Article

Indigenous Data Sovereignty: University Institutional Review Board Policies and Guidelines and Research with American Indian and Alaska Native Communities

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Abstract

American Indians, Alaska Native, and other Indigenous people throughout the world have undergone and continue to experience research abuses. Qualitative data such as intellectual property, Indigenous knowledge, interviews, cultural expressions including songs, oral histories/stories, ceremonies, dances, and other texts, images, and recordings are at risk of exploitation, appropriation, theft, and misrepresentation and threaten the cultural sovereignty of American Indians, Alaska Native, and other Indigenous people. These issues are potentially magnified with the increasing use of big data. Partly as a result of past and current research abuse, the Indigenous data sovereignty, the control, ownership, and governance of research and data, is growing. In this article, I discuss American Indian political sovereignty, cultural sovereignty, and Indigenous data sovereignty, with an emphasis on qualitative data sovereignty. In addition, I explore whether Arizona's public universities—Northern Arizona University, Arizona State University, and University of Arizona—policies and guidelines support Indigenous data sovereignty and the extent to which they align with the Arizona Board of Regent's tribal consultation policy that governs relations between the three Arizona universities and Arizona American Indian nations. Overall expectations, requirements, and processes do not go far enough in supporting Indigenous data sovereignty. Although each university has specific research policies that follow the Arizona Board of Regent's tribal consultation policy, the university guidelines differ in scope in term of supporting Indigenous data sovereignty. In addition, none of the policies address qualitative data sharing, including those in big

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data sets. Based on the findings I make several recommendations for researchers, including supporting the Indigenous sovereignty movement and to reconsider big data use and past positions about qualitative data ownership and sharing with regard to American Indians, Alaska Native, and other Indigenous people.

Keywords
Indigenous data sovereignty, American Indian and Alaska Native, Indigenous people, qualitative data

American Indians (AI)[1] and Alaska Natives (AN),[2,3] and other Indigenous people (IP) have experienced a long history of and continue experiencing unethical practices and abuse as research subjects. Research abuse of AIANs extends back to the mid-1800s up to today. Among the many instances of abuse include the studies of Indian body parts. In the 1840s, Dr. Samuel Morton, considered the father of physical anthropology, collected Indian skulls to establish inferiority of the "savage" via empirical support. The United States embraced Morton's findings to justify ongoing genocide (Thornton, 1987). By 1868, the U.S. Surgeon General ordered soldiers and army personnel to collect Indian skulls and other body parts from battlefields, hospitals, and burial grounds for the Army Medical Museum. Not until 1990, with passage of the Native American Graves Protection and Repatriation Act (NAGPRA), was a formal process created for AI nations to reestablish ownership and repatriate items, including human remains, burial items, and sacred objects, held by universities, museums, and federal agencies (Trope & Echo-Hawk, 1992). Thus far, over 5,000 sacred objects, 57,000 human remains, and over 1 million funerary objects have been repatriated (National Park Service, n.d.). This article discusses research related concerns and their potential to be magnified with the growing use of big data.

Unlike human remains or sacred objects that can be returned to tribes under NAGPRA; other cultural property such as stories, songs, and prayers recorded and held in government archives and often used in research, cannot be returned to AIAN communities. For instance, in 1928, Edward Proctor Hunt, from the Acoma Pueblo, recounted creation and migration songs and stories to scholars at the Smithsonian Institution Bureau of American Ethnology. Published in 1842 by the U.S. Government Printing as Bulletin 135, *Origin Myth of Acoma and Other Records*, it told the creation and migration story of the Acoma Pueblo in New Mexico. Peter Nabokov re-edited the original book and it was republished in 2015 as *Origin Myth of the Acoma Pueblo* (Hunt, 2015). The Acoma Pueblo claim the stories as cultural and intellectual property, not the property of the government, Hunt, or Nabokov. However, since the original publication was a government document held over 75 years, it is part of the public domain, and pursuing a lawsuit based on intellectual property is futile (Hurley, Kostelecky, & Aguilar, 2017; Vallo, 2015).

Another recent research abuse is wih the Arizona State University (ASU)-Havasupai Blood Case. In 1990, as part of a larger study with the Havasupai, the

"Diabetes Project," blood samples from over 200 tribal members were taken by ASU researchers to examine potential links between genetics and diabetes risk. Whereas the Havasupai believed that the blood samples were only used for diabetes research, unknown to the Havasupai, the blood samples were shared with other researchers and additional studies were performed with the blood, including studies of schizophrenia, inbreeding, evolution, and migration. Several dissertations and numerous research articles were published using the Havasupai blood samples. By 2003, the Havasupai learned of the studies not related to diabetes and demanded the return of their blood samples. In 2010, after 6 years of litigation, the Arizona Board of Regents and Arizona State University reached a settlement with the Havasupai Indian Tribe for improper use of blood samples taken from tribal members. Arizona State University agreed to return remaining samples to the tribe. The "Havasupai Blood Case" illustrates several important issues, including risks of harm, cultural harm, informed consent, stigmatization, identification, and control and ownership of data (Harmon, 2010).

