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Roberto Abadie

University of Nebraska-Lincoln, rabadie2@unl.edu

Kathleen Heaney

Hennepin County Medical Center, Minneapolis, MN

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“We can wipe an entire culture”: Fears and promises of DNA biobanking among Native Americans

Roberto Abadie¹ and Kathleen Heaney²

¹ Department of Sociology, University of Nebraska–Lincoln,
1223 Oldfather Hall, Lincoln, NE 68588, USA

² Hennepin County Medical Center, Minneapolis, MN, USA

Corresponding author — Roberto Abadie, rabadie2@unl.edu

Abstract

This paper explores Native American perceptions on DNA biobanking. A qualitative study was conducted among self-declared Native Americans living off reservation in two Midwest cities. Findings demonstrate a paradox: Informants maintain strong hopes for the transformative power of gene-based research while voicing very particular social anxieties. Emerging genomic technologies elicit concerns over the potential for genetic stigmatization or discrimination based on race, preventing access to health insurance or employment. Frequently, social anxieties adopt the narrative form of conspiracy theories which portray powerful agents exploiting or abusing a disenfranchised population. We argue that while Native Americans do not have a monopoly on the production of conspiracy narratives, their anxieties originate in a unique set of historical and social circumstances that position genetics research as part of a much larger political narrative. We conclude by suggesting that tribal approaches to biomedical research and in particular the use of biobanks that use concepts such as “DNA on loan” and emphasize trust building, collaboration and benefit sharing present a good model to deal with some of the anxieties elicited in this research but could also be taken as a model for biobank governance in general.

Keywords: Biobanking, Native Americans, Genomics research, Ethics, Tribal governance

... someone might discover that, 'Hey, with this certain combination, or this certain gene, we can wipe out an entire culture, or an entire people with this type of mapping.' You know? 'Oops.' That wasn't the intention, but that's what they discovered. In the wrong hands someone can actually do a lot of damage with that. Now, that's a negative aspect, but that's more paranoia theories than anything (NA2).

Introduction

Genomics has been heralded as a breakthrough in biological science, promising to revolutionize both research and medical practice. Biobanking—the creation of collections of biological samples linked to health information—plays a key role in the genomics enterprise. Biobank infrastructures are used extensively in research, including personalized medicine, pharmacogenomics, a range of clinical trials, public health, the army and the judicial system (Kaiser 2002; Hagan et al. 2004; Smith et al. 2005; Levitt 2007; Chalmers 2011; Hamburg and Francis 2010).

A biobank is a collection of human biological specimens such as tissue or blood. It may correlate genotype data prospectively with phenotype information. In addition to allowing the study of gene–gene interactions, data in biobanks can be used to correlate genes with environmental and lifestyle information to help explore gene–environment interactions. Biobanks can be used in biomedical research, epidemiology, forensics, criminal investigation and personal identification. The diversity of biobank uses seems to correspond with an increasing trend toward larger and more inclusive databases (Ploeg 2007). One area in which this trend is particularly visible is in the existence of large sample banks in the medical sector.

Some biobanks are disease based; others are population based. Scientific developments, capital investment, legal and institutional frameworks have contributed to transform a DNA molecule into a commodity. In this context, biobanks are perceived to be instrumental in the creation of biovalue (Novas and Rose 2000; Rose 2001; Saunder 2006). As such, biobanks are being developed by both public and private actors. For example, deCode is a privately funded population-based biobank located in Iceland. The UK Biobank is funded by a public–private enterprise, while public funds support biobanks in Japan, Latvia, Canada, Norway and Sweden, among others. While some privately funded biobanks—and deCode in particular—have elicited concerns over issues of privacy, consent, profits and benefit sharing (Pálsson

and Rabinow 1999), the pharmaceutical industry has extensive biobanks (to further drug development research), which have received little or no attention (Lewis 2004). The National Institutes of Health has also supported the development of biobanks linked to medical records research—(McCarty et al. 2011).

