



We Have “Gifted” Enough: Indigenous Genomic Data Sovereignty in Precision Medicine

Krystal S. Tsosie, Joseph M. Yracheta, Jessica A. Kolopenuk & Janis Geary

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“Gifts are always about long-term relations, creating collective associations, and opening futures,” writes anthropologist P. Wenzel Geissler (2011, 59). This resonates with our research, where enrollees framed the benefits of their participation in generational terms that extended the obligations of their “gift” long into an imagined future in which (in the words of one staff member) “I can make sure that other people in my family or my neighbors don’t have the same health challenges that I face.” Yet, long before these hoped-for scientific discoveries may arise, participants may receive information about their own genetics that carry serious negative implications for their own health and demand medical attention beyond their means. Fulfilling the moral obligations of precision medicine requires collaboration across actors and sectors to address both present challenges to care and to deliver on futures promised—and hoped for—by those whose genetic “gifts” make research possible.

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ORCID

Carolyn P. Neuhaus  <http://orcid.org/0000-0002-8563-5632>

Johanna Tayloe Crane  <http://orcid.org/0000-0002-8687-4889>

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We Have “Gifted” Enough: Indigenous Genomic Data Sovereignty in Precision Medicine

Krystal S. Tsosie^{a,b} , Joseph M. Yracheta^{a,c} , Jessica A. Kolopenuk^d , and Janis Geary^{d,e} 

^aNative BioData Consortium; ^bVanderbilt University; ^cJohns Hopkins University Bloomberg; ^dUniversity of Alberta; ^eArizona State University

In “Obligations of the ‘Gift’: Reciprocity and Responsibility in Precision Medicine,” Lee (2021) rightly points out that disparities in health care access also lead to disparities in precision medicine research participation. Lee (2021) adds that an emphasis on individual consent among research ethics fails to

adequately address Indigenous expectations for the governance of research specimens. As Lee summarizes in their conclusion, it is important to account for the ways that “group history and structural inequities” (64) continue to shape 21st century advances in medicine. While Lee frames their discussion within the

CONTACT Janis Geary  jdgeary@asu.edu  Arizona State University, Tempe, AZ 85287-1004, USA; Department of Medicine, University of Alberta, Edmonton, Canada.

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context of clinical practice and the US healthcare system, our commentary extends consideration of the conditions that impact Indigenous participation in precision medicine research and also the potential benefits derived from it. We argue that Lee's paper (not unlike much of the field of precision medicine) takes for granted the colonial power relations that shape the aforementioned structural inequities as the basis of Indigenous peoples' relationship to health care systems. We contend that such erasure of the ongoing resistance of Indigenous peoples to protect and exercise their sovereignty, self-determination, and governance leads to the problematic framing of Indigenous participation in research as being a matter of "gifting" and "reciprocity." Alternatively, and from our perspectives as Indigenous (in genetics—KST and JMY, science and technology—JK) and community-engaged (public health—JG) researchers, we offer the concept of "DNA on Loan" (Arbour and Cook 2006) to open pathways toward Indigenous genomic and data sovereignty in precision medicine.

Contemporary biomedical research with and affecting Indigenous peoples must consider the histories and present experiences of research exploitation and harm perpetuated by medical institutions and researchers. Research has too often been done *to* and *about* Indigenous peoples, rather than *for*, *with*, or *by* Indigenous peoples (Dalton 2002). The fundamentally colonial and inequitable relationship between Indigenous peoples and the predominantly non-Indigenous research institutions that control access to healthcare and funding is a crucial context for reframing the so-called exchanges of gifts in precision medicine. Current policy structures that fund Indigenous health research do not ensure that funding goes

directly to Indigenous communities, nor do policies ensure that those conducting research on behalf of communities follow procedures to prevent their exploitation. Therefore, the idea of "gift" implies a requisite trust by the gifter toward the receiving research institution. However, when "consultation" attempts from funders with Tribal leaders inevitably raise the issue of Indigenous data sovereignty or Tribal control of samples, funders quickly dismiss that as not commensurate with conventional research practices. This lack of trust in the Tribal partners' ability to grant fair and consistent access is readily apparent not only in funding partnerships but with editors of major journals who recommend removing such phrases as "Tribal control & authority." Such ability to dismiss the very real concept of tribal control demonstrates the extreme power imbalance of "gifting." The structural power imbalance left in the wake of this policy gap is also apparent when Indigenous peoples are offered participation in research initiatives after the terms of participation have been predetermined by research institutions or funding authorities. Indigenous communities and scholars must then choose to accept the imposed terms or risk losing out on research opportunities entirely (Figure 1).

Though touched upon briefly by Lee, there are two important points that must be emphasized in order to understand why this gift-giving analogy is problematic in Indigenous constructs. First, centering the "right to gift access" to one's own body or bodily specimens on the individual is a notion that is rooted in Western bioethics but is culturally incongruent with Indigenous group or communitarian ethics (Tsosie, Yracheta, and Dickenson 2019). Secondly, tying gift-giving to an individual's right to transfer from one



Figure 1. The cycle of victim-blaming and coercion that Indigenous peoples experience in research.

entity to another may lead to questions of ownership of said bodily materials or authority for unconsented secondary analysis of primary data (Zeiler 2014), which echoes Indigenous peoples' concerns of co-optation and biocolonial prospecting of Indigenous genomes. The ethics and governance of secondary data is another topic where consultation with sovereign peoples has not been addressed in-depth, but out of the scope of this commentary.

