigenous communities are resolved to the prospect of being subjects of genetics research; such a presumption elicits a purely reactive response to the certainty of genetics research, without acknowledging the role that Indigenous people have in determining what research takes place in their own communities. Implicit in the framing of the question was the suggestion that the role of Indigenous people in research was to react or respond, but not to impact or influence, or that Indigenous people are always subjects of research and not partners in or directors of research. Thus, the data collection tools were revised to generate open-ended conversation allowing participant responses to be less reactive to pre-selected questions and more directive of future research by voicing their own concerns.

The addition of an Indigenous staff person to our research team was also instrumental in easing the apprehensions of individuals who expressed interest in participating in the project but otherwise exhibited hesitation around non-Indigenous researchers and staff. Two examples include clarifying project goals and consent form language in ways that were accessible to most participants, and facilitating respectful and trusting interactions between participants and project staff so that project staff were ultimately invited to utilize participants' homes, churches, or community centers for project activities. Knowing to shake everyone's hand upon entering a room, engaging in the appropriate amount of "small talk" ahead of formal discussions, providing, serving and partaking of food in locally customary ways, and conducting group discussions according to appropriate gender and age dynamics of social interaction- these are all nuances of culturally appropriate interactions understood by an Indigenous researcher in ways that are not always apparent to non-Indigenous research assistants. Exerting a style of engagement that is reflective of local practices is not for purposes of coercing participation of otherwise hesitant individuals, but is key for establishing fruitful and respectful discussions with community members.

The presence of an Indigenous researcher was particularly helpful in the recruitment of participants residing in tribally heterogeneous populations where the representation of Indigenous people on the research team, regardless of their specific tribal backgrounds, was positively acknowledged by people we met. Oklahoma is home to 39 distinct tribal nations and often citizens of these tribes reside in urban areas outside of particular tribal boundaries, such as Oklahoma City or Tulsa, making intertribal churches, social organizations, and cultural events suitable hubs for recruiting self-identified "Native American" participants without regard to their specific tribal affiliation(s). It is noteworthy that the presence of an Indigenous researcher did not directly influence recruitment in more rural, tribally homogeneous communities where social ties and trust are established less on the basis of simply "being Native" and more on the basis of having the social and family ties within that specific tribal community. Our research team found the most effective means for community outreach in these areas was to work through intra-community and culturally specific mechanisms, such as locally recognized leaders, community councils, church elders, or other acceptable avenues as determined by ethnographic engagement.

Conclusion

Indigenous populations have long been suspicious of the value of genetics research, citing reasons of scientific exploitation, cultural prohibitions against donating bio-specimens, power imbalance and lack of mutual benefit between researchers and communities, and the use of genetics to discredit origin stories and kin relations (Bowekey & Davis, 2005; Burhansstipanov et al., 2005; Tsosie, 2007). We knew that the process of collecting qualitative data about the risks and benefits of GAT across diverse tribal populations would present unique challenges related to the contested nature of genetics research in these communities. The process itself revealed distinct opportunities to improve genetics-related research with Indigenous communities in culturally and methodologically appropriate ways, including issues related to participant recruitment and tribal advisory boards, the challenges of self-identification as a consistent mechanism for recruitment, the necessity of Indigenous researchers, and the importance of recognizing the complexity with which Indigenous peoples generate both individual and collective decisions about the role of genetics in their personal lives and community experiences.