Largely in response to the Havasupai case, the Arizona Board of Regents (ABOR) approved a Tribal Consultation policy (1-118) in 2016, to inform the policies at Arizona State University, Northern Arizona University, and the University of Arizona. ABOR's tribal consultation policy recognizes the sovereignty of federally recognized tribes and governs interactions between AIAN and the state universities. The policy emphasizes the government-to-government commitment of ABOR with guiding principles, including respect and acknowledgment of tribal culture, tribal laws and regulations, expectations of consultation, and on-going communication related to issues of shared interests. The policy lays out instances where consultation is expected and required, as well as the consultation process. It establishes liaisons to sovereign tribes and expectations of universities to disseminate information about the consultation process. Finally, the policy establishes guidelines for the resolution of issues and enforcement of violations (ABOR, 2016).

Although ABOR's policy is a significant step in the right direction, the policy falls short in that it does not specifically address the important concern of cultural sovereignty. AIAN and other IP continue to fight to maintain and protect their cultural sovereignty, that is "the effort . . . to exercise their own norms and values in structuring their collective futures (Coffey & Tsosie, 2001, p. 196)," and to exercise jurisdiction over tangible and intangible aspects of their cultures (Cook-Lynn 1996). The use of qualitative data, including intellectual property, Indigenous knowledge, interviews, cultural expressions including songs, oral histories/stories, ceremonies, dances, and other texts, images, and recordings (Bernard, Wutich, & Ryan, 2016), for research threaten cultural sovereignty and is of particular concern to IP and AIAN. These types of qualitative data are at risk of exploitation, appropriation, theft, and misrepresentation.

In addition to the risks mentioned above, another threat to AIANs and other IP is the growing use of big data. boyd and Crawford (2012) define big data as

a cultural, technological, and scholarly phenomenon that rests with an interplay of: 1) Technology: maximizing computation power and algorithmic accuracy to gather, analyze, link, and compare large data sets. 2) Analysis: drawing on large data sets to identify patterns in order to make economic, social, and technological, and legal claims. 3) Mythology: the widespread belief that large data sets offer a higher form of intelligence and knowledge that can generate insights that were previously impossible, with the aura of truth, objectivity, and accuracy. (p. 663).

Some examples of big data sets include information from "large social networks (including online networks such as Twitter), automated data aggregation and mining, web and mobile analytics, visualization of large data sets, sentiment analysis/opinion mining, machine learning, natural language processing, and computer-assisted content analysis of very large datasets" (Parks, 2014). The use of big data is of particular concern to not only AIAN and other IP, but with researchers, especially qualitative researchers. The growing use of big data has spurred issues and questions around ethics, accessibility, privacy, data ownership, and the role of qualitative research, as examples (boyd & Crawford, 2012; Mills, 2017; Qui, 2015; Strong, 2014). As boyd and Crawford (2012) state,

Just because content is publically available does not mean that it was meant to be consumed by just anyone . . . data were created in highly context-sensitive spaces, and it is entirely possible that some users would not give permission for their data to be used elsewhere (pp. 672-673).

Because big data is generally used without context, qualitative data is particularly vulnerable to misinterpretation, misuse, inappropriate use, and may be misleading, this is especially problematic with qualitative research since data is decontextualized (Mills, 2017). Data sharing and ownership of big data are of particular concern because of the nature of the data. Much of the data come from various sources; some data are proprietary so accessibility is problematic and some are web-based open access archives of web pages, legislation, social media content, and other types of information (Mills, 2017, Qui, 2015). Because of these issues, AIAN and IP are largely unable to control, own, or have a say in data, in its many forms, about them.

Qualitative data such as intellectual property, Indigenous knowledge, interviews, cultural expressions are at continued risk of exploitation, appropriation, theft, and misrepresentation; and have important implications for the nascent ethics and practice of qualitative data sharing. Additionally, these data, when used for research purposes, threaten the cultural sovereignty of AIAN and IP. These threats are magnified and will become an issue with the growing use of big data. In this article, I discuss AI political sovereignty, cultural sovereignty, Indigenous data sovereignty, AIAN governance over data collection, ownership, and application of data, with an emphasis on qualitative data sovereignty. The article argues that researchers should support the Indigenous sovereignty movement by reconsidering big data use and past positions about qualitative data ownership and sharing with respect AIAN and IP.

American Indian and Alaska Native Sovereignty and Research Governance

In order to better understand the rights of AI nations and AN corporations to govern research and data gathering that occurs with their people and on their lands, it is important to be familiar with their unique political status as sovereigns. This distinctive status can be traced back early European contact. Initially, European nations and later the United States, recognized the inherent sovereignty of Indigenous nations by entering into a number of treaties establishing promises, benefits, and obligations. As a result of this history, federally recognized AI nations and AN corporations have political statuses that are different than other racial/ethnic groups in the United States. Members of AI nations and AN corporations are not only part of a racial ethnic group, they are part of a political group subject to special rules, regulations, and exemptions, as well as special rights and benefits from the federal government.

Federally recognized AI nations and AN corporations are sovereign entities with rights of sovereignty. Whereas sovereignty is often defined as absolute or supreme power, AI sovereignty is limited by the "reserved rights" doctrine. The "reserved rights" doctrine holds that

> Indian nations maintain all rights [of sovereignty] not specifically ceded by treaty or explicitly removed by federal legislation, unless these rights are inconsistent with their status as dependent nations . . . thus, [Indian nations] have full jurisdiction over their affairs has been explicitly restricted by Congress (Harvard Project on American Indian Economic Development et al., p. 38).