Advances in genomics science like the completion of the mapping of the human genome project in 2000 have fueled the emerging prominence of techno-scientific desires in media, government, capital investors and the scientific community. In some scientific accounts, but mainly in the media coverage, a direct link between genotype and phenotype is introduced. As with other media coverage of scientific news this deterministic approach offers a story that lacks the complexity and nuance in benefit of effect and readership (Nelkin 1987). In turn, other voices have cautioned against genetic determinism and spoken to the complexities of gene–gene interaction and gene–environment interaction, including epigenetics, the roles of proteins and cell functions (Lock et al. 2006).

The promise of improved treatments, potential cures and personalized medicine—fueled not only by developments in genomic sequencing but also by capital investment and media coverage—has been contested by Native American groups. The Human Genome Diversity Project (HGDP) promised great benefits from preserving genetic samples from diverse population groups (Cavalli-Sforza 2005). Yet, indigenous peoples, including Native Americans, were among the most vocal critics of the HGDP and continue to offer notable resistance to participation in genetics research—as evidenced by tribal government bans (Indigenous People Council on Biocolonialism 2000; TallBear 2007; Caulfield et al. 2009). The production of genomics knowledge, far from being neutral, raises questions such as who has the right to define or study a population and who should benefit from research? While biobanks linking DNA data and personal health information are essential resources of genomic science, their implementation raises a policy debate around control, access and data sharing requirements.

These issues have been heightened by the recent out-of-court settlement of the Havasupai trial which, after years of litigation, confirmed that researchers had improperly obtained and used members' DNA samples (Mello and Wolf 2010; Drabiak 2010). Initially interested in the high prevalence of diabetes among members of the tribe, researchers from Arizona State University obtained consent to use DNA samples to study this disease. But without securing the tribal consent, the samples were subsequently used to explore a possible genetic basis of schizophrenia, as well to confirm a theory about migration patterns, attempting to confirm a theory that contradicted tribal narratives about their origin.

While the institutional views of Native American tribes are well established, less is known about how individual tribal members might respond to

biobanking research. As biobanking becomes integrated with routine medical care, those members living off reservation might be asked to participate in this type of research on a regular basis. Would they be aware of their tribe position regarding genomic research and, if so, would they chose to follow it or would they instead trust their medical providers and participate in the collection of genetic material? In order to respond to this question, we conducted an empirical study of two Native American groups living off reservation in Minnesota. To our knowledge, this is the first empirical study to explore this topic. Findings from interviews with American Indians in two Minnesota cities demonstrate a paradox: Informants maintain strong hopes for the transformative power of gene-based research while voicing very particular social anxieties. Emerging genomic technologies elicit concerns over the potential for genetic stigmatization or discrimination based on race, preventing access to health insurance or employment. Frequently, social anxieties adopt the narrative form of conspiracy theories which portray powerful agents exploiting or abusing a disenfranchised population. The conspiracy themes portray governmental use of genetic information to “wipe out” a particular culture or ethnic group, or the production of bioweapons for the same purpose. Although Native Americans do not have a monopoly on the production of conspiracy narratives, their anxieties originate in a unique set of historical and social circumstances that position genetics research as part of a much larger political narrative. This paper suggests that Native American concerns about genetic science can only be understood against the backdrop of historical and present grievances and aspirations. The current concerns brought out by this emerging technology index Native Americans’ anxieties over their status in American society. Further, we suggest that the politics of genomics research should be considered in the implementation of any policies regarding DNA collection among Native Americans. Furthermore, some ideas such as community oversight, participatory research, benefit sharing or DNA on loan that are currently in practice in Native American communities provide insight into best practices around DNA biobanking that can be extended to other groups.