Ownership and control of data and specimens has both financial and health impacts. A 2013 report estimated that “the Human Genome Project and related federal research are linked to \$965 billion in economic activity, more than 53,000 direct genomics-related jobs and \$293 billion in personal income” (Battelle Technology Partnership Practise 2013). Without explicit ownership of their data, Indigenous communities not only lose out on the potential to participate in this economic activity, but risk having their identities misrecognized, commodified, and sold as ancestry tests (Fox 2020). Commercial exploitation of DNA taken from Indigenous peoples is, unfortunately, part of a cycle that continues to be perpetuated in the era of precision health and genomics research. Open access genomes from Indigenous groups from large-scale diversity projects such as the Human Genome Diversity Project and 1000 Genomes are now widely used by industry agents who have used biomarkers derived from Indigenous communities for corporate profit, while those same Indigenous communities fail to benefit from medical innovations that might improve health outcomes. To ask Indigenous peoples to continue participating in newer large-scale precision health projects, such as the All of Us Research Program, is to ask for their trust in a system that has historically exploited them through systemic inadequacies and anti-Indigenous politicking. Therefore, a publicly funded research agenda with a clear path to commercialization but without a clear path for Indigenous health or economy is fundamentally flawed. Thus, tying gifts of genomic and health data to private or even public domains of ownership without equitably distributing potential health benefits is an untenable relationship by which Indigenous peoples have and will, unfortunately, continue to receive nothing in return for their gift.

Instead of conceptualizing samples and data in terms of gift-giving, we consider framing their possession in research in terms of *stewardship*. In this perspective, Indigenous-derived samples and data accepted for research are considered the continued

property of the donor/community involved; hence DNA is considered “on loan” (Arbour and Cook 2006) to the researcher as opposed to being a gift. Those accessing the samples and data for research are entrusted to use the DNA for the purposes of consented research only, but *ownership* remains with the Indigenous donor/community.

The cycle of extractive research exploitation can be mitigated by ensuring that Indigenous communities govern and benefit from precision medicine research (Tsosie et al. 2021). There are a growing number of Indigenous-led precision medicine initiatives to draw guidance from. Guided by Indigenous governance structures, the Silent Genomes Project in Canada and the Aotearoa Variome in Aotearoa/New Zealand are developing background variant libraries of Indigenous genomes (Caron et al. 2020). Additionally, the Native BioData Consortium was created by Indigenous scientific and bioethics experts to proximally keep Indigenous research samples and data within the provenance and governance of Indigenous communities (Native BioData Consortium 2020). While not limited to precision medicine, the Institute of Indigenous Peoples' Health (IIPH), a part of the Canadian Institutes of Health Research (CIHR), has developed policies and procedures to enable direct funding support for Indigenous communities and scholars (Government of Canada, Canadian Institutes of Health Research 2003). IIPH is helping direct a targeted investment of 4.6% of CIHR's overall budget (to match the proportion of Indigenous Peoples in Canada's population), and working to ensure that funding either goes to Indigenous scholars, or non-Indigenous scholars with a vetted approach to community-engaged research.

Inclusive research practices must consider the ways that inequitable relationships between Indigenous peoples and scientific fields continue to disproportionately structure the risks and benefits of precision medicine, otherwise they will perpetuate harms and fail to address Indigenous demands for governance of the research that affects them. As Lee accurately points out, a commitment to justice requires addressing inequities that go beyond the discrete gift exchange that overwhelms many discussions about specimen donation in precision medicine. Hence, meaningfully engaging Indigenous communities in precision medicine must also entail restructuring research ecosystems from an anti-colonial standpoint. The language of gifting dishonors all that has already been taken for the benefit of others.

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ORCID

Krystal S. Tsosie  <http://orcid.org/0000-0002-7291-670X>

Joseph M. Yracheta  <http://orcid.org/0000-0002-0691-8504>

Jessica A. Kolopenuk  <http://orcid.org/0000-0002-2741-7928>

Janis Geary  <http://orcid.org/0000-0002-0743-8713>

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Responsible Research with Human Tissues: The Need for Reciprocity Toward Both Collectives and Individuals

Michael A. Lensink^a , Karin R. Jongsma^a , Sarah N. Boers^{a,b}, Johannes J. M. van Delden^a, and Annelien L. Bredenoord^a 

^aJulius Center, University Medical Center; ^bUtrecht General Practice Training Institute, University Medical Center Utrecht

Precision medicine research involving human biological material is becoming an increasingly central component of healthcare, and its potential is quickly growing due to rapid technological progress. As the infrastructural and governance groundwork is currently being laid to accommodate these developments, Lee rightly stresses the importance of ensuring fair

and equitable distribution of benefits across society. However, the advances in tissue research have also led to substantial and growing concerns for the protection of *individual* rights and interests of tissue providers, such as bodily integrity and the right to self-determination (Boers, van Delden, and Bredenoord 2019; Waldby and Mitchell 2006).

CONTACT Michael Lensink  m.a.lensink-3@umcutrecht.nl  Department of Medical Humanities, Julius Center, University Medical Center, Utrecht, The Netherlands.

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