Wilkins and Stark (2011) have also defined AI sovereignty as

> The intangible and dynamic cultural force inherent in a given indigenous community, empowering that body towards the sustenance and enhancement of political, economic, and cultural integrity. It undergirds the way tribal governments relate to their own citizens, to non-Indian residents, to local governments, to the state government, to the federal government, to the corporate world, and the global community (p. 38).

Some of the sovereignty rights of AI nations include choosing a form of government with rights to impose and collect taxes, determine citizenship criteria, pass and implement laws and policies, including processes for research taking place on their lands. Because of their sovereign status, AI nations and AN corporations have a government-to-government or nation-to-nation relationship with the federal government that establishes rights and responsibilities of both parties and entails a trust responsibility. The trust responsibility holds that the federal government must support and encourage tribal self-government for economic prosperity and protect tribes' political, economic, social, and cultural interests. The inherent sovereignty of AI nations and the trust relationship has been recognized, reaffirmed, and limited through the Constitution, treaties, statues, and numerous court cases (Wilkins, 2010; Wilkins & Stark, 2011).

Self-determination and self-governance are crucial ways for AI nations and AN corporations to exercise political sovereignty. Over 40-years ago, self-determination became formal U.S.-Indian policy with passage of the Indian Self-Determination and Education Act of 1975 (PL 93-636), that politically strengthened AI governments and AN corporations by allowing contracts with the Secretary of the Bureau of Indian Affairs, and the Secretary of Health, Education, and Welfare (now Health and Human Services), to administer federal programs, services, and activities with associated funds by allowing greater control, including development and implementation of programs affecting their citizens. Subsequent amendments and the Tribal Self-Governance Act of 1994 (25 U.S.C. 458aa et seq.) broadened AI nations and AN corporations control of program funding toward a policy of self-governance. Self-governance is the right of AI nations and AN corporations to govern themselves through federal funding, expanding control of programs and responsibilities and minimizing federal oversight. The policy of self-governance became permanent in 2000 and has expanded to include non-Bureau of Indians programs within the Department of the Interior and non-Indian Health Services Programs within the Department of Health and Human Services. To date, more than 50% of all federal Indian programs are administered by AI nations and AN corporations (Strommer & Osborne, 2015).

American Indian nations and AN corporations continue to struggle to maintain and exercise the right to assert their sovereignty as it relates to governance, culture, and research, to name a few. Research in AIAN communities has always been a power struggle. As Lomawaima (2000) explains, "until quite recently . . . researchers could set their own research agendas, devise their own questions, develop whatever methodology suited their agenda, and do as they pleased without having to consult with or defer to tribal polities" (p. 6). Research is often seen as a way to exploit native culture for the benefit of nonnative scholars and others (Brayboy & Deyhle, 2000). As a result, AI nations and AN corporations are asserting their political and cultural sovereignty to determine research that occurs on their lands and secure legal rights and recognition to knowledge, objects, and places that researchers may consider to be data.

Indigenous Data Sovereignty and Qualitative Data

Data ownership and sharing, particularly with big data sets containing qualitative data, is a growing concern not only with AIAN and IP people but with qualitative researchers as well. Qualitative data analysts have raised significant concerns, for many years, about the ethics, feasibility, and value of qualitative data sharing. These concerns are also raised when it comes to big data sets (boyd & Crawford, 2012; Mills, 2017; Qui, 2015; Strong 2014). Qualitative data contain sensitive information that could pose significant harms to respondents and communities (Heaton, 2004). For instance, some researchers have expressed concerns that it is logistically impractical to anonymize qualitative data or strip it of sensitive information. Others believe that once anonymized or stripped of sensitive information, such qualitative data becomes useless for reanalysis. Even if that challenge could be overcome, others have argued, reanalysis of

qualitative data is largely useless because only the primary researcher has sufficient insight into the context and meaning of the data to interpret it meaningfully (Mills, 2017; Qui, 2015; Thomson, Bzdel, Golden-Biddle, Reay, & Estabrooks, 2005).

There is a growing sense that the tide is turning. Governmental and foundation funders of research grants are increasingly requiring applicants to submit data sharing plans—including qualitative data. In addition, the "replication movement" that has swept social psychology and allied fields in recent years also raises questions, for some, about the replicability, reliability, and validity of qualitative analyses (Tsai et al., 2016). Qualitative data analysts seeking ways to meet increasing demands for data sharing have found succor among archivists who have worked long and hard to develop methods of addressing these concerns about the ethics, feasibility, and value of data sharing (Elman, Kapiszewski, & Vinuela, 2010).

Yet, in all this back-and-forth about the ethics of data sharing, very little has been said about an influential new approach to thinking about qualitative data ethics: The Indigenous data sovereignty movement. Indigenous data sovereignty is the right of Indigenous people, including AIAN, to govern data collection, ownership, and application of its own data. In the broader sense, data sovereignty is data that are subject to laws, policies, or governance of a nation in which data are collected (Maurer, Morgus, Skierra, & Hohmann, 2014), and data governance is the management of data including availability, usability, integrity, and security (TechTarget Network n.d.). Proponents of data sovereignty argue that AIAN and IPs have "inherent and inalienable rights and interests . . . relating to the collection, ownership and application of data about their people, lifeways and territories (Kukutai & Taylor, 2016, p. 2)." This inherent right is also upheld in Article 31 of the United Nations Declaration on the Rights of Indigenous Peoples, adopted by the United Nations General Assembly on September 13, 2007, which states,

> Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions (Kukutai & Taylor, 2016, p. 11).