Background: the politics of genomics research involving Native American populations

Native American tribes so far have been very critical of genomics research. The Indigenous People’s Council on Biocolonialism, an international umbrella organization, vehemently opposed the HGDP in the 1990s and continues to oppose contemporary attempts to do similar genetic mapping. Currently, efforts to involve Native Americans in The Human Genographic Project, a new version of the HGDP (although with different sources of funding and

principal investigators) supported by the National Geographic Society and IBM, have failed. Tribes declared opposition to this new attempt to enroll them in genetic biobanking, bringing the project to a virtual standstill in North America (Declaration of Indigenous Peoples 2006). Native American DNA was also not included in recent “big science” cases like the Hap Ma or the 1000 genomes project that attempt to map human diversity due to tribal refusal. In these cases, behind ethical disagreements over informed consent issues, the fundamental challenge to the HGDP and its sequel concerned the politics of genomics research: Who should conduct it and for what purposes? Critics pointed to the racial politics behind the HGDP (Marks 2005; Reardon 2005; Reardon and TallBear 2012; TallBear 2013). Jenny Reardon and Kim TallBear have argued that these scientific projects based on DNA extraction utilize a universalistic narrative about the right of the Western world to find out about their ancestry and origins making a moral claim to the samples that obscures another form of colonialism. This scientific discourse unlike the evolutionist approaches in the XIX century employs a post-racial, or color blind narrative, but according to these authors this rhetoric might lead to another form of reasserting dominant property rights and to new forms of dispossession.

Genomics research has been perceived by Native Americans as challenging their identity and cultural narratives about origin. And more importantly, this research is viewed as a threat to sovereignty and political power (Brodwin 2005). In addition, genomics research has been perceived as a fertile ground for commercialization and the HGDP was not immune to these critiques either. Tribes targeted the project as another example of biocolonialism, or what David Harvey terms “accumulation through dispossession” (Harvey 2003), accusing scientists of behaving like “vampires,” taking Indigenous blood to further academic or commercial gain but leaving no benefits to the tribes. Other academic research has been implicated in these conflicts, the Havasupai case being the most recent.

Another Southwest tribe, the Navajo, has banned all research without approval of their local IRB, which demands that the researchers respect traditional beliefs and research issues of interest to the community. Additionally, the tribe requests that researchers share in the possible benefits and donate infrastructure used during research to the community. Reflecting this complex political landscape involving genomic research, the Navajo Nation also issued a moratorium on all types of *genetic* research until the community started a process of consultation including political, spiritual, traditional and scientific leaders as well as community members to determine under which conditions such research should be conducted (Garrison 2010).

There have also been cases of tribal cooperation with academic research who are willing to engage in Community-Based Participation Research respecting the tribal research principles. Under this model, researchers have

done work in South Dakota on the genomic basis of cancer and in Alaska on pharmacogenomics. Tribal groups in Mexico have also agreed to participate in genomics research conducted to improve their health (National Congress of American Indians 2012).

The politics of genomics science has become a matter of anthropological dispute as well. Schroeder et al. claim, based on the findings of a survey, that Native American opposition to genomics research is far from monolithic. They argue that while there is opposition at the tribal level—based, they specify, on claims to land and revenue rather than on spiritual or identity considerations—individual members do desire the benefits of genetic research (Schroeder et al. 2006). However, the authors recognize that trust issues prevent individuals from engaging in research. Critics reply by criticizing the inherent bias in the survey's self-selected sample, while decrying the use of scientific authority and objectivity through the production of survey data to further the researchers' own agenda (Marks 2006).

The politics of genetic research extended to our own research project. Our research team conducted a community engagement with a broad sample of participants from Olmsted County, Minnesota, where the Mayo Clinic is located. Community members recommended that we interact proactively with local tribal government, in order to plan carefully for situations in which Native Americans might be invited to participate in Mayo Clinic's biobank as part of their routine medical care. Although great effort was made to work directly with Native Americans living on reservations also, this proved impossible. Reservation authorities suggested we speak to elders and write down their stories. However, we were turned down by the tribal administration after they learned that the research concerned "genetics," and we were never invited by the tribal council or government to present our project. We therefore chose to focus our attention on Native Americans living off reservation; in the USA, approximately 60 % of those self-identifying as Native American do not live on reservation, or they maintain multiple residences. By working with two Native American advocacy groups (the Division of Indian Works in Minneapolis MN and the Native American Center of Southeastern Minnesota in Rochester), we were able to identify Native American participants to be interviewed.

