



## *Annual Review of Genomics and Human Genetics*

# Genomic Research Through an Indigenous Lens: Understanding the Expectations

Nanibaa' A. Garrison,<sup>1,2</sup> Māui Hudson,<sup>3</sup>  
Leah L. Ballantyne,<sup>4</sup> Ibrahim Garba,<sup>5,6</sup>  
Andrew Martinez,<sup>6</sup> Maile Taulii,<sup>7</sup> Laura Arbour,<sup>4,8</sup>  
Nadine R. Caron,<sup>9,10,11</sup> and Stephanie Carroll Rainie<sup>6,12</sup>

<sup>1</sup>Treuman Katz Center for Pediatric Bioethics, Seattle Children's Research Institute, Seattle, Washington 98101, USA

<sup>2</sup>Department of Pediatrics, University of Washington, Seattle, Washington 98101, USA; email: nanibaa@uw.edu

<sup>3</sup>Faculty of Māori and Indigenous Studies, University of Waikato, Hamilton 3240, New Zealand; email: maui.hudson@waikato.ac.nz

<sup>4</sup>Department of Medical Genetics, University of British Columbia, Vancouver, British Columbia V6H 3N1, Canada; email: leah.ballantyne@ubc.ca

<sup>5</sup>James E. Rogers College of Law, University of Arizona, Tucson, Arizona 85721, USA

<sup>6</sup>Native Nations Institute, Udall Center for Studies in Public Policy, University of Arizona, Tucson, Arizona 85719, USA; email: garbai@email.arizona.edu, andrewmartinez@email.arizona.edu, scrainie@email.arizona.edu

<sup>7</sup>Center for Health Research, Kaiser Permanente, Honolulu, Hawaii 96817, USA; email: maile.m.taulii@kp.org

<sup>8</sup>Division of Medical Sciences, University of Victoria, Victoria, British Columbia V8W 2Y2, Canada; email: larbour@uvic.ca

<sup>9</sup>Department of Surgery and Northern Medical Program, University of British Columbia, Prince George, British Columbia V2N 4Z9, Canada

<sup>10</sup>Centre for Excellence in Indigenous Health, University of British Columbia, Vancouver, British Columbia V6T 1Z3, Canada

<sup>11</sup>Canada's Michael Smith Genome Sciences Centre, BC Cancer Agency, Vancouver, British Columbia V5Z 1L3, Canada; email: nadine.caron@ubc.ca

<sup>12</sup>Mel and Enid Zuckerman College of Public Health, University of Arizona, Tucson, Arizona 85724, USA

Annu. Rev. Genom. Hum. Genet. 2019. 20:6.1–6.23

The *Annual Review of Genomics and Human Genetics* is online at [genom.annualreviews.org](http://genom.annualreviews.org)

<https://doi.org/10.1146/annurev-genom-083118-015434>

Copyright © 2019 by Annual Reviews.  
All rights reserved

### Keywords

Indigenous, genomics, data sovereignty, data governance, bioethics, policy

### Abstract

Indigenous scholars are leading initiatives to improve access to genetic and genomic research and health care based on their unique cultural contexts



and within sovereign-based governance models created and accepted by their peoples. In the past, Indigenous peoples' engagement with genomic research was hampered by a lack of standardized guidelines and institutional partnerships, resulting in group harms. This article provides a comparative analysis of research guidelines from Canada, New Zealand, Australia, and the United States that pertain to Indigenous peoples. The goals of the analysis are to identify areas that need attention, support Indigenous-led governance, and promote the development of a model research policy framework for genomic research and health care that has international relevance for Indigenous peoples.

## INTRODUCTION

Genomic research has long-standing problems with diversity, especially for Indigenous peoples. Indigenous populations face health and socioeconomic inequities and barriers to health care that result in poorer health outcomes compared with those of non-Indigenous groups (3). While genomic research has advanced health outcomes in mainstream populations, the dearth of relevant genomic research for Indigenous peoples stands to increase health and health-care inequities. Indigenous people are underrepresented in genome-wide association studies conducted worldwide, estimated at 0.06% in 2009, 0.05% in 2016, and 0.02% in 2019 (10, 59, 68, 74). Furthermore, there is a lack of reference variant data from these populations for the interpretation of targeted gene panels and genomic sequencing. For example, the Genome Aggregation Database (gnomAD; <http://gnomad.broadinstitute.org/about>) includes reference exome and genome variant information on more than 141,000 individuals globally (29) and is often utilized to assist in clinical genomic variant analysis, but it lacks information about Indigenous populations. Consequently, the population frequency of variants detected in sequencing is not known for Indigenous populations, resulting in potentially less precise diagnostic results compared with those for well-represented populations. Unequal access to genomic technologies, negative socioeconomic determinants, and lack of relevant population genetic variation data all contribute to the limited relevance and reduced effectiveness of genetic and genomic research for Indigenous peoples.

Indigenous communities have been the subject of western science and research for centuries. Unethical behavior, lack of clear communication, disrespect of cultural and spiritual beliefs, and a failure to address the interests and priorities of particular Indigenous communities and their membership have created an environment of mistrust between researchers and Indigenous communities (101). In addition to mistrust, fatigue from years of being studied with no benefit or return of results, exploitation of potentially patentable genetic material, and co-optation and theft of traditional knowledge (e.g., medicinal plants) and other intellectual property (19, 35) have resulted in Indigenous peoples' hesitancy to participate in genetic and genomic research and clinical testing when it is available. Harms from research also create a barrier to involvement, as tribes have experienced disrespect and harm to their dignity, lack of community benefits (e.g., health care), and injustices in the misuse of samples and protected information (84). For example, some Indigenous communities have experienced harms from genetic research that traces human origins or interprets results in ways that stigmatize groups. For tribes that have not participated in research, obstacles include limited resources to recruit ethical scientists for their projects, lack of experience with research, and limited health literacy to evaluate risks and benefits of research participation.

How do we bridge between the lessons of past flawed genomic research practices and a future with better practices? Recognition and understanding of sovereignty is fundamental

6.2 Garrison et al.

Review in Advance first posted on  
March 20, 2019. (Changes may  
still occur before final publication.)



for relationship building and must be reflected in genetic and genomic research frameworks. Sovereignty, or self-determination, is the inherent right and capacity of Indigenous peoples to develop culturally, socially, and economically along lines consistent with their respective histories and values. Through efforts such as community-engaged research, effective guidelines, and policies assuring Indigenous communities that their interests are protected, more Indigenous leaders, communities, and individuals may participate. Resources are emerging to help tribal communities make decisions about genetic research (14, 61, 63, 85), resulting in the establishment of tribal research review boards to evaluate research studies. Systematic efforts to fully engage Indigenous groups can promote equity in genomic research by creating ways for Indigenous peoples and researchers to collaborate in developing ethical research practices and honoring community interests. The emergence of large-scale projects that plan to recruit large numbers of people in order to study genetic diversity and address medical issues, such as the *All of Us* Research Program in the United States (20) and the UK Biobank resource (11), presents grand challenges for the active inclusion of Indigenous peoples in genomic research.

Indigenous peoples have been subjected to genetic and genomic research for decades. In recent years, they have begun to establish stronger mechanisms for protecting their rights and interests. The issues and concerns that Indigenous peoples have faced in genomic research are strikingly similar around the world. Throughout Canada, New Zealand, Australia, and the United States, Indigenous scholars and policy advocates are leading initiatives to improve access to genetic and genomic research and health care based on their unique cultural context and within governance models acceptable to their peoples. These countries have also endorsed the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). UNDRIP acts as a framework for recognizing and respecting both the human rights and the self-determination of Indigenous communities (94). UNDRIP does not create new rights for Indigenous peoples; rather, it elaborates on existing human rights instruments while clarifying their application to Indigenous peoples to include genetic and genomic research. For example, Article 31 states, “Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, including human and genetic resources” (94). In this article, we aim to identify the common challenges that Indigenous peoples face in genomic research and how to address them.

## INDIGENOUS PEOPLES' EXPERIENCES WITH GENETIC RESEARCH

Concerns about lack of engagement, inadequate informed consent, fear of exploitation, and group harms in genetic research are long-standing. Communities that interface with genetic research often worry about their samples being misused or research results being presented in stigmatizing ways. Here, we highlight three examples in which genetic research has resulted in harms to Indigenous communities: lack of community engagement, lack of informed consent for secondary research, and negative representation in publications. The cases below illustrate a vivid narrative landscape rife with reasons for Indigenous peoples' reluctance to participate in genomic research.

