



## LETTER TO THE EDITOR

American Journal of  
PHYSICAL  
ANTHROPOLOGY

WILEY

# Indigenous data sovereignties and data sharing in biological anthropology

In their commentary on data sharing in biological anthropology, Turner and Mulligan (2019) lay out guiding principles and best practices resulting from the American Association of Physical Anthropologists (AAPA) ad hoc committee on data access and data sharing workshop. Their commentary has invited a crucial conversation on data practices in the field and has produced numerous comments and responses on the topic (Boyer, 2020; Leigh, 2020; McDade, 2020; Wagner, 2020). This conversation has made multiple points regarding the inclusivity of the workshop and moving toward a shared set of data management principles in the field. However, we note that the current conversation lacks engagement with Indigenous data sovereignties, which can offer additional models of data governance and further inform the ways that biological anthropologists approach questions of data access and data sharing. Here, Indigenous data sovereignties are defined as the “rights and interests of Indigenous peoples relating to the collection, ownership, and application of data about their people, lifeways, and territories” (Kukutai & Taylor, 2016). The lack of conversation regarding Indigenous data sovereignties is concerning given that Indigenous and allied thinkers have often intervened in questions of data governance and advocated powerfully for greater attention to Indigenous self-determination and sovereignty. Yet, the concerns of Indigenous peoples regarding data access and data sharing have often been overlooked or have been significantly compromised by non-Indigenous researchers. Given this, our goals in this letter are twofold. First, we seek to engage with a number of key issues, assumptions, and gaps in the existing commentaries and letters on this topic. Second, we aim to redress the current lack of attention to Indigenous data sovereignties by bringing these critically necessary insights into the ongoing conversation that has been unfolding in the pages of the *AJPA* over the last year. Importantly, our intent in raising these concerns does not come from a position that is antiscientific or anti open data, but rather *pro-sovereignty*, with the goal of heightening attention to the power relations that pervade data practices in relation to Indigenous peoples. Given that the institutions of biological anthropology, including this journal and the professional association, were made possible in no small measure by exploitations of Indigenous bodies by Aleš Hrdlička and many others (Colwell, 2017; Pérez, 2019), it is essential that questions of Indigenous sovereignty be part of how biological anthropologists envision and develop data practices moving forward.

Among the current letters and comments, there is little acknowledgement of ongoing colonialisms, the power hierarchies that have historically shaped this field in relation to Indigenous peoples, and

how these problems can be perpetuated in contemporary data practices. In instances where issues of power have arisen, the focus has largely been directed at the vulnerabilities of researchers themselves and the possible impediments to the academic career pipeline (Leigh, 2020). Other commentaries have framed vulnerability in terms of unscrupulous data repositories and the risks that they pose for both researchers and participants (Wagner, 2020) as well as the risks of deductive disclosures (McDade, 2020). These are all valid points of concern. Nonetheless, an Indigenous data sovereignty perspective can greatly enrich this conversation by bringing more attention to the power dynamics of researcher–participant relationships in the context of marginalized communities, as well as the relationships between Indigenous researchers and the field of anthropology itself. Biological sampling and data practices that seemingly bolster scientific progress have often come at the expense of Indigenous peoples, who have seldomly benefited from research conducted within and about their communities (Claw et al., 2018; Garrison, 2013). Questions regarding the power hierarchies and benefit structures of research must therefore be central to data access and data sharing practices, with the recognition that conditions of power and vulnerability shift over time and across communities.

In recent exchanges on the topic of data access and data sharing in *AJPA*, there appears to be a consensus that principles and practices of open data are necessary to produce good science. Increasing data access in the field has even been framed in decolonial terms, as a set of practices that redress problems of colonialism by democratizing science and promoting scientific progress (Boyer, 2020; Leigh, 2020). The appeal to scientific advancement is concerning given that discourses of progress, including assumptions about “primitive/advanced” societies have been central to violence against Indigenous peoples within and beyond the field of biological anthropology. It is therefore a mistake to think about modern scientific advancements (including the bioethical and data sharing policies that regulate them) and colonialism as distinct entities, or as mutually exclusive possibilities, when they have long been one and the same (Mann & Daly, 2018). Therefore, the presumed decoloniality of increasing data access and data sharing is neither self-evident nor universal. Nevertheless, the assumption that open data practices are implicitly decolonial has persisted even after the conclusion of landmark settlements between research institutions and Indigenous communities following unconsented re-analyses of study samples and the generation of new data (Garrison, 2013). At stake here is ensuring that Indigenous peoples have control over and benefit from information