The refusal by the tribal governments illustrates the difficulties in conducting research on genomics with this population. In addition to the basic stance on "genetics," broader misgivings in relation to research operated as a barrier for participation. For example, when initially contacted, a particular Native American health care worker agreed to participate. The very day she was to be interviewed, she received an envelope in the mail from a different study containing someone else's name and personal health information. She was so disturbed by this mistake that she called saying she could not trust the research and canceled the interview.

Methods

The interviews reported here are part of a larger study on potential donors' views on DNA biobanking at the Mayo Clinic, in Rochester, Minn., that also includes participants in a community biobank, and groups of patients with particular conditions (cancer, addiction, and heart disease). It is critical to understand the perspectives of Native Americans who might be approached as possible biobank donors as they seek regular medical care.

Sixteen in-depth interviews with self-defined Native American residents in Minneapolis and Rochester were conducted by two trained qualitative interviewers. An interview guide was piloted with the first few participants and revised to explore additional emerging themes with subsequent participants.

Although interviewees did not reside on reservations at the time of the interviews, most had kin ties to reservations and were enrolled in tribes. Some had lived in reservations in the past but had moved by the time the interviews were conducted. We are aware that the composition of our sample might diverge from other groups of Native American living off reservation elsewhere, particularly those living in urban areas who might only recently self-identified as belonging to this group. This population is almost equally divided by sex, with a slight prevalence of males. Ages ranged from 22 to 54 years old. Half of the subjects self-reported to have between 50 and 100 % Indian blood quantum. Several different tribes were represented, including Navajo Nation, Leech Lake Ojibwa and Turtle Mountain Chippewa.

Research was conducted with IRB approval from Mayo Clinic (interview sites did not require local IRB approval). A \$25 gift card was provided as compensation for their participation. With their consent, interviews lasting approximately 1 h were audio recorded. Employing a semi-structured questionnaire we explored participants' knowledge of genomics science and biobanking, as well as, their perceptions around the perils and promises of this emerging technology. The research design employed a semi-structured questionnaire to explore the attitudes, beliefs and knowledge about this emerging biotechnology. While biobanking and genomics are closely related, emphasis was placed on perception of the risks and benefits of participating in a biobank, issues such as privacy, sample security, trust and financial compensation. The interview transcripts were coded by two independent coders to identify key themes. NVivo7 was used to conduct the analysis of the data.

One limitation of our design is due to the fact that since those we were successful in recruiting were people who wanted to talk to us about genetics, it is likely they were more favorably disposed toward this kind of research, and this may have introduced a bias in our sample. However, we believe that their positions illustrate the ambiguities, hopes and anxieties concerning genomics research in the larger Native American population.

Findings

Techno-scientific desires

Among Native Americans interviewed, DNA biobanking is perceived as an important source to address diseases that affect their community, such as diabetes, alcoholism and arthritis. Some even believed this kind of research to be a potential answer to most, if not all, human ailments.

One participant said:

For research, for disease, for health and nutrition, for anti-aging because we all want to look young, feel young, act younger. If it can deal with any type of mental illnesses or anything like that, with any type of disease, I think that's basically it. Then also, if anything can be utilized based on my DNA that they can learn anything that may help kids, or my kids or their kids or your kids (NA13).

One woman, a self-declared member of the Navajo Nation, wondered whether DNA would reveal an existential secret: "How long will I live? Will that determine it?" (NA14). Though genetic science is actually far from being able to determine the duration of a life span or abolish all disease, it is significant that genomic research is thought to produce such outcomes. These comments also illustrate the hopes and expectations elicited by this new technology. This is a testament to the symbolic power of genomics science and in particular of the image of DNA, which in American culture has come to represent the "ultimate fingerprint" that indexes the self (Nelkin and Lindee 1995).