### Lack of Community Engagement

Building strong relationships with Indigenous communities before research commences is critical for creating a strong foundation for any research (18). Community engagement principles alongside open dialogue and collaboration should be incorporated into an overall research policy framework. Early community engagement allows for mutually beneficial dialogue regarding the research goals and methods, which increases the potential benefits to both researchers and the

community and can lead to successful genetic research. Such activities build trust and can enhance research participation throughout the study's duration.

Two large-scale efforts to study human migrations around the world through DNA mapping received pushback from Indigenous scholars and communities. First, in the 1990s, genetic and anthropological researchers from the Human Genome Diversity Project were “racing the clock” (78, p. 1614) to collect DNA samples from “isolates of historical interest” (35, p. 24), such as the “Yanomami Indians of the Amazon rainforest, who [were] literally becoming extinct” (78, p. 1614), without considering whether these types of projects were even of interest to the targeted populations (76). Many tribes became distrustful and accused researchers of dropping in to collect samples and leaving shortly after, never to be heard from again (so-called helicopter or vampire research). Several Indigenous organizations called for a halt to these DNA collection efforts, citing a legacy of distrust (35, 81). At the peak of the controversy between project organizers and Indigenous protestors, Dr. Frank Dukepoo, a Hopi geneticist, eloquently described his view of DNA: “To us, any part of ourselves is sacred. Scientists say it’s just DNA. For an Indian, it is not just DNA, it is part of a person, it is sacred, with deep religious significance. It is part of the essence of a person” (73). The significance of blood to many people is integral to their sense of identity and cultural cohesion. In a similar vein, National Geographic’s Genographic Project launched in 2005 and targeted Indigenous peoples with a similar sense of urgency, raising concerns from a number of Indigenous people (34, 77, 87, 88). Large-scale efforts to map human migrations have not been of interest to many Indigenous peoples, who constantly feel that their resources are under threat and see no benefit in participating.

### Lack of Informed Consent for Secondary Use

As emerging genomic research incorporates larger data sets and as researchers are encouraged to share data, concerns have arisen around appropriate and fully informed consent. Biospecimen collection requires respecting any property, including Indigenous biospecimens and biodata. The collection of samples must include the free, prior, and informed consent of the Indigenous communities involved (94, 100). This entails early engagement, participatory procedures, and ongoing consultation with Indigenous communities before and during participant recruitment and throughout the research process.

**The Havasupai Tribe in Arizona, USA.** In the 1980s, Havasupai tribal leaders approached a trusted anthropologist, Dr. John Martin, with whom they had a long-standing relationship, to help address rampant diabetes in their community. In 1989, he brought a genetic researcher, Dr. Therese Markow, from Arizona State University to collect DNA samples and perform genetic studies. The research project was designed to offer direct benefit in the form of community education on diabetes, but the researchers did not establish a genetic link to diabetes. Without approval from the tribe, Markow and other researchers subsequently used the DNA samples for unrelated studies on schizophrenia, migration, and inbreeding, all of which are taboo for the Havasupai. While the researchers initially took steps to build trust and engage the community, these steps did not neutralize the unethical steps that led to an egregious breach of community trust and a subsequent lawsuit.

Carletta Tilousi, a study participant, learned in 2003 that the samples were used for studies well beyond the initial diabetes research, without tribal approval. She became the lead plaintiff when the Havasupai Tribe filed a lawsuit in 2004 against the Arizona Board of Regents and researchers for misuse of DNA samples and lack of informed consent (80), alleging that the researchers’ actions resulted in “cultural, dignitary, and group harm to the participants” (25, p. 176). The case

6.4 Garrison et al.

Review in Advance first posted on  
March 20, 2019. (Changes may  
still occur before final publication.)



settled in April 2010, with the university agreeing to provide financial compensation, scholarships and assistance to obtain funds for a clinic and school, and, most significantly, the return of their DNA samples (2, 32, 36, 57). The progression of events during the research study and subsequent litigation demonstrates a failure to identify risks and harms to Native American tribes (25, 36). Even after the settlement, Dr. Markow maintained that there was no wrongdoing and that she obtained consent for “behavioral/medical problems” (36, p. 1). Such lingering disagreement emphasizes the need for transparent community dialogue.

**The Nuu-chah-nulth in British Columbia, Canada.** A similar case took place in Canada, where the Nuu-chah-nulth people learned that their DNA samples, collected to study rheumatoid arthritis, were instead used for studies on human migration and retroviruses (105). In the 1980s, the Nuu-chah-nulth hoped to learn why they were affected with arthritis so frequently and severely (5). They provided more than 800 blood samples to a genetic researcher, Dr. Ryk Ward, at the University of British Columbia (24). The research was carried out collaboratively but was never completed, reportedly because the database linking medical phenotypes to the blood samples crashed. The serum samples were then processed to isolate DNA, at a time when genetic migration studies were emerging as a tool for anthropological sciences. The samples were subsequently moved to the United States and the United Kingdom as Dr. Ward moved for various academic appointments. The samples were shared with other researchers and used in secondary research by Dr. Ward’s team (98, 99) and others (72) without the knowledge or explicit consent of the Nuu-chah-nulth people (24). Although there was no consent for this secondary research, the migration research was funded through reputable funding agencies, including the National Institutes of Health, and was approved through multiple university ethics review boards.

Dr. Ward and his collaborators published more than 100 papers, many referring to the Nuu-chah-nulth, but did not report results back, as would be expected with community-based methodologies known to anthropologists at the time. The community members became aware of the secondary research after a documentary aired featuring the Nuu-chah-nulth and their historical migration proposed by Dr. Ward’s genetic studies (104). When the tribe learned of the misuses of samples in 2000, tribal officials demanded an explanation for the secondary studies and sought to get the samples back. After Dr. Ward died suddenly in 2003, Dr. Charles Scriver of McGill University contacted the University of Oxford, where the samples were stored. University officials and researchers, including Dr. Laura Arbour of the University of British Columbia, worked with the Nuu-chah-nulth community to recover the blood samples in 2004. During the return of the samples, the Nuu-chah-nulth formed their own research ethics committee to review all research protocols and contributed to the Canadian Institutes for Health Research’s *Guidelines for Health Research Involving Aboriginal People (2007–2010)* (13). The guidelines included the concept of “DNA on loan,” ensuring that participatory research with Indigenous peoples also included the handling, storage, and use of biological samples (13). This case study is an example of community capacity and involvement in policy change that many Indigenous communities and organizations continue to strive for today.

### Negative Representation in Publications

The warrior gene is the most notorious example of genetic research associated directly with the Indigenous Māori population in New Zealand (79). It caused a great deal of consternation and concern among both the Māori community and the genetics community for the lack of care associated with both the scientific rigor (58) and cultural sensitivity (41, 42) of the hypothesis. The researchers, who were working primarily on identifying different phenotypes associated with

high- and low-nicotine metabolism, used the term warrior to hypothesize a connection between population genetics (Polynesian migration routes), social traits (aggressive behavior in monkeys), and health outcomes (Māori rates of smoking cessation). The lack of sensitivity and accountability was heightened by the apparent focus on the Māori population despite the variant being present in all populations, albeit at differing frequencies. The ensuing media storm exacerbated the levels of mistrust that Māori communities harbored toward genomic researchers and made engagement and collaboration on related projects more difficult to initiate (58). The inaccurate association of a specific phenotype with a specific ethnicity created a narrative representation of the Māori as a genetically aggressive population. While this may not have been the intention of the researchers, the desire to promote the study findings and create a compelling story line provided the conditions for controversy.

These examples reflect, but by no means exhaust, the experiences engendering distrust among many Indigenous peoples. They support concerns that the voices of Indigenous peoples regarding genetic and genomic research are suppressed. The issues presented must be addressed with and by Indigenous leadership, in partnership with allies who advocate for the involvement of Indigenous peoples in research about them. The creation and implementation of effective guidelines and policies responsive to Indigenous perspectives can create space for research partnerships that are respectful, ethical, and culturally safe.

## COMPARATIVE ANALYSIS OF RESEARCH GUIDELINES

Despite past research harms, many Indigenous people see potential benefits to participating in genetic and genomic research. However, the decision to participate is often influenced by the availability of appropriate protections. This prompted us to examine existing policies and guidelines pertaining to Indigenous peoples in four countries: Canada, New Zealand, Australia, and the United States. This work builds on three previously published studies that examined policies and guidelines created by Indigenous organizations, professional societies, and federal entities pertaining to Indigenous peoples in research (50, 84, 89). We focus on guidelines, policies, or research codes that address genetic research.