Qualitative data about community perceptions of GAT suggest that concerns in some Indigenous communities over the exploitive and harmful nature of genetics research coexist alongside positive assessments of genetic ancestry technologies as having the potential to satisfy personal curiosities, to reveal meaningful information about ancestral linkages, and to provide health benefits to individuals, families, and entire communities. Our very first outreach efforts in various tribal communities produced varying levels of interest in the project. Recall that while many individuals expressed interest in the prospect of a genetic ancestry project and viewed the topic as compelling, tribal government representatives and advisory board members expressed more palpable levels of concern over such a project. The increasing availability and use of ancestry testing for members of Indigenous and other historically marginalized communities may have significant implications for both those seeking to authenticate specific ancestral identities to secure tribal membership, for example, as well as for tribal nations whose sovereign rights to determine membership may be challenged by the imposition of such testing. Further, there were discrepancies between ideas expressed (or withheld) in focus group settings and those conveyed in more informal interactions suggesting that there are important factors influencing privately-held versus publically communicated perspectives about genetics research. Despite the disapproval, mistrust or indifference toward genetics research expressed in focus group settings, it was not uncommon in individual interviews or casual group conversations for the same individuals to express at least minimal curiosity about the potential of genetics research and even hopefulness that it could contribute positively to their families and communities. The discrepancies between responses in public versus private settings, or in individual versus group conversations, point to the methodological need to refine and select qualitative approaches in such a way to capture the nuance with which participants engage sensitive topics like genetics research.

The duality with which respondents view GAT suggests that the wholesale rejection of genetics research across Indian Country is premature and oversimplified. TallBear (2001) has cautioned against the wholesale rejection of genetics research by Indigenous peoples in

favor of a tribal-specific approach that considers the critique, promotion, or denunciation of genetics research in specific tribal communities. Beyond Tallbear's recommendation for a tribal-specific approach, we also suggest that an intra-community approach that recognizes nuanced divisions and experiences within specific communities is useful for contextualizing the diversity of perspectives on GAT held across Indigenous communities in the U.S. and beyond. Certainly, the perspectives about GAT encountered over the course of this project cannot be attributed to any one tribal community, but they absolutely reflect the fluid and often contested nature whereby communities redefine their relationship to things like genetics research.

It is vital for researchers to more fully understand the sensitive nature and potential implications of some research topics for Indigenous communities. One way to approach the prospect of controversial research topics is to have Indigenous researchers and community members shaping the research protocol at all stages. Community-based approaches to research are working to address the underrepresentation of Indigenous peoples in all areas of research by reinforcing the importance of building trust and implementing culturally appropriate interventions and methodologies (Jacobs et al., 2010). It remains, however, that Indigenous peoples continue to be underrepresented as participants and, significantly, as researchers and recipients of federal funding in the area of genetics related research. The role of Indigenous researchers is not to ensure the ease with which non-Indigenous researchers work in Indigenous communities; rather, one role of Indigenous researchers is to challenge the paradigm informing health and genetics research that positions Indigenous peoples as perpetual subjects and samples of agendas that do not reflect their experiences and perspectives.

Non-Indigenous researchers must be receptive to the notion that responsible engagement with Indigenous communities must always be committed to the process of engagement, including the interplay of diverse interests that shape that process, ahead of any particular research design. The issue of GAT prompted a variety of concerns and questions among the participants with whom we worked; ensuring that our project responded to these concerns required continual reconfiguration of the project itself, including flexibility with the research design, recruitment strategies and project personnel. Researchers must recognize that it is in protection of sovereignty that tribes negotiate the social and political costs of research vis-à-vis their own interests, and it is deference to sovereign rights that researchers must also rethink the goals of research that effect Indigenous populations.

Best Practices

- Employ prolonged community engagement to identify and appropriately address sources of mistrust and historical trauma associated with generations of exploitative research practices in many underserved and underrepresented communities
- All research involving tribal communities should respect appropriate protocol for research approvals in these communities, and should engage both formal and informal mechanisms of community support

- Abstain from the identification of specific tribal communities and individuals, especially in cases where reporting attitudes and beliefs about sensitive issues has the potential to negatively impact participants
- Participant recruitment strategies should reflect naturally occurring processes of social organization in the communities of interest, so that study protocol does not define or violate existing social networks and local organizing principles
- Research involving Indigenous populations should include Indigenous personnel in all phases of the research process

Educational Implications

All researchers working in Indigenous populations should be properly educated on the history of malpractice and mistrust associated with research in these communities. Further, all researchers should be trained in a variety of methods related to community engagement and data collection, including both disciplinary methods and Indigenous methodologies, in order to make judicious and responsible decisions about the appropriateness and feasibility of any given research objective. Finally, responsible community engagement in Indigenous American and other historically exploited communities requires ongoing consultation with both formal and informal community leaders, clear articulation of project goals and outcomes, and opportunities for community members to review and respond to research findings.