generated from their communities, otherwise open data practices act as just another form of colonial dispossession. Holding Indigenous data sovereignty as paramount, we question whether the attempt to normalize data access and data sharing in biological anthropology is truly feasible, and we are concerned about the consequences of decisions within the discipline regarding data management that impact Indigenous peoples. Addressing problems of colonialism will ultimately not entail whether open data practices are implicitly and universally decolonial, but whether Indigenous peoples have shared governance over the afterlives of data generated about and affecting them.

Ideals of “democratization” in science suffer from similar problems. In practice, democratization has often meant widening the conscription of Indigenous peoples as the *objects* of scientific research rather than as knowledge producers. This represents a failure to address the underlying power asymmetries of science in relation to Indigenous and other marginalized peoples. We therefore caution against assuming a false equivalence between the goals of decolonizing and democratizing science. There is a profound difference between widening the practice of science *upon* Indigenous peoples and transforming science *in relation* to them. Even when democratization means addressing inequities in representation within science, this still may not be sufficient considering that Indigenous peoples often make up a small fraction of the population and an even smaller proportion of scientists, although this is changing. If democratization only maximizes benefit for the greatest number of individuals, then unfortunately, Indigenous peoples will often continue to be disenfranchised and bear disproportional burdens of risk under the auspices of the “greater good.” Indigenous data sovereignties should not be relegated to “minority viewpoints” within the field but should be centered as expert knowledges which are vital to the processes of data generation, interpretation, and management (Bolnick, Smith, & Fuentes, 2019). In addition to questions of representation, it is important that attention to Indigenous sovereignties rise to a level that is commensurate with the field's foundation upon the exploitation of Indigenous bodies and lands.

There are no one-size-fits-all approach to data access and data sharing when it comes to Indigenous peoples. Some communities may be amenable to open data access, others may place conditions on future data use (as the Confederated Tribes of the Colville Reservation did in the case of Rasmussen et al., 2015), and others may not want data shared or reused beyond the scope of a single project. The point is that Indigenous peoples' sovereignty over their data ought to be respected, including their ownership, control, access, and possession of it (OCAP®, n.d.). As other commentators have rightly pointed out (Wagner, 2020), there may be a lack of alignment between various community, institutional, and governmental policies and guidelines for data management. In addition to this, there are instances where research with Indigenous peoples and territories will be governed by the oversight of tribal or Indigenous research review boards (RRBs) (Claw et al., 2018). Indigenous-led RRBs may regulate research more broadly than university institutional review boards (IRBs) and can include alternative positions on what does and does not constitute human subjects research and its attendant data practices. This means that tribal research regulatory structures may be restrictive to forms

of research that might otherwise be exempted as non-human subjects research. Guidance for researchers navigating these various issues should include the possibility that not every research project with Indigenous peoples will be feasible, not all research that is feasible will result in open access data, and not all research inquiries will be seen as valuable to Indigenous communities and therefore may never materialize. For non-Indigenous researchers who have little experience or training in navigating Indigenous research structures, this can seem daunting. However, this is by no means a reason to find ways of interrogating questions about Indigenous peoples and their lands without Indigenous oversight.

We also note that social, cultural, and legal definitions of community differ substantially between Indigenous groups, and there are instances where the participation of one community may implicate and/or necessitate consent from another. In addition, it can be difficult to determine which representatives should be defining data access policies on behalf of their communities. Different communities have different values and governance structures around who represents their interests, and researchers have a responsibility to engage with the various forms of representation the community chooses.