### Guidelines for Genomic Research with Indigenous Peoples

**Table 1** illustrates Indigenous research guidelines across the four countries we are examining. The Canadian Tri-Council Policy Statement (TCPS) was updated in 2010 and again in 2014 (TCPS-2) to guide the ethical conduct of federally funded research in Canada (15). Chapter 9 of TCPS-2 exclusively addresses research involving Aboriginal peoples. New Zealand adopted guidelines for health research with Māori in 2010 (37) and are in the process of drafting and seeking input on new national ethical standards for health and disability research (64), which we include in our analysis. Australia released two updates in 2018 to its *Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities* (65) and *National Statement on Ethical Conduct in Human Research* (66) documents. The United States updated its Federal Policy for the Protection of Human Subjects in 2017, which went into effect in 2018 after two implementation delays (26), and the National Institutes of Health released its Genomic Data Sharing Policy in 2014 (27) and recently sought public input on proposed key provisions. We include the Indigenous Research Protection Act (with “Indigenous” as the country in the tables) because it contains language that has been developed for the goal of protecting Indigenous peoples in research but has not yet been adopted into practice (48).

**Table 1 Indigenous research guidelines in comparison countries**

Country	Title	Year	Author(s)
Canada	<i>Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS-2)</i> (15)	2014	Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada
New Zealand	<i>Guidelines for Researchers on Health Research Involving Māori</i> (37)	2010	Health Research Council
	<i>Draft National Ethical Standards for Health and Disability Research: Consultation Document</i> (64)	2018	National Ethics Advisory Committee
Australia	<i>Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders</i> (65)	2018	National Health and Medical Research Council
	<i>National Statement on Ethical Conduct in Human Research</i> (66)	2018	National Health and Medical Research Council, Australian Research Council, and Universities Australia
United States	Final NIH Genomic Data Sharing Policy (27) <sup>a</sup>	2014	National Institutes of Health
	Federal Policy for the Protection of Human Subjects (26)	2017	Multiple US government agencies
Indigenous	Indigenous Research Protection Act (48)	2000	Indigenous Peoples Council on Biocolonialism

<sup>a</sup>The National Institutes of Health recently solicited public input on proposed key provisions for a future data management and sharing policy.

### Guidelines for Genomic Research with Indigenous Peoples

The original comparison of research guidelines pertaining to Indigenous peoples by Sharp & Foster (84, p. 173) describes “five complementary principles for the collection, use, and storage of biological materials”: community consultation, sample collection and informed consent, use and storage of biological materials, prioritization of research uses, and postresearch obligations. These principles are based on the authors’ analysis of eight research policy statements as well as on insights gleaned from their work with investigators. Two subsequent updates maintained the five principles and 15 associated analytical subcategories (50, 89).

**Table 2** summarizes the intent in the 15 analytical subcategories, modifying some and including several additional items. To address more recent developments in research practice with Indigenous peoples, it rearranges them under four different principles: community engagement, rights and interests, institutional responsibilities, and ethical/regulatory oversight. Our reorganization is prompted by two major developments in genomic research. The first stems from the challenges of governing data in a digitally networked world where policies regarding biological materials have been inadequate for protecting Indigenous research interests. The push within the research community to make raw genetic data widely available in the interest of accelerating discovery and translation [e.g., the 1996 Bermuda Principles (67) and the 2014 National Institutes of Health Genomic Data Sharing Policy (27)] only underscores the importance of addressing this growing divide between Indigenous governance policies for self-determination and increased data sharing for the benefit of science. Considering these factors, we have included data-related analytical subcategories pertaining to access, agreements, and Indigenous codes or protocols. The second change is a shift in emphasis within research regulation from principles and recommendations to governance and mechanisms. Underlying this change is an evolving understanding of Indigenous communities as partners in, rather than merely subjects of, research, as evidenced in the literature surrounding community-based participatory research. The evolution also reflects

Table 2 Comparison of Indigenous research guidelines

	Canada	New Zealand	Australia	United States	Indigenous
<b>Community engagement</b>					
In protocol development	X <sup>a</sup>	X <sup>b,c</sup>	X <sup>d</sup>	NR	NR
Before collection of samples	X <sup>a</sup>	X <sup>b,c</sup>	NR	NR	X <sup>h</sup>
Respect for cultural differences embodied	X <sup>a</sup>	X <sup>b,c</sup>	X <sup>d,e</sup>	NR	X <sup>h</sup>
Potential uses defined prior to sample collection	X <sup>a</sup>	X <sup>e</sup>	X <sup>e</sup>	X <sup>f,g</sup>	X <sup>h</sup>
Discussion of secondary uses with contributors (DI or DC)	DI <sup>a</sup> DC <sup>a</sup>	DC <sup>c</sup>	DI <sup>e</sup>	DI <sup>f,g</sup>	DC <sup>h</sup>
<b>Rights and interests</b>					
Formal community approval required	X <sup>a</sup>	NR	X <sup>d,e</sup>	X <sup>f</sup>	X <sup>h</sup>
Secondary uses require community approval	X <sup>a</sup>	NR	X <sup>e</sup>	NR	X <sup>h</sup>
Should benefit contributing population	X <sup>a</sup>	X <sup>e</sup>	X <sup>d,e</sup>	X <sup>g</sup>	X <sup>h</sup>
Clear position on commercial applications	X <sup>a</sup>	X <sup>e</sup>	X <sup>e</sup>	NR	X <sup>h</sup>
Cultural review (in a culturally sensitive manner)	X <sup>a</sup>	X <sup>b,c</sup>	X <sup>e</sup>	NR	X <sup>h</sup>
<b>Institutional responsibilities</b>					
Provision for withdrawal of samples (IW or CW)	IW <sup>a</sup> CW <sup>a</sup>	IW <sup>c</sup>	IW <sup>e</sup> CW <sup>e</sup>	IW <sup>f,g</sup>	CW <sup>h</sup>
Ongoing research updates to participating communities	X <sup>a</sup>	X <sup>e</sup>	X <sup>d</sup>	NR	X <sup>h</sup>
Need to develop and implement Indigenous guidelines	X <sup>a</sup>	X <sup>e</sup>	X <sup>d</sup>	NR	X <sup>h</sup>
Community review of study findings before release	X <sup>a</sup>	X <sup>b,c</sup>	NR	NR	X <sup>h</sup>
Biobanking (agreements, plans, etc.)	X <sup>a</sup>	X <sup>e</sup>	X <sup>e</sup>	X <sup>g</sup>	X <sup>h</sup>
Data-sharing agreements	X <sup>a</sup>	X <sup>e</sup>	X <sup>e</sup>	X <sup>f</sup>	X <sup>h</sup>
<b>Ethical/regulatory oversight</b>					
Possible collective harm (e.g., group discrimination) discussed as part of informed consent process	X <sup>a</sup>	X <sup>b,c</sup>	X <sup>d,e</sup>	X <sup>f,g</sup>	X <sup>h</sup>
Sanctions for misuse of samples or data	NR	NR	NR	X <sup>f</sup>	X <sup>h</sup>

Abbreviations: X, discussed in reference; NR, not discussed in reference; IW, individual withdrawal; CW, community withdrawal; DI, discussion held with individual; DC, discussion held with community.

<sup>a</sup>*Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (15).

<sup>b</sup>*Guidelines for Researchers on Health Research Involving Māori* (37).

<sup>c</sup>*Draft National Ethical Standards for Health and Disability Research: Consultation Document* (64).

<sup>d</sup>*Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders* (65).

<sup>e</sup>*National Statement on Ethical Conduct in Human Research* (66).

<sup>f</sup>Final NIH Genomic Data Sharing Policy (27).

<sup>g</sup>Federal Policy for the Protection of Human Subjects (26).

<sup>h</sup>Indigenous Research Protection Act (48).



broader developments in international law pertaining to Indigenous peoples. UNDRIP expresses that Indigenous peoples have the right and capacity to choose paths of development that are consistent with their respective histories, values, and aspirations, including in the area of health.

The focus on governance and mechanisms steers the discussion toward responsibilities and responsible parties, an emphasis that shapes the choice of our organizing principles. The four principles align in varying degrees with various stakeholders in genomic research and an increasing expectation from Indigenous communities that research organizations be accountable for their actions. The alignment between responsibility and the stakeholder is more a reflection of the stakeholder's knowledge, interest or concern, and capacity than it is a rigid assignment of duty. This is especially true given the complexity of genomic research and differences in regulatory environments across the countries surveyed. Hence, in **Table 2**, community engagement is regarded as a bilateral relationship-building process and aligns with both Indigenous peoples and researchers, ensuring that research respects the values of the community. Rights and interests represent an assertion of authority over the use of samples and data, which should be the responsibility of Indigenous peoples. Institutional responsibilities align with researchers and sponsors, who should adopt policies and practices that build trust and accountability with Indigenous communities. Finally, ethical/regulatory oversight reflects the responsibilities of funders, sponsors, or other third parties to maintain the trust of Indigenous communities in the integrity of the research system.