Acknowledgments

Funding for this research comes from the following grant: *Public Perspectives and Experience Regarding Genetic Ancestry Testing*. National Institutes of Health: R01 HG006295-01A1.

References

- The American Society of Human Genetics. Ancestry Testing Statement. 2008 Nov 13. Retrieved from http://www.ashg.org/pdf/ashgancestrytestingstatement_final.pdf
- Bardill J. Native American DNA: Ethical, legal, and social implications of an evolving concept. *Annual Review of Anthropology*. 2014; 43:155–166.
- Bates BR, Harris TM. The Tuskegee Study of Untreated Syphilis and public perceptions of biomedical research: a focus group study. *Journal of the National Medical Association*. 2004; 96(8):1051. [PubMed: 15303410]
- Blanchard J. Inequitable partners in collaborative research: reflections on community-based participatory research. *Applied Anthropologist*. 2011; 2(31):29–36.
- Bolnick DA, Fullwiley D, Duster T, Cooper RS, Fujimura JH, Kahn J, ... TallBear K. The science and business of genetic ancestry testing. *Science*. 2007; 318(5849):399–400. [PubMed: 17947567]
- Bowekaty MB, Davis DS. Cultural issues in genetic research with American Indian and Alaskan Native People. *IRB: Ethics and Human Research*. 2003; 25(4):12–15.
- Burhansstipanov L, Bemis LT, Dignan M. Native American recommendations for genetic research to be culturally respectful. *Jurimetrics*. 2002; 42(2):149–57. [PubMed: 15119329]
- Burhansstipanov L, Krebs LU, Bradley A, Gamito E, Osborn K, Dignan MB, Kaur JS. Lessons learned while developing ‘Clinical Trials Education for Native Americans’ curriculum. *Cancer Control*. 2003; 10(5):29–36. [PubMed: 14581902]