One of the perceived benefits of emerging technology is the implicit promise that we can change ourselves by "fixing" our DNA. This hope has been reinforced by the neoliberal emphasis on individual entrepreneurship in relation to one's own health; it is a hope elicited by an ideology that gives individuals responsibility for their own wellbeing (Rose 2006). Current policy debates center around the question of whether incidental findings and individual research results ought to be returned to biobank participants (Wolf et al. 2012). Within this context, we found many Native Americans interviewed expressed their desire to be apprised of negative health information revealed in the course of research, in an attempt to "manage" and be "pro-active." In this respect, these views are not different from those expressed by other racial and ethnic groups in the USA. Even in the event that nothing could be done to ameliorate a disease prediction, volunteers expressed their desire to know whatever genetic testing could tell. "Even if you can't control it, I still would want to know so that I could figure out a way to work

with it, live with it, or change it” (NA13). Only a few echoed ethicists’ concerns over the dilemma presented by knowing about future negative health outcomes but being unable to treat or prevent them. Increased self-knowledge was perceived by most of the group as a benefit of this kind of technology. It should be noted, however, that this response is rooted solely in ideological predispositions, not based on actual experience, since no one in this group was a biobank donor. Their answers reflect a hypothetical decision-making process that might or might not reflect their likely responses to a real situation.

Genetic discrimination based on race

The Native Americans interviewed express concerns over the invasion of privacy and the possible use of their personal or medical information to discriminate against them. These concerns are shared by other groups. Nonetheless, fears of discrimination based on racial classifications, or of race-based genetic profiling, are distinctly pertinent characteristics of this group, one that has been exploited and oppressed in the past. Interviewees are wary of the potential for genetic discrimination tied to race that might compromise their access to insurance or health care, particularly for those diseases prevalent in their community. One middle-aged male, self-identified as a White Earth Tribe member said: “The HMOs could abuse the power, and just say: Well, all Natives are susceptible to diabetes, so based on genetics they can nitpick even more” (NA 13). A Chippewa woman displayed similar concerns:

Insurance companies ...always look for a reason to disqualify you. So, what if you have a genetic code that says you’re predisposed to be alcoholic? (NA 12)

Fears of genetic discrimination based on race also fuel concerns over genetic stigmatization. While other groups share these same concerns, Native Americans perceive the risk of a double stigmatization, fearing being discriminated on the basis of the “the alcoholic or diabetic gene” in addition to the negative stereotypes about their race. Such fears might shape their concerns over biobanking research.

Stereotypes of how people have looked at Native Americans in the past made me scared that, you know, all of a sudden there might be a gene that says: ‘Oh, yeah, you can tell that this person drinks.’ The Native Americans might feel hesitant to show their DNA. ‘Oh, that’s the alcoholic gene, right there.’ (NA 3)

Cloning fears

Not all Native American concerns can be explained in reference to the politics of genetics research and racial politics. For example, fears of reproductive cloning reflect another form of social anxiety, one shared by lay publics in relation to this emergent technology, which is perceived as challenging nature, identity and the very notion of self.

As far as cloning human beings, or something like that, no. Why would you do that? I guess I'm kind of a futuristic type of a deals, like, if there's a way to use my DNA to actually regenerate a heart, to keep me alive longer, to keep me healthier, then I don't have a whole lot of problems with that. But there again, that's where I would draw the line (NA1).