Further to this point, we recognize that issues of “consent” and “confidentiality” may differ in Indigenous contexts when it comes to data generation and management, including data curation and reuse. Many informed consent procedures in science privilege or grant sole agency to the individual in whether they agree to participate in research and how their data will be used. Centering Indigenous data sovereignties means recognizing that many Indigenous groups align with a more collective ethic when it comes to issues of consent and confidentiality. For example, Indigenous peoples may make decisions by group consensus or referring to a council of their defined authority. This means that researchers must think differently not only about how data are generated but also how it is governed, and the forms of consent and confidentiality beyond the individual level that may be necessary (Kamanzi & Romania, 2019; Tsosie, Yracheta, & Dickenson, 2019). While more collective and community-based participatory research (CBPR) models have been gaining traction in science, we note that not all community-centered approaches are commensurate with Indigenous data sovereignty models. While CBPR often involves implementing greater reciprocity between researchers and participants, what researchers consider to be valid forms of community-based consent and representation may not always align with those of Indigenous peoples. Furthermore, CBPR may not go far enough in destabilizing the power hierarchies of the researcher-participant relationship. Assuming that CBPR automatically solves these problems can risk collusion with existing colonial power structures by imposing non-Indigenous value systems at the expense of Indigenous sovereignty. In addition, as a set of guidelines, policies, and suggestions, even the positive aspects of CBPR models are easily circumvented or manipulated, allowing for the veneer of ethical behavior without Indigenous sovereignty. Therefore, while CBPR sometimes represents hopeful steps toward generating greater reciprocity, it is not always the “ethical fix” that many researchers believe it to be.

An alternative to data management policies centered within non-Indigenous institutions and repositories is the creation of Indigenous-led alternatives (Garrison et al., 2019), including the development of regional, independent bio-data repositories (BDRs). Indigenous-led BDRs are another avenue of exercising Indigenous sovereignty in research and data management. Indigenous BDRs exert control through leveraging existing forms of institutional recognition, transaction, and jurisdiction and bringing these systems under the purview of Indigenous peoples. Indigenous-led BDRs provide the possibility of a trusted venue in which research and learning of consequence to communities can take place and where the curation and circulation of data can be extracted from non-Indigenous control. Perhaps most importantly, BDRs also bring the possibility of supporting knowledge production from existing Indigenous experts while also generating new Indigenous scientists and academics under curricula created locally that uniquely blend Indigenous and non-Indigenous methods of knowledge creation. It is important that Indigenous BDRs be included in what constitutes a trusted database and for whom.

Given the global resurgent attention to racial violence, it is incumbent upon practitioners of biological anthropology to continue to reflect upon the field's investments in colonialism and ensure that contemporary scientific technologies and practices do not work in opposition to Indigenous sovereignties (Athreya, Hlusko, Antón, Nelson, & Fuentes, 2020; Fuentes et al., 2019; Kolopenuk, 2018; TallBear, 2013). Practitioners who benefit from this field of study have a responsibility to intervene in these problems in ways that center Indigenous sovereignties, including but not limited to the ways that researchers approach questions of data access and data sharing.

#### CONFLICT OF INTEREST

KST and JMY serve as non-compensated board members of a non-profit 501(c)3 Indigenous biobank initiative, the Native BioData Consortium, in the United States. JK and RWAS do not declare any conflicts.

#### AUTHOR CONTRIBUTIONS

**Krystal Tsosie:** Conceptualization; writing-original draft; writing-review and editing. **Joseph Yracheta:** Conceptualization; writing-original draft; writing-review and editing. **Jessica Kolopenuk:** Conceptualization; writing-original draft; writing-review and editing. **Rick Smith:** Conceptualization; writing-original draft; writing-review and editing.

Krystal S. Tsosie<sup>1,2</sup>

Joseph M. Yracheta<sup>2,3</sup>

Jessica Kolopenuk<sup>4,5</sup>

Rick W. A. Smith<sup>5,6,7</sup> 

<sup>1</sup>Vanderbilt University, Nashville, Tennessee

<sup>2</sup>Native BioData Consortium, Eagle Butte, South Dakota

<sup>3</sup>Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland

<sup>4</sup>Faculty of Native Studies, University of Alberta, Edmonton, Alberta, Canada

<sup>5</sup>Indigenous Science Technology and Society Lab, Faculty of Native Studies, University of Alberta, Edmonton, Alberta, Canada

<sup>6</sup>Department of Sociology and Anthropology, George Mason University, Fairfax, Virginia

<sup>7</sup>Women and Gender Studies, George Mason University, Fairfax, Virginia

#### Correspondence

Rick W. A. Smith, Department of Sociology and Anthropology, George Mason University, MSN 3G5, Fairfax, VA 22030-4444.

Email: rsmith86@gmu.edu

#### ORCID

Rick W. A. Smith  <https://orcid.org/0000-0002-3207-0519>

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