Indigenous data sovereignty seeks not only control, ownership, and governance of research and data ownership but also protecting sovereignty and culture. For many IP, sovereignty and culture are interlinked. AI nations, AN corporations, and other IP exercise sovereignty not only politically but also culturally. As W. Richard West, former director of the National Museum of the American Indian said,

> Political sovereignty and cultural sovereignty are linked inextricably, because the ultimate goal of political sovereignty is the protecting of a way of life. . . . But it is important,

perhaps even more important, is to protect Indian ways of life and ways of thinking (as cited in Bordewich, 1997, pp. 171-172).

Cultural sovereignty is essential for the survival of AIAN and IP as distinct societies; culture—language, songs, oral histories/stories, dress, ceremonies, and dances, for example—in addition to land and community are at the core of Indigenous identity and way of life (Coffey and Tsosie, 2001). As Wunder (1999) states,

> Sovereignty, in the final instance, can be said to consist more of continued cultural integrity than of political powers and to the degree that a tribal nation loses its sense of cultural identity, to that degree it suffers a loss of sovereignty (p. 123).

Violations of cultural sovereignty such as exploitation, appropriation, theft, and misrepresentation of culture, especially qualitative data threaten the political sovereignty of AI nations and to other IPs.

Mechanisms for American Indian/Alaska Native Sovereignty Over Qualitative Data

Lakota scholar Vine Deloria, Jr., writing in 1968, asked the simple question about anthropologists: Are they interested in academic freedom, or academic license? And, herein lies the rub with any arguments or examinations of the role of review boards and scholars examining the role of data and IPs. Academic freedom is the freedom of academics to launch lines of inquiry and the expression of ideas (either written or oral) without fear of reprisal from their academic institutions. Academic freedom is a bedrock of intellectual inquiry and engagement. However, academic freedom and academic license are not the same thing. Although Deloria (1968) does not define academic license, I take it to mean that an academic can take up and use whatever data he or she is exposed to without being held responsible for its use. Academic license has been conflated with academic freedom; the latter is a crucial part of the academic enterprise. The former creates a significant amount of angst and raises significant ethical and moral issues.

Many social scientists and other scholars working in a participatory mode advocate for taking a contextually relevant and culturally sensitive approach to research with AIAN and other IP. To this end, Dickert and Sugarman (2005) have developed a framework of four ethical goals of research permissions among Native American Tribal populations. These are enhanced protection, enhanced benefits, legitimacy, and shared responsibility. These approaches, while an improvement over modes of research that presume the researcher is the data owner, may still place AIAN communities and nonnative researchers in unequal roles. This is inappropriate, given (1) historical inequalities and power imbalances between AIAN Native and non-native peoples and (2) IP' rights to data sovereignty and ownership (Kukutai & Taylor, 2016; Simpson, 2016).

To address the collection and use of data, AIAN communities are increasingly putting in place their own research and ethics boards and other controls over

scientific research, data ownership, and data archiving (e.g., Macaulay et al., 1998). Nason (1996) found that tribal councils often required prior research approval and a number of tribal communities and nations had developed formal written policies governing tribal research. The nine Apache tribes, for example, identified a wide array of cultural property types—ranging from historical items to beliefs and ideas—that they stated could not be used for unauthorized commercial and other purposes. The next year, a symposium recommended that a "Council of Elders" should be composed to clarify which cultural practices should be protected and to limit "exploitation of our cultures by exposing our religions, social practices, languages, and cultural knowledge" (Bull, 1997). Lomawaima (2000) found that Hopi and Navajo research protocols prioritized "concerns about commercialization, alienation, and inappropriate dissemination of intellectual property and cultural patrimony" (p. 13). In particular, she noted the establishment of tribal archives as one way that AIAN were addressing concerns about data ownership, availability, and release. The National Congress of American Indians Policy Research Center and the Montana State University Center for Native Health Partnerships (2012) have raised similar concerns about the protection of knowledge in the research process (including collection and dissemination).

In 1991, Indian Health Services (IHS) implemented institutional review board (IRB) protocols and policies for research taking place in IHS facilities or involving IHS staff. These protocols helped to define what kind and under what specific conditions health data can be collected, shared, and disseminated (Morton et al., 2013). In 2001, the Indian Health Council (IHC), a consortium of nine tribes collaborating to achieve better health outcomes with regard to "Indian Health, wholeness, and well-being" (http://www.indianhealth.com/about-us), created their own tribal IRB with funding from federal entities (Morton et al., 2013). Several years afterward, the Navajo Nation was the first tribe to create formal mechanisms to regulate research on their lands. Since 1989, the Navajo Nations has required researchers to obtain a formal permit from the Historic Preservation Office in order to conduct ethnographic research. Later, they adopted the 1995 Navajo Nation Health Research Code, which was followed by the establishment of the Navajo Nation Human Research Review Board in 1996. The scope of the review board extends to journalism and secondary research (Brugge & Missaghian, 2006).

For qualitative data, including big data, there are not yet any overarching legal structures governing AIAN data ownership in the United States. As a result, these data could be vulnerable to nonconsensual release by researchers. Such acts would not be surprising, as the list of unethical practices by Western researchers among AIAN communities is too long to list here (Dippie, 1982; Hinsley, 1981). And, even in the absence of clear research malfeasance, publication or dissemination of specific information about any AIAN community may cause harm (Tsosie, 2007). As a result, qualitative data, including those contained in big data sets, originating in AIAN communities in the United States could be vulnerable to the violations related to open data access and public data ownership.