As this quotation indicates, reproductive cloning was perceived as taboo, but it did not proscribe the possibility of therapeutic cloning. Anxieties about reproductive cloning are widespread among the lay public, but unfounded. Since the creation of Dolly in the 1997, no human beings have been cloned, and in response to social and professional concerns, many governments explicitly prohibit reproductive cloning. Despite these efforts, the idea of reproductive cloning seems to be vividly present to the lay public through its presence in popular culture and media (e.g., movies like *Jurassic Park*). Cloning anxieties in the lay public persist despite scientists' claims to have no interest in this area. In some countries, however, science is moving closer to therapeutic cloning, principally through stem cell research. Clearly, discourse of genetic research has spawned imagined techno-scientific scenarios that are deeply embedded in the popular consciousness.

DNA sample: "it's me," "it's mine"

The Native Americans in this study seem to integrate scientific and media discourses that present DNA as a source of uniqueness, self and personhood into their own discourses on the subject. Employing narratives such as the "blueprint for life," this group assumes an essentialist view in which DNA becomes conflated with personal identity. In addition, DNA is interpreted through the lens of possessive individualism, in a language of proprietary rights (Macpherson 1962). Thus, the genetic sample becomes not only "me" but it is also perceived to be "mine." These two dimensions come together to construct a personal and proprietary relationship with the sample. This personal and proprietary relationship with the DNA sample creates another set of expectations and concerns about sample storage, uses, security, privacy and confidentiality.

I guess I get leery of the fact that your DNA is stored somewhere. And when it's taken [the sample] that's you, it identifies you. Can it be abused in any way? You could run across situations where people have access to the DNA. Is it staying on site? The DNA is yours. It's self-identifying, it belongs to you and nobody else. Are the people who are using it, taking good care of it? I mean, that's a part of you (NA15).

Many participants expected a continuing connection with donated bio-samples. They see samples as having "social lives" (Kopytoff 1986) which they expect to be informed of: Where their sample is stored, what has been done to it and what discoveries have been made from it.

I think it would be informative, to know what are they doing with the sample, what they think they could do, what are they trying to do, and are they anywhere near, their goals?

Some even formalize this sense of connection even more strongly: they expect to have the sample destroyed or returned to their families after they die. "It's mine. And I'm just loaning it out." (NA1)

Their attachment to the sample does not derive solely from a "possessive individualism" but also from the belief in the integrity of the body. Many Native Americans interviewed expressed a holistic notion of the body that entails that they should not be separated from any body parts (e.g., hair and nails). However, we do not want to essentialize Native American beliefs regarding their expectations in relation to the sample use. Although many expressed hesitation, the main oppositions expressed to giving away a DNA sample did not derive from challenges to their body integrity. Instead, the primary barriers are the lack of trust in governmental or private institutions and the possibility that their sample might be commodified, leaving them once again, dispossessed.

Gift or commodity?

Many participants in this sample resisted the language of "gift" to describe a donation of biological material. Most felt they should be compensated, particularly in the context in which private corporations and governments intend to benefit financially from it. Perceiving biospecimens as a source of biovalue, they prefer to treat them as economic commodities. When asked how much he should be paid for his sample, one participant said:

As much as I can get. I'm human! I admit it. Billions! I have a wife to take care of. I'd say, 'Show me the money!' (Laughs) I think if

there's people makin' money on it, if your DNA's helping' make that money, I think the person would be entitled. You have a producer, you have a manager, they get a cut; and you'd look at the drug that's made, you've got the people that made it, and you've got probably other people, administration, whatever and they gotta get theirs. I think they're doing all the footwork, you know, so that they should get the most, but the people with the DNA involved, also should get some... maybe 10 %. I mean, you're probably talkin' big money for a new medicine like that (NA1).

The perception of the sample as a commodity instead of a gift is related to poverty, but it is also related to social exclusion and their memories of past abuses and exploitation by governments and corporations. On the other hand, most individuals who assert their right to be compensated *if* there is a financial outcome from the research still believe that would give a sample as a "gift" for scientific research or research that does *not* produce immediate financial gains.