Other efforts to bridge the gap and help guide ethical research engagement with Indigenous communities include the development of a framework by Indigenous geneticists that proposes six key considerations for respectful engagement and necessary steps to promote inclusion and equity: understanding sovereignty and research regulation, engaging with the community, building cultural competency, improving transparency, and disseminating research findings in appropriate ways (18). These principles can be implemented by recognizing the importance of sovereignty and the rights of Indigenous peoples.

While many policies in our analysis provide protections for sample collection, secondary uses, benefits, and withdrawal from the research, there is less consistency in coverage for other aspects pertaining to protecting the cultural aspects, rights, and interests of Indigenous peoples. In this analysis, the United States falls behind other countries on policies pertaining to Indigenous peoples. The US Federal Policy for the Protection of Human Subjects recognizes the exercise of tribal sovereignty via tribal lawmaking that may dictate additional protections (26), and genomic data-sharing policies allow several exceptions for tribes (27), but the United States has not created any enforceable policies focusing on Indigenous research, as other countries in our analysis have done. In the next section, we describe examples of how the main principles in **Table 2** have been implemented in Indigenous communities involved in genetic or genomic research.

## CURRENT EFFORTS TO BRIDGE THE GAP

As tribes took note of the research misconduct that took place with Havasupai and Nuu-chah-nulth biospecimens, many enacted restrictions, bans, or stronger research ethics oversight on a wide range of research within their nations (2, 60). Yet many Indigenous peoples are generally supportive of research and see its potential benefits, provided that they have control over primary and secondary uses of biological samples and associated data. Individual informed consent, collective rights, tribal sovereignty, and self-determination must all be addressed in genetic and genomic research frameworks. An example established in Canada is how First Nations communities can adopt the principles of OCAP® (Ownership, Control, Access, and Possession), which is a registered trademark of the First Nations Information Governance Centre (FNIGC) and establishes principles as standards regarding First Nations data (28, <http://www.fnigc.ca/OCAP>).

First, Indigenous peoples have a right to develop economically, socially, and culturally on their own terms. Although phrased broadly, this right protects Indigenous peoples against approaches to community engagement in genomic research that overlook their internal resources and assets (e.g., traditional knowledge, spiritual beliefs, values, and modes of social organization) in policies and procedures. For example, Indigenous understanding of the human body requires serious consideration in the formulation of genomic research frameworks, rather than reflexive dismissal or treatment as a barrier or inconvenience. Incorporating this right into policy could include that tissue or data derived from tissue remain the sole property of the person donating, even after collection and the transfer of material to a research facility.

Second, trends in genomic research are moving toward greater recognition of Indigenous control, if not ownership, of collected specimens (21, 30, 51). For instance, the model of DNA on loan influenced by the Nuu-chah-nulth case was adopted by the Canadian Institutes for Health Research in its guidelines for health research involving Aboriginal peoples, with researchers being in a position of stewardship with respect to collected specimens and the Indigenous community retaining ownership (4, 13, 55). These concepts were integrated into the broader TCPS on ethical conduct for research involving humans, which governs research in Canada that is funded through the three major national funding agencies (15). In the United States, the Havasupai case has raised new ethical and legal questions regarding ownership, use, and control of research specimens, prompting more careful attention to broad consent language for human subjects research (26). In one study, Alaska Native respondents proposed including options for special instructions on consent forms such as the destruction of specimens by a predetermined date or upon the donor's death (40). Other proposed modifications to consent forms involve creating options for returning specimens after testing or other research uses (70).

Third, researchers engaging Indigenous communities in genomic research have a responsibility to recognize, respect, and engage Indigenous representatives and abide by local research regulations (18). These persons and bodies are a crucial means of securing self-determination for their communities. Especially for genetic and genomic research, in which findings can affect entire populations, an established best practice is to seek prior agreement of the community through its representatives before seeking informed consent from its individual members (4). Some commentators have suggested a more robust expression of self-determination for research involving genomic data—for example, advocating intersovereign accords over the protections offered under current US federal law (e.g., the Common Rule) (31, 51). The following sections describe current efforts to bridge the gap between previous research that resulted in mistrust, violations, and restrictions or bans on research, and emerging research practices that respect and are guided by Indigenous peoples' rights and interests.

### Fostering Community Engagement

Community engagement and outreach activities come in many forms, such as speaking the language of the community, addressing community priority areas, and reporting research results back, all of which can have meaningful impacts on communities. Researchers should strive for creativity in communication that could incorporate culturally relevant examples, metaphors, or even new terminology in the community's language so that community members can understand the research goals and procedures. An interdisciplinary team that includes Indigenous scientists can foster trust and mutual respect and can allow for them to act as cultural navigators, which may increase capacity for ongoing research. Sowing the seeds for future Indigenous scientists is a benefit of community-engaged research that should not be underestimated. Being open to the communities' perspectives about research findings may offer new insights about the interpretations, which

6.10 Garrison et al.

Review in Advance first posted on  
March 20, 2019. (Changes may  
still occur before final publication.)



could empower the community and allow for more robust interactions. As Indigenous peoples represent a range of preferences, cultures, and views, it is important to take a global look at Indigenous community perspectives and experiences with genetic and genomic research. Addressing the concerns from Indigenous peoples through higher levels of engagement can address the genomic research gap.

**Community protocol development.** Several genomic research studies that have engaged with Indigenous peoples and communities have built strong partnerships. Both Canada and New Zealand have policies that respect community engagement through mutual protocol development, including defining potential uses prior to sample collection and discussions on the secondary uses of samples. In New Zealand, a progressive policy environment that supports both collaborative research platforms and Māori participation in research has contributed to an increasing number of community partnerships. Genomics Aotearoa is a multi-institutional advanced genomics platform that focuses on building capacity in genomics, bioinformatics, and *te ao Māori* (engagement with Māori). Genomics Aotearoa has committed to embedding New Zealand's guidelines in its activities and building an Indigenous genomics platform that consists of infrastructure for a Māori genome data repository as well as policies and processes to support the development of better community partnerships. Australia and the United States do not have research guidelines to engage Indigenous communities prior to the collection of samples, and the United States is additionally silent on research ethics for the protocol development and respect for cultural differences embodied in the relationship between researchers and Indigenous communities or individuals. Despite a lack of guidance, some investigators take the initiative to engage research participants and their communities in shaping the research questions to develop strong partnerships and research protocols. One such example is the Pharmacogenomics Research Network, in which investigators partnered with the Yup'ik people in Alaska to discuss what research studies should be prioritized in their communities. After several years, the research project began to explore the genetic basis for obesity. When the community recognized a need to develop genetic terminology in the Yup'ik language, the researchers supported their efforts to learn about genetics and develop new language (102).

**Promoting Indigenous-led initiatives in genomics.** As Indigenous peoples are becoming experts in genomics, bioethics, and policy, they are being positioned to lead research in genomics. One such example is the Silent Genomes project, a four-year grant funded predominantly by Genome Canada and the Canadian Institutes for Health Research with the goals of reducing health-care disparities and improving diagnostic success for children with genetic diseases from Indigenous populations. The project emphasizes and promotes Indigenous-led governance, community engagement, community education, and student capacity building. Silent Genomes partners with multiple Indigenous organizations across Canada and includes an International Indigenous Genomics Advisory Committee comprising Indigenous scholars grappling with similar issues. The project includes experts in Indigenous health, clinicians, genetic counselors, bioinformaticians, and other scientists with the collective goal of improving access and the effectiveness of genetic diagnosis for Indigenous children with single-gene disorders. To accomplish these goals, the project focuses on four key activities: (a) integrating Indigenous-led governance, community engagement, community education, and student capacity building across all activities; (b) improving access to and utilization of precision genomic diagnosis for Indigenous children; (c) developing a First Nations background variant library as a reference to allow effective precision diagnosis; and (d) studying the economic impact of activities b and c.

Silent Genomes promotes Indigenous-led governance of the project and includes the development of a model research policy framework that considers international relevance for best



practices of genomic research and health care where Indigenous peoples are involved. Additionally, it will support Indigenous students and scholars in receiving mentorship and training in Indigenous population health practices, including mixed-methods epidemiology, enhanced knowledge of First Nations data governance and the role of genomics in health care, and applied skill building in real work settings.

**Specifying potential uses through free, prior, and informed consent.** Such community-led initiatives can be further enhanced through the direct inclusion of UNDRIP articles into research frameworks; Article 18, for example, calls for the Indigenous community's right to participate in decision-making matters through representatives chosen by themselves. Furthermore, the research team should consult and cooperate in good faith with the Indigenous peoples, integrating their own processes of research approval in order to obtain their free, prior, and informed consent before adopting any administrative measures. In practical terms, free, prior, and informed consent means that the research team must create space for ethical review boards or committees and collaborate on consensus between the Indigenous community and research team.