In terms of research supervision, university review processes overseeing the collection and archiving of qualitative data are generally not designed to advocate for the interests or protect the concerns of communities beyond the university (Lomawaima, 2000, p. 11). Recent revisions to the "Common Rule" overseeing human subjects research permissions in the United States have adopted changes—such as promoting single IRBs in cooperative research and exempting research categories (e.g., oral history), that are at odds with the interests and desires of many AIAN communities (NCAI Policy Research Center & MSU Center for Native Health Partnerships, 2012). Specifically, university review processes tend to focus on *academic freedom* rather than the rights and interests of AIAN communities. Lomawaima (2000) cites the case of a university human subjects review committee that, after "concerns about limits on academic freedom," exempted disciplines such as history and social/behavioral sciences from review (p. 10).

Method

As an increasing number of AI nations and AN corporations assert and exercise their sovereignty over research, more universities are not only acknowledging the Indigenous lands on which they are built, they are also acknowledging AIAN sovereignty. Of particular concern in this article is qualitative data, including types of data, and qualitative sharing, such as data anonymization/deidentification, data reanalysis, use of "public" or already archived data, and data restrictions. AI nations and Alaska Corporations are trying to address these issues through their own IRBs, however, what are universities doing to support and address the concerns of AIAN people? I explore this question by examining and determining the extent that each of Arizona's three universities—Northern Arizona University (NAU), Arizona State University (ASU), and University of Arizona (UA)—AIAN specific policies and guidelines support Indigenous data sovereignty and the extent to which they align with ABOR's consultation policy. ABOR's consultation policy governs relations between the three Arizona universities and Arizona AI nations.

ABOR Consultation Policy

ABOR's policy addresses research, education policy, and land use, on AI reservations. Under the policy, research is based on collaboration, consultation, data ownership agreements, and confidentiality. The guiding principles of the policy include (1) committing to a government-to-government relationship with tribes; (2) respecting and acknowledging culture, traditions, beliefs, governance processes, tribal laws, codes, regulations, and protocols; (3) establishing requirements and expectations for good faith consultation with tribes; and (4) encouraging ongoing relationships and communication relating to consultation and student success. In addition to guiding principles, the policy provides guidelines regarding consultation, board and university tribal liaisons, consultation process, education, and resolution and enforcement. Below are sections of the policy that are relevant to research.

Consultation. The obligations of the board and universities to sovereign tribes are fourfold:

1. "Communicate early, regularly, and in good faith . . . regarding proposed research . . . that may have foreseeable implications for tribes and individuals as members of a tribe (ABOR, 2016, p. 1)."
2. Acknowledge that existing research guides and protocols may not sufficiently protect individuals in research or the interests of sovereign tribes.
3. In university–sovereign tribe research partnerships, the university will consult with all parties on matters pertaining to "confidentiality, ownership of data and results, use of land or other resources, ownership and disposition of any biological materials collected in the course of research, proposed changes in the research, and proposed publications or presentations relating to the research (ABOR, 2016, p. 2)."

   Research activities that may require consultation include participation in research whose results, publication, and dissemination potentially have implications for the tribe or individual tribal members; human subjects research such as "genetic testing or testing of blood, tissue or other biological materials (ABOR, p. 2)" that identify tribal affiliation resulting in assumptions and generalizations of AI individuals or nations; research or activities that involve human remains, funerary and sacred objects, or objects of cultural patrimony, subject to the Native American Graves Protection and Repatriation Act; and research on tribal lands.

Consultation Process. Tribal consultation involves different processes depending on the activities of the board or university. The process involving research state that in consulting with or seeking consent from an AI nation, university IRBs must document proof of consultation or approval of research according to tribal protocols or processes.

Resolution of Issues and Enforcement. Research specific processes for resolving issues and enforcement such as allegations of research protocol violations involving university personnel, requires notifying the university tribal liaison and university president. Which then, the AI nation is informed of the issue. Violation allegations are subject to relevant university or student policies, such as research compliance and integrity. Finally, activities covered by the policy are also subject to tribal, state, and federal laws, codes, ordinances, and research protocols and regulations.

The consultation process outlined by the policy is significant in that it acknowledges the sovereign powers of tribes regarding research conducted on their lands with respect to data ownership, use of data, and publications and presentations.

Data Collection and Analysis

Since the Havasupai case, the increasing number of tribal IRBs, and the data sovereignty movement, many universities are addressing the issues of research, research

ethics, and data ownership with AIAN people. In addition, more states and state universities, are creating and implementing statutes that govern relationships and address research with AIAN people.

Drawing from Arizona's three public universities' human subjects websites, I downloaded AI- and AN- or IP-specific guidelines for that were available on each universities' website.