Suggesting altruistic motivations, some participants said they should not get any financial compensation. For some, donating DNA is equivalent to the act of donating blood. A frequent blood donor explained his position:

I think it'd be on a volunteer basis. If I felt comfortable with the research that was taking place and the experiments that would take place with that DNA, I wouldn't mind. I think it's almost like donating blood. I wouldn't expect to get paid for doin' somethin' like that (NA 2).

These altruistic donors rationalize their position noticing that if they expected to receive payment for their sample, then, in the event that any if a commercial product would be developed, its market value would have to be increased to accommodate the costs of acquiring the DNA sample from volunteers.

If they do develop something commercial that would, you know, say like cure eczema or something like tat, then that would make that become more expensive (NA 7).

Being a donor: Individual or tribal decision?

Genomics research involves not only individuals but also their families and ultimately their communities. Should consent be individual or collective? What is the role of the community (i.e., tribal government) in individual

decision making? In the politicized context of genomics research among Native Americans, these questions acquire especially fraught overtones.

Collective consent was originally devised to enhance the legitimacy of the HGDP and to overcome the critiques from organized tribes. But there are some problems with this form of consent. Collective consent cannot overcome individual consent. Also, how do we define a group without reifying it? But as we will argue in this paper, perhaps the most serious critique of collective consent is that it does not equal tribal consent where the tribe could dispose of mechanisms to discuss with the researchers the goals, risks and benefit of the scientific enterprise taking into consideration not only the researchers' goals but also the tribe's needs and aspirations.

While these questions remain the subject of an open-ended debate among the group we interviewed, genetic essentialism and proprietary beliefs about the nature of the DNA sample converge to shape Native Americans' approach on this issue. For these individuals, participation in research is not a tribal decision but an individual one:

From a DNA perspective I am Alaska Native, but I'm also a person independent of my culture. Even though I take pride in my culture, I know that I'm more than just that. And so if an elder came up to me and said, "As Tlingit people, we are not gonna participate in this," I guess I would question that. And if I knew that by participating or doing this I was being disrespectful and they pointed that out in detail, how it was disrespectful to the tribe, or my people, then I'll take it into consideration. But, for the most part I strongly believe in it being individual basis (NA2).

Recall that the subjects interviewed were not living on reservations, although many maintain close ties with extended family who reside there. Those living on reservations may harbor a different perception about this issue. But in our sample, the belief that tribes do not have "any jurisdiction" on those living beyond the reservation: "That's my personal choice. ... They're a sovereign nation but that's only the reservation, and I don't live on the reservation... so, you know, they have no jurisdiction" (NA7). Another participant said, "I don't think I should ask permission to [give a genetic sample]. That's my choice" (NA8). Thus, though for this group the decision to participate or not is clearly perceived as an individual choice. This is an extremely contentious issue, linked to other issues of politics and identity, and other studies involving NA living on reservations might lead to very different results.

The politics of trust

Caught between deep anxieties and enticing promises, Native Americans remain ambivalent about biobanking. Their lack of trust is embedded in historical and current social grievances with the government and other actors.

I think that Native Americans and a lot of people of color can be very skeptical. I think there's plenty of reasons to be skeptical when you look at our history. Being lied about things, you know? Given things, or supposedly given something, and then taking them back. Or, when we were told we were given something, it was not what it was supposed to be. The boarding school era. I mean, there's just so much, so many incidences, to be very cautious (NA15).

In contrast to government agencies, Mayo Clinic and some other research institutions were trusted and seen as "respectable" even if they received federal funds for genomics research.

Even though Mayo's probably funded by the federal government, I would rather give my DNA sample to Mayo Clinic for their research purposes than do it for just any governmentally-funded program, agency. Just for the fact [that] I just don't trust government (NA13).

Of course, a certain bias could have been introduced to this sample since they were interviewed by Mayo researchers.

Reading 'Mayo Clinic' [on the participant information sheet] tells me that's a well-known clinic, it's got an impeccable reputation, you know? So a clinic like that I would trust (NA10).