Perhaps if the researchers working with the Havasupai Tribe had had UNDRIP Articles 18 and 19 to guide them, they could have avoided harming members of the tribe. The poignant statement made by study participant and tribal member Carletta Tilousi exemplifies the importance of collaboration and consultation: "I'm not against scientific research. I just want it to be done right. They used our blood for all these studies, people got degrees and grants, and they never asked our permission" (33). The Havasupai case settlement left no legal precedent surrounding informed consent, creating ambiguity for researchers and research regulatory boards on best practices for informed consent, particularly when broad language is used. But even so, lessons learned from this broken trust can inform and guide researchers on how to respectfully and legally partner with Indigenous communities. Consent is required in relation to research involving biospecimen collection and all genetic and genomic research within Indigenous communities worldwide.

### Understanding Rights and Interests

Indigenous data sovereignty is the right of Indigenous peoples and nations to govern the collection, ownership, and application of data about their peoples, lands, and resources (95). It builds on the discourse of research ethics, cultural and intellectual property rights, and Indigenous rights, asserting that Indigenous data should be subject to Indigenous governance. Indigenous data include any information and knowledge, in any format, about Indigenous peoples, lands, or resources that affect Indigenous lives at the collective and/or individual level (75, 97). The nature of Indigenous rights and interests in data is currently being articulated through a variety of formal Indigenous-led, nation-based networks in New Zealand (Te Mana Raraunga, the Māori Data Sovereignty Network; <https://www.temanararaunga.maori.nz>), Australia (the Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective; <https://www.maiamnayriwingara.org>), the United States (the US Indigenous Data Sovereignty Network; <http://usindigenoudata.arizona.edu>), and emerging collectives in Canada, Scandinavia, and Latin America. These networks are creating principles for Indigenous data sovereignty and Indigenous data governance to inform the appropriate management and sharing of data (62, 91, 95).

What do these principles have to do with genomics? Fundamentally, Indigenous data sovereignty affirms the rights and interests of Indigenous peoples in relation to genomic data and underscores the necessity of engaging with Indigenous peoples, not merely in a consultative way, but rather as partners and knowledge holders informing how others steward Indigenous

6.12 Garrison et al.

Review in Advance first posted on  
March 20, 2019. (Changes may  
still occur before final publication.)



biospecimens and genomic data. Taken as a whole, these themes reflect the shift described by Winickoff (103), who suggested that partnership governance is required for genomic research to move the focus from benefit sharing to power sharing. In the context of genetic research, Indigenous data include data from biological specimens, genetic sequences, annotated clinical data, and genealogies. Expectations of Indigenous data governance anticipate Indigenous values informing the stewardship and control of the genetic data wherever they are stored (7, 43, 75, 97). The networks offer preexisting contacts for research entities to find appropriate partners and Indigenous academics to engage with Indigenous perspectives, insert those perspectives into genomics practices and biobanking, train Indigenous genomics scholars, and increase community engagement and capacity. The implementation of Indigenous data sovereignty principles in the governance of Indigenous data through guidelines and practices will enhance the cultural responsiveness of biobanks and data repositories and increase Indigenous genomic research participation while protecting and honoring the rights and interests of Indigenous peoples in relation to their data.

**Respect for withdrawal and management of biospecimens.** For some Indigenous peoples, it is important to ensure that biomedical samples can be returned at the end of the study so that the specimens can be reunited with the people who provided them, to avoid a cultural state of feeling “fragmented” (82). To address this, researchers should ask participants how they want their samples handled at the conclusion of the study or if a research participant passes away. Options could include long-term storage in a biobank, destroying the samples, or returning them so that they are not left in a freezer beyond the lifetime of the participant. If DNA samples remain in a freezer, some Indigenous peoples believe that as their spirit transitions to the next world, they run the risk of not being whole because their DNA sample is not with their body (82). A comparison of tribal research and specimen policies reiterated both the diversity of views within Indigenous communities and the importance of culturally specific protocols to enhance respect and trust (6). In New Zealand, protocols have been established for the culturally appropriate collection and disposal of samples (22, 54). The importance of having a personal choice regarding such management within the spectrum of the Indigenous lens is vital for preserving trust and demonstrating respect for research participants.

Prompted by the transgressions in research with the Nuu-chah-nulth, Arbour & Cook (4) advocated for DNA on loan, such that participants dictate how their samples are used in research studies for which consent was obtained, and the biological materials do not become the property of the researchers or the researchers’ institutions; instead, ownership of the materials remains with the participant or community. This concept challenges the dominant view of ownership in research studies and promotes responsible stewardship that can build trust between researchers and tribal community members, which in turn can make them more apt to participate in other research projects. While many researchers disclose that benefits to participants may not be direct, tangible, or timely, given the historical abuses, researchers should also consider that benefits from their efforts at practicing research ethically will build trust and pay off over time.

**Ongoing research updates to participating communities.** Lack of research updates and engagement prompted the San people in southern Africa to develop a code of ethics. The San are an Indigenous group of approximately 100,000 people living in five southern African countries, the majority in Botswana, Namibia, and South Africa. The San have been studied extensively by scientists researching questions on the group’s traditional medicines, languages, and hunting–gathering lifestyle among other topics, often with minimal benefits to the San communities (1, 23). More recently, the community has been of special interest to scientists conducting genetic research among southern African populations (17, 23). In 2009, a group of researchers began the process of



obtaining individual consent and samples for whole-genome and exome sequencing of four older San men and a black South African man after approval from institutional ethics review boards and the Namibian government (12, 17, 83).

Following publication of the results in *Nature* in 2010 (83), elected San leadership criticized the study's findings for various reasons. Concerns included use of a derogatory term for the San ("Bushmen"), failure to obtain collective consent before securing individual consent, publication of findings unrelated to genomic research, breaches of privacy, inadequate ethics review, and inattention to existing Indigenous research protocols (17). San leadership made multiple requests for information on the informed consent process from the authors, but the authors did not recognize the need to engage the San collectively through their traditional governance mechanisms, bodies that often are not fully recognized by their national governments (17). In response, San leaders organized a series of consultative workshops and entered partnerships with scientists, ethicists, and lawyers to draft and publish an ethics code. Published in 2017 (69), the code has five sections: respect, honesty, justness and fairness, care, and process. The code takes a broad approach, while addressing the specific issues raised by the *Nature* publication, such as respectful engagement, insulting language, prepublication consultation, and community consent. Publication of the code brought increased awareness to research engagement and ethical practices, thus raising expectations of researchers to abide by it and respect the communities' preferences about research.

**Developing and implementing Indigenous guidelines.** There is an emerging body of literature from Indigenous academics promoting different strategies for enhancing engagement and describing what good research practice looks like for genomic research with Indigenous communities (18, 53, 90, 93). Over time, these good practices are codified in the form of guidelines; prime examples are *Te Mata Ira: Guidelines for Genomic Research with Māori* (44) and *He Tangata Kei Tua: Guidelines for Biobanking with Māori* (43). These documents were developed on the foundation established by *Te Ara Tika: Guidelines for Māori Research Ethics* (45), which provides general advice for best practices in health research with Māori. The guidelines describe the cultural logic that underpins Māori concepts and how they relate to the context of biobanking and genomic research (47). They identify the key issues for Māori communities and provide a framework that researchers and communities can use to discuss them (7, 46). The guidelines have been adopted by genomic research groups (38) and Genomics Aotearoa and have also been integrated into New Zealand's draft national ethical standards for health and disability research (64). A genetic resource guide for tribes and researchers has been developed in the United States (<http://genetics.ncai.org>) that poses discussion questions and offers templates for informed consent. However, culturally based guidelines for genomic research have not yet been developed in Canada, Australia, and the United States to support the increasing number of genomic research collaborations in Indigenous communities. Recently, there has been increased discussions about genomic research, biobanking, and a recognized need to develop guidelines.

**Biobanking for future uses.** Biobanks support the formal collection and curation of samples for future use and have become a more important part of the biomedical science infrastructure with the increasing need for large-scale genomic studies. While a number of research studies have historically collected and consented samples for future use, the samples are usually under the control of the researchers without formal governance or independent access protocols. The issues outlined above highlight the inappropriate secondary uses of samples that often arise from a context where the ethical expectations of the researchers differed from those of the community whose samples and data are being used. The informal biobanking nature of these research collections can be contrasted with the more systematic collections and processes associated with formal biobanks.

6.14 Garrison et al.

Review in Advance first posted on  
March 20, 2019. (Changes may  
still occur before final publication.)