The documents found from these searches were then downloaded and imported into MaxQDA for a more detailed coding and analysis. I used ABOR's tribal consultation policy and broad Indigenous data sovereignty principles as frameworks to guide the examination and coding of the guidelines. The university documents were analyzed and coded for qualitative data, sovereignty, culture, traditions, beliefs, governance, agreements, partnerships, collaboration, data ownership or ownership of data, and IRB protocols. In addition, I analyzed ABOR's policy with respect to Indigenous data sovereignty. After the coding was complete, I summarized the data. For the AIAN specific guidelines, I explored the manner in which the procedures aligned with broad data sovereignty principles and with ABOR's tribal consultation policy. I also determined whether the university policies and guidelines addressed or provided definition(s) of qualitative data, big data, qualitative data sharing, and ownership. Of the three universities, the UA aligned with ABOR's policy and, to a certain extent, supported Indigenous data sovereignty.

Results

ABOR Consultation Policy

ABOR's consultation policy loosely supports Indigenous data sovereignty and does not fully support data collection, ownership, and application of data. In addition, the policies do not specifically address qualitative data. However, the policy subjects researchers and their research to violations of research specific laws, policies, and processes. The guiding principles relevant to Indigenous data sovereignty include respecting culture, tradition, governance processes, and complying with tribal laws, codes and regulations, and protocols. In addition, the policy requires good faith consultation with tribes. In terms of consultation, connections to Indigenous data sovereignty include communication concerning proposed, protecting interests affected research, and collaboration. Although the collaboration guidelines somewhat support Indigenous sovereignty, it is not sufficient. The sections call for collaboration in research design, however, AI nations have to choose to participate to become a joint partner. If an AI nation is jointly involved in the research, then consultation regarding confidentiality and ownership of data and results, and publications and presentations are required. Research that falls under the consultation guidelines includes any research involving results with implications and proposed publications, any research activity subject to the Native American Graves and Repatriation Act, and any research taking place on AI lands. In term of the consultation process, university IRBs must have proof of AI nation

approval of research in accordance with relevant protocols or processes. Finally, in terms of resolution and enforcement violations of AI nation protocols, agreements, policies, or laws, are subject to university policies. Finally, all activities, including research, may be subject to relevant AI nation, state, and federal laws, codes, ordinances, and research specific processes.

Arizona State University

ASU's *Guidelines for Working with Indian Tribes or on Projects Having the Potential to Impact a Tribal Government, its Community or its Members*, serves to supplement ABOR's consultation policy, set forth guidelines, and enhance university–AI governmental relationships. The guidelines lay out researcher responsibilities and best practices that correspond with ABOR's required consultation and consultation processes but do not fully support Indigenous data sovereignty. Like ABOR's policy, ASU's guidelines fall short with respect to data and data ownership. Absent from the guidelines are any mention of qualitative data and only loosely refer to "data" in general. Researchers are instructed to consider the distribution, change, impact on perceptions and reflections of specific tribes, individuals, culture, health, or aspects, of their "results (ASU, p. 3)." Like ABOR's policy, ASU guidelines do not mention or address qualitative data.

Northern Arizona University

At Northern Arizona University (NAU), the Office of Native American Initiatives works in collaboration with the IRB for the Protection of Human Subjects in Research for proposed activities with Native American individuals and communities. NAU's tribal consultation and approval guidelines does not fully support Indigenous data sovereignty, but it mirrors ABOR's consultation process only, and are graphically displayed as a flowchart. Absent from the flowchart are any mention of sovereignty, types of data, and data ownership. No additional written guidelines or policies regarding research with tribes were found on the university's website. In addition, no references to qualitative data were found.

University of Arizona

The University of Arizona's (UA's) guidelines follow and extend on ABOR's policy and to a certain extent, supports Indigenous data sovereignty. Although UA's guidelines partially support Indigenous data sovereignty in the areas of ownership and application of data, data sovereignty and governance are not fully supported. Of the three universities, the UA has the most comprehensive guidelines for research with Indigenous populations. In addition, the UA is the only university that has a standalone department, the Native Peoples Technical Assistance Office, dedicated not only to providing support for university researchers but also offers a variety of resources for AIAN and other IP, including research support and capacity building.

University research support consists of information on UA requirements for research with Native nations and online access to tribally specific research policies and protocols.

Two different, but complimentary guidelines, were found on the Native Peoples Technical Assistance Office and human subjects website, *Native American or International Indigenous Populations in Human Research* and *University of Arizona Guidelines for Research and Institutional Engagement with Native Nations*. Important to note is that UA's guidelines include not only Native Americans, but Indigenous populations across the globe. Following are the ways in which UA's guidelines expand on ABOR's policy.

The first document, *Native American or International Indigenous Populations in Human Research*, unlike ASU's or NAU's guidelines, explicitly defines what constitutes "Native Americans" or "Indigenous Populations." In addition, the document includes specific consent procedures for genetic research, the following paragraph is required for informed consent:

> If you are Native American and agree to participate in this study there may be risks associated with the research that impact your community. Health information, especially genetic information, can be applied to more than just you. Genetic analysis may be able to provide information about a person's parents, siblings, children, or others. Some genetic research can produce new information about entire subpopulations and individual racial or ethnic groups. It is unknown exactly what the researchers will discover because this study involves unspecific future research. Risks may include legal, financial, social, or physical harm. Information may be published that conflicts with your communities' culture, traditions, mythologies, or spiritual beliefs. (p. 2)

Unlike qualitative research, the wording for genetic research does not support data sovereignty and ethical principles including informed consent; in genomic research, samples may be stored indefinitely, shared broadly, and limited or no control over access, use, and disclosure (McGuire & Beskow, 2010).