- Burhansstipanov L, Schumacher SCSA. Lessons learned from community-based participatory research in Indian country. *Cancer control: Journal of the Moffitt Cancer Center*. 2005; 12(Suppl 2):70. [PubMed: 16327753]
- Burlew K, Larios S, Suarez-Morales L, Holmes B, Venner K, Chavez R. Increasing ethnic minority participation in substance abuse clinical trials: lessons learned in the National Institute on Drug Abuse's clinical trials network. *Cultural Diversity and Ethnic Minority Psychology*. 2011; 17(4): 345–356. [PubMed: 21988575]
- Buseh AG, Underwood SM, Stevens PE, Townsend L, Kelber ST. Black African immigrant community leaders' views on participation in genomics research and DNA biobanking. *Nursing outlook*. 2013; 61(4):196–204. [PubMed: 23219004]
- Bussey-Jones J, Garrett J, Henderson G, Moloney M, Blumenthal C, Corbie-Smith G. The role of race and trust in tissue/blood donation for genetic research. *Genetics in Medicine*. 2010; 12(2):116–121. [PubMed: 20098329]
- Champagne D, Goldberg C. Changing the Subject: Individual versus collective interests in Indian Country research. *Wicazo Sa Review*. 2005; 20(1):49–69.
- Christopher LGW, Cieslak LTJ, Pavlin JA, Eitzen EM. Biological warfare: a historical perspective. *Journal of the American Medical Association*. 1997; 278(5):412–417. [PubMed: 9244333]
- Christopher S, Saha R, Lachapelle P, Jennings D, Colclough Y, Cooper C, ... Webster L. Applying indigenous community-based participatory research principles to partnership development in health disparities research. *Family and Community Health*. 2011; 34(3):246–255. [PubMed: 21633218]
- Claw, K., Garrison, N. [accessed October, 2016] Bringing Indigenous Researchers to the Forefront of Genomics. n.d. <http://sacnas.org/about/stories/sacnas-news/winter-2015-indigenous-genomics>
- Corbie-Smith G. The continuing legacy of the Tuskegee Syphilis Study: considerations for clinical investigation. *The American journal of the medical sciences*. 1999; 317(1):5–8. [PubMed: 9892266]
- Dalton R. When two tribes go to war. *Nature*. 2004; 430(6999):500–502. [PubMed: 15282577]
- Di Chiro, G. Environmental justice and environmentalism: The social justice challenge to the environmental movement. 2007. *Indigenous Peoples and Biocolonialism: Defining the "Science of Environmental Justice" in the Century of the Gene*; p. 251
- Drabiak-Syed K. Lessons from Havasupai tribe v. Arizona state university board of regents: recognizing group, cultural, and dignity harms as legitimate risks warranting integration into research practice. *Journal of Health & Biomedical Law*. 2010; 6:175–226.
- Foster MW, Sharp RR. Genetic research and culturally specific risks: One size does not fit all. *Trends in Genetics*. 2000; 16(2):93–95. [PubMed: 10652537]
- Francis CD. In Search of Young American Indian/Alaska Native Scientists. *Journal of Health Disparities Research and Practice*. 2016 Summer;9:118–119. Special Edition 1.
- Fullwiley D. The biological construction of race: 'admixture' technology and the new genetic medicine. *Social Studies of Science*. 2008; 38(5):695–735. [PubMed: 19227818]
- Glover M, Kira A, Johnston V, Walker N, Thomas D, Chang AB, ... Brown N. A systematic review of barriers and facilitators to participation in randomized controlled trials by Indigenous people from New Zealand, Australia, Canada and the United States. *Global Health Promotion*. 2015; 22(1):21–31. [PubMed: 24842989]
- Harding A, Harper B, Stone D, O'Neill C, Berger P, Harris S, Donatuto J. Conducting research with tribal communities: Sovereignty, ethics, and data-sharing issues. *Environmental Health Perspectives*. 2012; 120(1):6–10. [PubMed: 21890450]
- Harry, D., Dukepoo, F. Indians, genes, and genetics: what Indians should know about the new biotechnology. *Indigenous Peoples Council on Biocolonialism*; 1998. <http://www.ipcb.org>
- Harry D, Kaneche LAM. Asserting tribal sovereignty over cultural property: Moving towards protection of genetic material and indigenous knowledge. *Seattle J Soc Just*. 2006; 5:27.
- Havasupai Tribe of Havasupai Reservation c. Arizona Board of Regents. (November 28, 2008). Nos. 1 CA-CV 07-0454, 1 CA-CV 07-0801.