There is limited literature explicitly exploring the views of Indigenous communities on biobanking. However, qualitative studies have been conducted to explore perspectives of Indigenous peoples in Alaska, Hawaii, and New Zealand, and discussions are under way with northern First Nations communities in British Columbia, Canada. Alaska Native perspectives on biobanking were explored through focus groups and include a desire to understand the researchers' motivations, a desire for community consent for the overall consent process, concerns about stigmatization, concerns about secondary uses when new technologies are developed, and a desire for appropriate dissemination of research findings to the community (39, 40). Native Hawaiian perceptions of and expectations for biobanking were explored through community workshops and highlighted six themes: biobank governance by the Native Hawaiian community, research transparency, priority of Native Hawaiian health concerns, leadership by Native Hawaiian scientists accountable to the community, re-consent each time a specimen is used, and education of Native Hawaiian communities (90). The study recommended that biobanks in Hawaii develop protocols for participation, governance, and education, guided by six principles that comprise "G.R.E.A.T. Research' (Governance, Re-consent, Education, Accountability, Transparency, Research priorities)" (90, p. 570). In New Zealand, Māori perspectives on biobanking suggest that issues of privacy, ownership, and consent extend beyond those of individual participants to communities of interest (8). The role of individual consent in allowing participants to provide samples for specific projects differs from the collective consent provided by communities in support of the projects being conducted (42). The importance of Indigenous participation in the governance of biobanks was reiterated in the development of the guidelines for biobanking with Māori (7). In Canada, the Northern Biobank Initiative is a research project that aims to create a biobank within northern British Columbia as a genomic research platform to facilitate partnerships in research that will include previously marginalized populations (92). Elements such as a culturally appropriate consent process and First Nations governance structure have been shared in an active consultation process that is now in its third year in partnership with the First Nations Health Authority (<http://www.fnha.ca>).

**Indigenous data governance.** Indigenous data governance mechanisms such as community data management and data-sharing agreements are tools that support sovereignty and self-determination (56). Data-sharing agreements are a formal/legal data governance mechanism that can be used to address the historical issues of data misuse and shift the power balance of research and data usage (52). While the funder may not require a data-sharing agreement, creating one may work in favor of all research partners and yield a better outcome for all parties. Creating data-sharing agreements at the beginning of the research project allows each of the partners to address their concerns, gain a better understanding of their roles and responsibilities, and work to define better short- and long-term outcomes for the research project (52).

For example, the control and ownership of digital data, including data-sharing agreements, are part of the Kahnawà:ke National Indigenous Data Centre established by the Mohawk community of Kahnawà:ke in Quebec. Grand Chief Joseph Tokwirot Norton of the Mohawk Council of Kahnawà:ke stated, "We are leveraging our existing Kahnawà:ke Indigenous Data Sovereignty Centre and working closely with global software companies to become the global leader in Indigenous Cloud, software and secure data management. The key to our success is that the data center is community owned" (J.T. Norton, personal communication). The data center ensures all data, servers, and applications (e.g., encryption keys) are hosted on sovereign territory. Decisions about governance, technical infrastructure, data management, and capacity development are made in partnership with the participating research institution and the host Indigenous community (56). The Mohawk Council of Kahnawà:ke bolstered the data-sharing network through a

formal memorandum of understanding between the university and the council, with the aim of increasing institutional responsibility. Breaches of the protocol result in full review of a project and a possible termination of partnership. Such data-sharing agreements can be examples for emerging guidelines.

### **Ethical and institutional responsibilities.**

Genomic research must be conducted in a manner that respects the rights and interests of Indigenous peoples. Institutions have a range of ethical responsibilities and mechanisms for financial accountability in the context of research that result from national regulations and guidelines through the development of institutional policies and protocols. From consultation policies to institutional review boards, financial protocols to data management agreements, institutions create environments to support ethical research. However, institutional research frameworks are demonstrably not always robust enough to stop unethical behavior, and further development of sanctions is necessary to ensure that research is conducted in a manner consistent with Indigenous ethical values or to stop unethical behavior. Researchers who wish to work with an Indigenous community should investigate whether that community has an established tribal research policy, as these policies may already address questions of collection, control, and ownership of samples or data for research projects.

Breaches of institutional ethical and regulatory policies are guided by institutional research ethics boards but can be bolstered through punitive liability or sanctions. Although the policies in our analysis have provisions to mitigate collective harms, they fall silent on sanctions for misuse of samples or data. Previous sanctions in the Havasupai and Nuu-chah-nulth cases included financial payments through scholarships and repatriation of samples. However, further development of sanctions is necessary. During the community engagement and protocol development stage of an Indigenous-focused research project, liability and sanctions could be designed and implemented directly in genomic research agreements to ensure extra steps for responsible research that prevents collective harm to participating Indigenous communities. Such sanctions might include fines, denial of grant authority, and restrictions on engaging with the community. While sanctions provide punitive opportunity, building positive relationships through measures such as training Indigenous scholars, supporting and promoting Indigenous community governance, and utilizing Indigenous community ethics and values to guide genomic research will bolster ethical and institutional responsibilities.

### **THE FUTURE OF INDIGENOUS GENOMICS**

What does the future of Indigenous genomics look like? First, Indigenous communities' aspirations for self-determination and the scientific need to improve understanding of Indigenous genomics will continue to grow, creating the conditions for both conflict and collaboration. The dystopian future sees the continued disempowerment of Indigenous communities through the appropriation of their genetic heritage. The utopian future shifts the frame from benefit sharing to power sharing, enabling Indigenous-led partnerships through investments in capacity building and infrastructure that support Indigenous community control over the use of Indigenous samples and genomic data.

A more collaborative approach to genomic research will be created through the development of hard (biorepositories and data repositories) and soft (networks and capacity-building initiatives) Indigenous infrastructure. Indigenous-led biorepositories address a fundamental concern expressed by Indigenous communities about the lack of control and governance over the use of



samples and data. They also provide a way of reconceptualizing consent for unspecified future use toward a form of delegated authority, whereby participants choose what organization can store their samples. Researchers could obtain consent for use for their project with the understanding that the samples and data would be lodged with the Indigenous biorepository or data repository at the end of the project.

Partnering in the governance of research and repositories will also create an environment to explore pathways for the repatriation of samples. There are several historical research collections involving Indigenous samples that were consented in times with very different ethical standards. These samples should be returned to their communities of origin with the knowledge that it will be up to the communities to decide whether it is culturally appropriate to dispose of the samples or allow them to be stored in Indigenous biorepositories for future use. Funders, publishers, and journal editors should expect clear statements of provenance and community levels of support in applications and manuscripts. Providing Indigenous communities control over the access and secondary use of samples and genomic data will lead to a corresponding increase in their levels of engagement in projects.

Finally, robust research partnerships provide a path toward ethical publications. In such collaborations, communities' approval, at a minimum, should be sought for publications to protect against the release of sensitive information and inappropriate and harmful statements, and to increase the usefulness of the content. Ideally, community partners and/or Indigenous scholars should be collaborators and coauthors on publications. To increase access to such publications, authors should seek to publish in open access journals or find other mechanisms to ensure community access to publications.

### Genomics Training for Indigenous Peoples

The Summer Internship for Indigenous Peoples in Genomics (SING) is a weeklong workshop aimed at training Indigenous scientists in genomics and bioethics (16). Modeled after the Genetic Education for Native Americans program (9), SING enables Indigenous students and community members to learn about genomics together by providing hands-on experience, integrative lectures, and discussion about the ethical, legal, and social implications of doing genomics with Indigenous communities. The workshop has been hosted at several universities and led by Indigenous faculty or faculty who work with Indigenous communities. The workshop goals are to train Indigenous students and community members in next-generation genomic and bioinformatics analyses and to build capacity for scientific research involving Indigenous communities. Since it began in the United States in 2010, SING has trained more than 100 individuals from Indigenous communities with an interest in genomics in order to empower young scientists to shape genomic research to benefit their communities (16, 96).

The SING program has expanded to New Zealand (Aotearoa) and Canada. SING Aotearoa was established in 2016 with support from the SING USA faculty and has since held four workshops at different universities, all focused on improving the capacity of Māori students and community members to engage with genomic research and genomic researchers (86). More than 50 interns have participated in the program to date, and a recently established SING Alumni Scholarship program provides support for former interns to attend conferences and training events. While the SING program has a primary focus on building capacity in Māori communities, it has also provided a unique opportunity to build capacity among genomic researchers who usually do not have the chance to listen to or participate in discussions about genomics led by Indigenous researchers and communities. Several invited speakers have commented on the value of the workshops and suggested that similar workshops for genomic researchers would be useful.