The UA guidelines for research, *Guidelines for Research and Institutional Engagement with Native Nations* support and extends from beyond ABOR's policy. The following are sections of the documents with notable extensions of ABOR's policy.

Research Where Documentation of Consultation Is Required. Neither ABOR's policy, NAU's or ASU's guidelines address genetic research. However, UA guidelines recognize that genetic research is of particular concern with Native Nations and recommends additional measures to address concerns in "planning and management of genetic research and in developing plans for the disclosure of research results" (UA, n.d., p. 2).

Definitions. In the definition section, several terms, not found in ABOR's policy or other university guidelines, include culture, research, and traditional intellectual property.

Culture: Culture and traditions vary greatly between Native Nations. Native peoples and communities also vary in adherence to their culture's origins and to Western cultural values and beliefs. For many Native people, spirituality and religion are generally perceived as an integral aspect of their culture. Spirituality also takes on many forms within Native American communities, from the use of traditional Indigenous practices to Christian beliefs.

Research: It is the use of systematic methods to gather and analyze information for the purpose of proving or disproving a hypothesis. Research may also include *evaluating concepts or practices*, adding knowledge or insight to a particular discipline or field, or demonstrating or investigating theories, techniques, or practices. A systematic investigation involves a prospective plan that incorporates data collection, either *quantitative or qualitative*, and data analysis to answer a question. For the purposes of these guidelines, research includes but is not limited to various types of qualitative research including anthropological and archaeological studies, ethnographic studies, and cultural or historical research.

Traditional intellectual property: The cultural information, knowledge, uses, and practices unique to a Native Nation's way of life. This property includes, but is not limited to knowledge by remembered histories and traditions; details of cultural landscapes and particularly sites of cultural significance; records of contemporary events of historical and cultural significance; sacred property, including images, sounds, and knowledge, material, cultural, or anything that is deemed sacred by the community; knowledge of systems of taxonomy of plants, animals, insects, and other beings; knowledge of current use, previous use, and/or potential use of land, water, plant and animal, fish, and insect species; knowledge of planting methods, ecosystem conservation, preparation, formulation, processing or storage of species; biogenetic resources that originate or originated on Native lands and territories; and cultural images, sound, crafts, art, dance, symbols, motifs, and names, practices, and performances.

The definition section is important in that serves to help researchers understand concepts and principles related to respectful research with AIAN. The inclusion of traditional intellectual property is significant since it is of particular concern to AIAN and IP and relevant for qualitative researchers.

Fundamental concepts. Tribal sovereignty is recognized as a necessary concept to understand and recognize with respect to research with AI nations. As part of tribal sovereignty, intellectual property is acknowledged and ownership in explicitly stated, "Each Native Nation is the *exclusive owner* of all property on its lands and *fully controls the disposition, development and use of* its physical and *intellectual property*" (n.d., p. 6). UA is the only university whose guidelines recognize the intellectual property and ownership of AI nations.

Community Risk: Academic–Tribal Community Partnerships: Community Risk/Benefit. Different than ASU or NAU, UA's guidelines address ABOR's policy on acknowledging

that sovereign tribes are potentially subject to insufficient research protection and risks to traditional knowledge and intellectual knowledge as the paragraph below illustrates.

> Native Nations require thorough consultation and assessment of the benefits and risks of research and institutional engagement activities to community members. Risks may be legal, financial, social, physical, psychological, or spiritual in nature. Risks should be analyzed from the perspectives of both the individual and the group while remaining cognizant of the potential benefits that can also accrue to the group. Generally, Native Nations are concerned with the risks of exploitation, appropriation, and misrepresentation of traditional knowledge and intellectual property. If the research or institutional engagement is conducted on a reservation in a tribal community, keep in mind that tribal communities are typically small, making confidentiality problematic when members are either the subjects of a research protocol, or participating as members of the research team. Consideration of issues such as public policy impact, benefits, and harms to communities and group consent may be necessary to address heightened risk. (p. 7)

The risk/benefit section supports political and data sovereignty in that consultation, and thus, the government-to-government relationship, are emphasized. It also takes into consideration issues related to cultural sovereignty. And finally, it recognizes that AIAN and other IP are subject to additional risks that are not considered under the Common Rule (45 Code of Federal Regulations § 46).

Research and Institutional Engagement Principles and Best Practices. ABOR's required and expected consultation includes minimum guidelines for collaborative research partnerships. In contrast, UA's guidelines lay out recommendations (not requirements) on Native Nation—University best practice principles and questions with respect to collaboration, cultural competency, data storage and collection, and compensation/benefits /costs (not covered). Following are summaries of each section.

   Collaboration. AI nations are best suited to pinpoint potentially adverse outcomes resulting from research, if they are knowledgeable about assumptions and methods of research. The guidelines highlight the need for *formal data—sharing agreements* that take into account tribal—university contexts. Finally, questions to consider include respectful negotiation regarding the roles of collaborators, co-authorship or acknowledgment of research partners in publications, dissemination of results to collaborators, and potential requirement of Native languages throughout the research process.
   In the section on collaboration, data sovereignty is supported by addressing data sharing, but not ownership, and the rights and interests of AI nations to apply the data.

   Cultural competency. Cultural competency is neither discussed nor mentioned in ABOR's policy, nor ASU's or NAU's guidelines. In this section, researchers are posed with questions relating to sensitivity to traditions, knowledge, and culture; privacy and data confidentiality (Native Nations have the right to exclude access or publication of information on culture, traditions, or spiritual beliefs) and limited access to or

prohibited information (Native Nations have the right to limit or prohibit information related to places, names, knowledge, oral traditions, objects, or practices).