Discussion: The politics and ethics of DNA biobanks involving Native Americans

This research shows that the Native Americans interviewed are ambivalent about genomics research. While they desire the benefits, real or imagined, they also have concerns about the potential for abuse or misuse of their genetic information.

In denying the characterization of their samples as a "gifts," this group shows an awareness of the body commoditization involved in genomics research. This attitude stands in clear contrast those of biobank donors in

Iceland, Sweden and the UK, where the idea of the “gift” seems to dominate (Hoeyer 2004; Tutton 2005). This difference might be explained in part by the prevalence of possessive individualism in America, which contrasts deeply with Nordic attitudes. Leslie Sharp has indicated that body tissue in Sweden and other European States is not represented as individual property but as a social, communal good (Sharp 2007). There is a different relationship between the European citizens with the state. European citizens from countries which have implemented biobanks—at least those from welfare states—depend on the state for their health care and other services. They trust their government, perceiving it as providing a decent standard of living for the citizens. This creates a framework that facilitates views of the sample as a gift as opposed to a commodity. In America, Native Americans have a different relationship with government, corporations, big business and research, a framework colored by their particular history. This helps explain their views of the sample as a commodity, specially in contexts in which they perceive research as going to produce financial benefits for corporations, governments or other institutions without benefiting them or their communities directly.

Although Native Americans interviewed for this study are distrustful, they also hope that this emerging new technology can help them cope with diseases that affect their communities. I would suggest that while this apparent contradiction is also present in other sectors of lay public, it has particular overtones among this population which has been essentialized in numerous analysis of Native American culture. Far from being irrational, research participants might be hopeful about some aspects of biobanking like the promise to advance diabetes treatments or other conditions that affect them disproportionately, while harboring misgivings about the ways governments or corporations might use the same resource.

Biobanking—if implemented properly—might contribute to a better understanding of the environmental and genetic interactions that contribute to disease. A central question then is: Is it possible to conduct genomics research in a way that serves both scientific advancement and Native American rights and interests?

This question introduces a relevant public policy issue which is in turn shaped by the politics of genetics research involving Native Americans. While we do not have a definitive answer, we suggest that the inclusion of Native Americans in biobanking should not be thought of as only a scientific or technical decision. Bruno Latour has noted that science has the pretension to be the measure of all things (Latour 2004). As we have seen, this claim has been challenged by Native Americans and Indigenous groups in relation to genomics research. Tribal governments in North America have already established some guidelines for genetic research defining the priorities, goals, and establish acceptable risks and desirable benefits (Sahota

2009). One central departure from existing standards is the notion of DNA “on loan.” Researchers can only use samples for those activities authorized by the tribal authorities, and although it might be requested by the community to return the sample after the research is completed which would be honored, the concept also allows for long-term storage of samples and the possibility of secondary research but only with continued involvement of participants and/or their governing bodies (Arbour and Cook 2006). By supporting the notion of DNA on loan, Native American tribes reassert tribal ownership and political control over the uses of their biological samples. In so doing, this group might provide policy makers and communities alike with a useful model for thinking about issues of community consent, privacy, ownership and benefit sharing.

In conclusion, Native Americans desire the benefits of genomics research and biobanking but fear the risks. This emerging technology seems to elicit profound hopes and anxieties. Some hopes of miraculous cures and fears of reproductive cloning are based on media hype more akin to science fiction than scientific development. These concerns are also voiced by other members of the lay public and reflect the treatment of genomic science in popular culture and media. Worries about privacy, insurance, employment discrimination and genetic stigmatization are shared by other groups, but for Native Americans, these issues are deeply embedded in racial politics. Some of their concerns adopt a conspiracy theory narrative, reflecting a distrust of the government and corporate agents that exploited and abused them in the past, and as the Havasupai case illustrates, continues to suffer numerous forms of dispossession in the present. Their social, cultural and historical context explains their lack of trust in governmental research and informs views about the commercialization of the body involved in genetic research.

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