The first SING Canada was held in 2018 and was designed in consultation with SING USA and SING Aotearoa (49). The workshop introduced advances in decolonial approaches to bioinformatics and the genomic, ethical, environmental, economic, legal, and social implications of genomic research with Indigenous communities and peoples. The workshop included presentations and discussion on epigenetics, genes (genetic diversity, population differentiation, structure, and evolution), and community-driven and collaborative research. Participants were given the opportunity to gain experience in a wet lab, which included DNA extraction and purification that was later used in bioinformatics labs for data analysis and phylogenetic results. Lastly, cultural activities were integrated throughout, including medicine walks, cedar weaving, and opening and closing prayers by local elders.

### Ethics Training for Researchers

Efforts are under way to train researchers in ethics, cultural competency, and communication to help make research more respectful, relevant, reciprocal, responsible, and ethical. The recently released Research Ethics Training for Health in Indigenous Communities Study (rETHICS) has adapted the online Collaborative Institutional Training Initiative research ethics training course aimed at researchers in the United States by developing an alternative training option for federally funded researchers working with Indigenous communities (71). While this curriculum is focused on social science research and needs to extend to biomedical research, it highlights the importance of understanding and respecting community values in order to engage in ethical research.

### Indigenous Data Sovereignty

Indigenous communities are increasingly aware of the value of their genetic resources and the opportunity to benefit from research through access to information, data, and future research partnerships and projects. Community expectations of access to raw data have emerged from the Indigenous data sovereignty movement, and access to future opportunities aligns with international expectations of benefit sharing. Balancing funders' expectations of open data access with community desires for the protection of future opportunities is a real challenge. Working toward a form of acknowledgment and annotation would allow future data users to contact and consult with the relevant Indigenous communities when they wish to access their genomic data from registries. The ability to maintain a connection between Indigenous communities, their genetic resources, and secondary research is central to engagement with innovation and value creation activities.

Opportunities for Indigenous communities to engage in commercialization activities will continue to emerge at the intersection between human and environmental genomics, which includes microbiomes and the genomics of flora and fauna. A fundamental driver of this change will be the increasing number of Indigenous researchers and community members trained in genomics and complementary disciplines. The expansion of Indigenous capacity-building initiatives and Indigenous research networks will drive the growth of collaborative partnerships with Indigenous communities and ensure that genomic science contributes to their development and well-being.

### CONCLUSION

Much has been learned from past practices that did not consider the necessity of including Indigenous voices in matters surrounding biological sample storage or the generation and use of genetic and genomic data. Standards of research practice have evolved and are continuing to

6.18 Garrison et al.

Review in Advance first posted on  
March 20, 2019. (Changes may  
still occur before final publication.)



evolve, ensuring that individual researchers, their funding agencies, and ethics review boards are accountable to Indigenous research participants and their governing bodies. Efforts to develop Indigenous student, researcher, and community capacity are expanding internationally. Supporting Indigenous-led partnerships, improving access to genetic and genomic research and health care based in unique cultural contexts, and promoting the development of a model research policy framework that considers international relevance for best practices provide the path forward for meaningful and ethical engagement with Indigenous peoples and genomic research. As such, Indigenous peoples are increasingly becoming partners in genetic and genomic research and, in many cases, are now leading it.

## DISCLOSURE STATEMENT

N.R.C. is a consultant for the First Nations Health Authority.

## ACKNOWLEDGMENTS

The authors are tremendously grateful to Abigail Hamblett and Danella Hall for their assistance with manuscript preparation. N.A.G. received support from the National Human Genome Research Institute (grant K01 HG008818). L.L.B., N.R.C., and L.A. received partial support from Genome Canada and the Canadian Institutes of Health Research (Genome British Columbia grant 275SIL). S.C.R. received partial support from the National Institute of Environmental Health Sciences (grant P50ES026089) and Environmental Protection Agency (grant R836151). A.M. and S.C.R. received partial support from the Morris K. Udall and Stewart L. Udall Foundation.

## LITERATURE CITED

1. Akst J. 2017. San people write ethical code for research. *Scientist*, Mar. 21. <https://www.the-scientist.com/the-nutshell/san-people-write-ethical-code-for-research-31810>
2. Am. J. Med. Genet. 2010. After Havasupai litigation, Native Americans wary of genetic research. *Am. J. Med. Genet. A* 152A:ix
3. Anderson I, Robson B, Connolly M, Al-Yaman F, Bjertness E, et al. 2016. Indigenous and tribal peoples' health (the Lancet-Lowitja Institute Global Collaboration): a population study. *Lancet* 388:131–57
4. Arbour L, Cook D. 2006. DNA on loan: issues to consider when carrying out genetic research with aboriginal families and communities. *Community Genet.* 9:153–60
5. Atkins C, Reuffel L, Roddy J, Platts M, Robinson H, Ward R. 1988. Rheumatic disease in the Nuu-Chah-Nulth native Indians of the Pacific Northwest. *J. Rheumatol.* 15:684–90
6. Bardill J. 2017. Comparing tribal research and specimens policies: models, practices, and principles. *Int. Indig. Policy J.* 8(4):4
7. Beaton A, Hudson M, Milne M, Port RV, Russell K, et al. 2017. Engaging Maori in biobanking and genomic research: a model for biobanks to guide culturally informed governance, operational, and community engagement activities. *Genet. Med.* 19:345–51
8. Beaton A, Smith B, Toki V, Southey K, Hudson M. 2015. Engaging Maori in biobanking and genetic research: legal, ethical, and policy challenges. *Int. Indig. Policy J.* 6(3):1
9. Burhansstipanov L, Bemis L, Dignan M, Dukepoo F. 2001. Development of a genetics education workshop curriculum for Native American college and university students. *Genetics* 158:941–48
10. Bustamante CD, Burchard EG, De la Vega FM. 2011. Genomics for the world. *Nature* 475:163–65
11. Bycroft C, Freeman C, Petkova D, Band G, Elliott LT, et al. 2018. The UK Biobank resource with deep phenotyping and genomic data. *Nature* 562:203–9
12. Callaway E. 2017. South Africa's San people issue ethics code to scientists. *Nature* 543:475–76



13. Can. Inst. Health Res. 2013. *CIHR guidelines for health research involving Aboriginal people (2007–2010)*. Guidel. Doc., Can. Inst. Health Res., Ottawa, Can. <http://www.cihr-irsc.gc.ca/e/29134.html>
14. Can. Inst. Health Res. 2018. Institute of Indigenous Peoples' Health. *Canadian Institutes of Health Research*. <http://www.cihr-irsc.gc.ca/e/8668.html>
15. Can. Inst. Health Res., Nat. Sci. Eng. Res. Council. Can., Soc. Sci. Humanit. Res. Council. Can. 2014. *Tri-Council Policy Statement: ethical conduct for research involving humans*. Policy Doc., Secr. Responsible Conduct Res., Ottawa, Can. <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default>
16. Carl R. Woese Inst. Genom. Biology. 2018. Summer internship for Indigenous peoples in Genomics (SING). *Carl R. Woese Institute for Genomic Biology*. <https://sing.igb.illinois.edu>
17. Chennells R, Steenkamp A. 2018. International genomics research involving the San people. In *Ethics Dumping: Case Studies from North-South Research Collaborations*, ed. D Schroeder, J Cook, F Hirsch, S Fenet, V Muthuswamy, pp. 15–22. Cham, Switz.: Springer
18. Claw KG, Anderson MZ, Begay RL, Tsosie KS, Fox K, et al. 2018. A framework for enhancing ethical genomic research with Indigenous communities. *Nat. Commun.* 9:2957
19. Cochran PAL, Marshall CA, Garcia-Downing C, Kendall E, Cook D, et al. 2008. Indigenous ways of knowing: implications for participatory research and community. *Am. J. Public Health* 98:22–27
20. Collins FS, Varmus H. 2015. A new initiative on precision medicine. *N. Engl. J. Med.* 372:793–95
21. Crump AD, Etz K, Arroyo JA, Hemberger N, Srinivasan S. 2017. Accelerating and strengthening Native American health research through a collaborative NIH initiative. *Prev. Sci.* In press. <https://doi.org/10.1007/s11211-017-0854-5>
22. Cunningham EH, Cameron VA, Evans J, Irvine V, Pitama S, Robertson P. 2007. The development of guidelines for handling samples and specimens collected for research involving Maori. *N.Z. Med. J.* 120:U2785
23. Daley J. 2017. San people of South Africa issue code of ethics for researchers. *Smithsonian*, Mar. 23. <https://www.smithsonianmag.com/smart-news/san-people-south-africa-issue-code-ethics-researchers-180962615>
24. Dalton R. 2002. Tribe blasts 'exploitation' of blood samples. *Nature* 420:111
25. Drabiak-Syed K. 2010. Lessons from Havasupai Tribe v. Arizona State University Board of Regents: recognizing group, cultural, and dignitary harms as legitimate risks warranting integration into research practice. *J. Health Biomed. Law* 6:175–226
26. Federal Policy for the Protection of Human Subjects, 82 Fed. Reg. 7149 (Jan. 19, 2017)
27. Final NIH Genomic Data Sharing Policy, 79 Fed. Reg. 51345 (Aug. 28, 2014)
28. First Nations Inf. Gov. Cent. 2014. *Ownership, Control, Access and Possession (OCAP™): the path to First Nations information governance*. White Pap., First Nations Inf. Gov. Cent., Ottawa, Can.
29. Francioli L, Tiao G, Karczewski K, Solomonson M, Watts N. 2018. gnomAD v2.1. *MacArthur Lab*, Oct. 17. <https://macarthurlab.org/2018/10/17/gnomad-v2-1>
30. Garrison NA. 2013. Genomic justice for Native Americans: impact of the Havasupai case on genetic research. *Sci. Technol. Hum. Values* 38:201–23
31. Harding A, Harper B, Stone D, O'Neill C, Berger P, et al. 2012. Conducting research with tribal communities: sovereignty, ethics, and data-sharing issues. *Environ. Health Perspect.* 120:6–10
32. Harmon A. 2010. Havasupai case highlights risks in DNA research. *New York Times*, Apr. 21. <https://www.nytimes.com/2010/04/22/us/22dnaside.html>
33. Harmon A. 2010. Indian tribe wins fight to limit research of its DNA. *New York Times*, Apr. 21. <https://www.nytimes.com/2010/04/22/us/22dna.html>
34. Harmon A. 2012. DNA gatherers hit snag: tribes don't trust them. *New York Times*, Dec. 10. <https://www.nytimes.com/2006/12/10/us/10dna.html>
35. Harry D, Howard S, Shelton BL. 2000. *Indigenous People, Genes and Genetics: What Indigenous People Should Know About Biocolonialism, Indigenous Peoples Council on Biocolonialism*. Wadsworth, NV: Indig. Peoples Council. Biocolon.
36. Hart S, Sobraske K. 2003. *Investigative report concerning the medical genetics project at Havasupai*. Unpubl. Investig. Rep., available at Ariz. State Univ. Law Libr., Phoenix