With respect to cultural competency, cultural and data sovereignty are supported; although not required, researchers are encouraged to take into account issues related to cultural sovereignty by limiting or excluding data on culture, tradition, or spiritual beliefs.

Data storage and sharing. Only UA's guidelines address data storage and sharing by posing questions on ownership of material and data from the Native Nation and sharing of data to third parties; access and use of material and data while meeting confidentiality requirements; and archived data and agreement compliance. Although not a requirement, researchers are encouraged to address data ownership, sharing, use, and storage, thus supporting data sovereignty.

Despite the good faith intentions of ABOR's policy, the expectations, requirements, and processes do not go far enough in supporting Indigenous data sovereignty. Only in one article of the policy is data ownership mentioned, but it only applies to joint projects. While each of the universities have separate and specific research policies that follow ABOR's tribal consultation policy, the university guidelines differ in scope in term of supporting AIAN sovereignty and data sovereignty.

Discussion and Conclusion

AI nations and AN corporations have struggled to maintain and exercise the right to assert their sovereignty in research within their communities. Arizona serves as a case wherein AIAN sovereignty is recognized by the governing body of the state's universities. The ABOR, identifying as a governmental entity, have tasked themselves and universities to establish government-to-government relationships with AIAN governments. Of the three Arizona universities, the AIAN and IP specific guidelines from the UA serve as an exemplary case for respecting, recognizing, affirming, and supporting Indigenous sovereignty both locally and globally. While the UA guidelines fall short in supporting all of the principles of Indigenous data sovereignty, researchers are asked to consider best practices and points of consideration including data sharing agreements, ownership of material and data, inclusion of AIAN partners as coauthors, sensitivity to traditions, knowledge, and culture, supporting the right of AIAN to limit or restrict various types of information. ABOR's tribal consultation policy, although significant because it acknowledges AIAN sovereignty, the policy falls short in that AI nations and AN corporations maintain a submissive role in the research process. Furthermore, it does not specifically address important concerns of AIAN people and governments, such as big data, archived data, data ownership, and sharing.

Because of their sovereignty, in particular, their cultural sovereignty, AIAN and other IP have the inherent right to govern research, including the research design, data collection, apply, and own data collected on their lands. Not all AI nations, AN corporations, or other Indigenous communities have mechanisms, such as IRBs, in place. Even if they do, for various reasons, they are often made subservient to outside

researchers and universities as university IRBs typically have the last say in the IRB process. Furthermore, the use of and issues associated with big data are rarely addressed, by both tribal and university IRBs, if at all. Additionally, because big data are often readily available, qualitative data containing AIAN and IP information are at an increased risk of research abuse and threaten cultural sovereignty.

Until formal policies are put into place, researchers must be cognizant and mindful of the kinds of qualitative data they are allowed to collect and be proactive enough to put safeguards around that data to protect it from harm. In addition, when using big data, researchers must be aware of the threats to AIAN and IP "data" and to minimize those risks. It is critical to build awareness of Indigenous sovereignty, cultural sovereignty, and particularly data sovereignty, so that it becomes second nature and/or common sense for all researchers—Western and Indigenous alike. Academic researchers and scholars may not be aware of Indigenous and AIAN sovereignty and the kinds of research permission protocols, which are in place among AIAN and IP due to a combination of ignorance and the lack of publicly visible codes, policies, and literature. I hope this encourages researchers and scholars to reach out to AIAN and IP and ask specifically about the use of data ownership rules and regulations, far in advance to their proposal of new research projects. In instances of big data use, I urge researchers to consult with AIAN and IP, when possible, to take into consideration cultural sovereignty, and to use ethical principles and guidelines that apply to human subjects as much as possible. In this way, the global movement for Indigenous data sovereignty may also inspire other (non-Indigenous) communities facing colonialism, exploitation, and other harms.

For far too long, AIAN and IP have been subject to research abuses. Qualitative data, including those in big data, such as intellectual property, Indigenous knowledge, interviews, cultural expressions including songs, oral histories/stories, ceremonies, dances, and other texts, images, and recordings have been subject to and are at continued risk of exploitation, appropriation, theft, and misrepresentation. With the growing Indigenous data sovereignty movement, researchers will increasingly face not only concerns of control, ownership, and governance of research and data ownership, but also cultural and political sovereignty. Protecting and respecting AIAN and IP cultural and political sovereignty is crucial in ensuring the survival of AIAN and IP as distinct societies. I encourage our colleagues, whether they work with Indigenous communities or not, to reconsider using big data as it relates to AIAN and IP and to reconsider past positions about qualitative data ownership and sharing.

Declaration of Conflicting Interests

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Notes

1. American Indian (AI) refer to members of federally recognized tribes, and AI nations refer to federally recognized tribes who have a government-to-government relationship with the federal government.
2. Alaska Native (AN) refer to members of federally recognized Alaska Native entities, and Alaska Native corporations have a government-to-government relationship with the federal government, but have different nonreservation governmental structures than AI nations.
3. Because of their different histories, governmental structures, and relations with the federal government, AI nations and AN corporations are distinctive in terms of their relationship with the federal government. As a result, throughout this article AI nations and AI corporations will be separated when necessary.

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