- Hoyo C, Reid ML, Godley PA, Parrish T, Smith L, Gammon MD. For the patient. Improving participation of African-American men in research studies. *Ethnicity & disease*. 2003; 13(4):547–548.
- Jacobs B, Roffenbender J, Collmann J, Cherry K, Lee Bitsói L, Bassett K, Evans CH. Bridging the divide between genomic science and indigenous peoples. *The Journal of Law, Medicine & Ethics*. 2010; 38(3):684–696.
- Jobling MA, Rasteiro R, Wetton JH. In the blood: the myth and reality of genetic markers of identity. *Ethnic and Racial Studies*. 2016; 39(2):142–161.
- Kelley A, Belcourt-Dittloff A, Belcourt C, Belcourt G. Research ethics and indigenous communities. *American Journal Of Public Health*. 2013; 103(12):2146–2152. [PubMed: 24134372]
- LaVallie DL, Wolf FM, Jacobsen C, Buchwald D. Barriers to cancer clinical trial participation among Native elders. *Ethnicity and Disease*. 2008; 18(2):210–217. [PubMed: 18507276]
- Lee SSJ. Race, Risk, and Recreation in Personal Genomics: The Limits of Play. *Medical Anthropology Quarterly*. 2013; 4(27):550–569.
- Lee SSJ, Bolnick DA, Duster T, Ossorio P, Tallbear K. The illusive gold standard in genetic ancestry testing. *Science*. 2009; 325(5936):38–39. [PubMed: 19574373]
- McGee R Jr, Saran S, Krulwich TA. Diversity in the biomedical research workforce: Developing talent. *Mount Sinai Journal of Medicine*. 2012; 79(3):397–411. [PubMed: 22678863]
- Morton D, Proudfit J, Calac D, Portillo M, Lofton-Fitzsimmons G, Molina T, ... Majel-McCauley R. Creating research capacity through a tribally based Institutional Review Board. *American Journal Of Public Health*. 2013; 103(12):2160–2164. [PubMed: 24134381]
- Pacheco CM, Daley SM, Brown T, Filippi M, Greiner KA, Daley CM. Moving forward: breaking the cycle of mistrust between American Indians and researchers. *American journal of public health*. 2013; 103(12):2152–2159. [PubMed: 24134368]
- Phillips AM. Only a click away—DTC genetics for ancestry, health, love... and more: A view of the business and regulatory landscape. *Applied & translational genomics*. 2016; 8:16–22. [PubMed: 27047755]
- Phillips RG, Byrd JR, Pim-Pong DS, Starks TD, Taylor AL, Mckinley RE, Li YJ. Recruiting intergenerational African American males for biomedical research studies: a major research challenge. *Journal of the National Medical Association*. 2011; 103(6):480. [PubMed: 21830630]
- Riedel, S. Proceedings. Vol. 17. Baylor University Medical Center; 2004. Biological warfare and bioterrorism: a historical review.
- Royal CD, Novembre J, Fullerton SM, Goldstein DB, Long JC, Bamshad MJ, Clark AG. Inferring genetic ancestry: Opportunities, challenges, and implications. *The American Journal of Human Genetics*. 2010; 86(5):661–673. [PubMed: 20466090]
- Sankar P, Cho MK, Condit CM, Hunt LM, Koenig B, Marshall P, Lee SSJ, Spicer P. Genetic research and health disparities. *Jama*. 2004; 291(24):2985–2989. [PubMed: 15213210]
- Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. *Journal of Health Care for the Poor and Underserved*. 2010; 21(3):879. [PubMed: 20693733]
- Strickland CJ. Challenges in community-based participatory research implementation: Experiences in cancer prevention with Pacific Northwest American Indian tribes. *Cancer Control*. 2006; 13(3):230. [PubMed: 16885920]
- TallBear, K. Racialising tribal identity and the implications for political and cultural development. Indigenous Peoples and Racism Conference; Sydney, Australia. 2001 Feb.
- TallBear, K. Genetics, culture and identity in Indian country. Seventh International Congress of Ethnobiology; 2000 Oct.
- TallBear K. DNA, blood, and racializing the tribe. *Wicazo Sa Review*. 2003; 18:81–107.
- TallBear K. “Native American DNA” tests: What are the risks to tribes? *The Native Voice*. 2004; 3(24):D2.
- TallBear K. Narratives of race and indigeneity in the genographic project. *The Journal of Law, Medicine and Ethics*. 2007; 35:412–24.
- TallBear K. Genomic articulations of indigeneity. *Social Studies of Science*. 2013; 43(4):509–533.

- TallBear K, Bolnick D. Native American DNA tests: What are the risks to tribes? *The Native Voice*. 2004 Dec.:3–17.
- Tsosie R. Cultural challenges to biotechnology: Native American genetic resources and the concept of cultural harm. *The Journal of Law, Medicine, & Ethics*. 2007; 35(5):396–411.
- Via M, Ziv E, Burchard EG. Recent advances of genetic ancestry testing in biomedical research and direct to consumer testing. *Clinical genetics*. 2009; 76(3):225–235. [PubMed: 19793051]
- Wagner JK, Cooper JD, Sterling R, Royal CD. Tilting at windmills no longer: A data-driven discussion of DTC DNA ancestry tests. *Genetics in Medicine: Official Journal of the American College of Medical Genetics*. 2012; 14(6):586–593. [PubMed: 22382803]
- Wagner JK, Weiss KM. Attitudes on DNA ancestry tests. *Human genetics*. 2012; 131(1):41–56. [PubMed: 21698460]
- Wiedman D. Native American embodiment of the chronicities of modernity: reservation food, diabetes, and the metabolic syndrome among the Kiowa, Comanche, and Apache. *Medical anthropology quarterly*. 2012; 26(4):595–612. [PubMed: 23361887]