6.20 Garrison et al.

Review in Advance first posted on  
March 20, 2019. (Changes may  
still occur before final publication.)



37. Health Res. Counc N.Z. 2010. *Guidelines for researchers on health research involving Māori*. Guidel. Doc., Health Res. Counc. N.Z., Auckland
38. Hēnare M. 2003. *The changing images of nineteenth century Māori society: from tribes to nation*. PhD Thesis, Victoria Univ. Wellington, Wellington, N.Z.
39. Hiratsuka VY, Brown JK, Dillard DA. 2012. Views of biobanking research among Alaska native people: the role of community context. *Prog. Community Health Partnersh.* 6:131–39
40. Hiratsuka VY, Brown JK, Hoeft TJ, Dillard DA. 2012. Alaska Native people's perceptions, understandings, and expectations for research involving biological specimens. *Int. J. Circumpolar Health* 71:18642
41. Hook GR. 2009. "Warrior genes" and the disease of being Māori. *MAI Rev.* 2009(2). <http://www.review.mai.ac.nz/MR/article/view/222/243.html>
42. Hudson M. 2009. Changing genes: science and being Maori. *MAI Rev.* 2009(2). <http://www.review.mai.ac.nz/MR/article/view/250/254.html>
43. Hudson M, Beaton A, Milne M, Port W, Russell K, et al. 2016. *He tangata kei tua: guidelines for biobanking with Māori*. Guidel. Doc., Māori Indig. Gov. Cent., Univ. Waikato, Hamilton, N.Z. [https://www.waikato.ac.nz/\\_data/assets/pdf\\_file/0019/321535/He-Tangata-Kei-Tua-Biobanking-Guidelines.pdf](https://www.waikato.ac.nz/_data/assets/pdf_file/0019/321535/He-Tangata-Kei-Tua-Biobanking-Guidelines.pdf)
44. Hudson M, Beaton A, Milne M, Port W, Russell K, et al. 2016. *Tē mata ira: guidelines for genomic research with Māori*. Guidel. Doc., Māori Indig. Gov. Cent., Univ. Waikato, Hamilton, N.Z. [https://www.waikato.ac.nz/\\_data/assets/pdf\\_file/0018/321534/Te-Mata-Ira-Genome-Research-Guidelines.pdf](https://www.waikato.ac.nz/_data/assets/pdf_file/0018/321534/Te-Mata-Ira-Genome-Research-Guidelines.pdf)
45. Hudson M, Milne M, Reynolds P, Russell K, Smith B. 2010. *Tē ara tika: guidelines for Māori research ethics: a framework for researchers and ethics committee members*. Guidel. Doc., Health Res. Counc. N.Z., Auckland
46. Hudson M, Southey K, Uerata L, Beaton A, Milne M, et al. 2016. Key informant views on biobanking and genomic research with Maori. *N.Z. Med. J.* 129:29–42
47. Hudson M, Wilcox P, Smith B, Beaton A, Milne M, Russell K. 2018. (C)ELSI-us: reducing friction with indigenous communities in genomic research. *Am. Anthropol.* 120:330–32
48. Indig. Peoples Council. Biocolon. 2000. Indigenous Research Protection Act. *Indigenous Peoples Council on Biocolonialism*. <http://www.ipcb.org/publications/policy/files/irpa.html>
49. Indig. Sci. Technol. Soc. 2018. SING Canada 2018. *Indigenous Science, Technology, and Society*. <http://indigenousts.com/sing-canada/sing-canada-2018>
50. Jacobs B, Roffenbender J, Collmann J, Cherry K, Bitsoi LL, et al. 2010. Bridging the divide between genomic science and indigenous peoples. *J. Law Med. Ethics* 38:684–96
51. James R, Tsosie R, Sahota P, Parker M, Dillard D, et al. 2014. Exploring pathways to trust: a tribal perspective on data sharing. *Genet. Med.* 16:820–26
52. Jarquín PB. 2012. *Data sharing: creating agreements in support of community-academic partnership*. Guidel. Doc., Community Health Data Monit. Comm., Colo. Clin. Transl. Sci. Inst., Aurora, CO
53. Kowal E, Anderson I. 2012. *Genetic research in Aboriginal and Torres Strait Islander communities: continuing the conversation*. Discuss. Pap., Lowitja Inst., Carlton, Aust.
54. Leggat M, Cameron V. 2017. *Kaupapa Maori research protocols information sheet: Multi-Ethnic New Zealand Study of Acute Coronary Syndromes (MENZACS Study)*. Inf. Sheet, Fac. Med. Health Sci., Univ. Auckland, Auckland
55. McInnes RR. 2011. 2010 Presidential Address: culture: the silent language geneticists must learn—genetic research with indigenous populations. *Am. J. Hum. Genet.* 88:254–61
56. McMahon R, LaHache T, Whiteduck T. 2015. Digital data management as indigenous resurgence in Kahnawà:ke. *Int. Indig. Policy J.* 6(3):6
57. Mello MM, Wolf LE. 2010. The Havasupai Indian tribe case—lessons for research involving stored biologic samples. *N. Engl. J. Med.* 363:204–7
58. Merriman T, Cameron V. 2007. Risk-taking: behind the warrior gene story. *N.Z. Med. J.* 120:U2440
59. Mills MC, Rahal C. 2019. A scientometric review of genome-wide association studies. *Commun. Biol.* 2:9
60. Natl. Congr. Am. Indians. 2006. *Supporting the Havasupai Indian Tribe in their claim against the Arizona Board of Regents regarding the unauthorized use of blood samples and research*. Resolut. SAC-06-019, Natl. Congr. Am. Indians, Washington, DC



61. Natl. Congr. Am. Indians. 2012. Genetics research and American Indian and Alaska Native communities. *National Congress of American Indians*. <http://genetics.ncai.org>
62. Natl. Congr. Am. Indians. 2018. *Support of US indigenous data sovereignty and inclusion of tribes in the development of tribal data governance principles*. Resolut. KAN-18-011, Natl. Congr. Am. Indians, Washington, DC
63. Natl. Congr. Am. Indians Policy Res. Cent. 2009. *Research that benefits native people: a guide for tribal leaders*. Curric. Doc., Natl. Congr. Am. Indians, Washington, DC
64. Natl. Ethics Advis. Comm. 2018. *Draft national ethical standards for health and disability research: consultation document*. Consult. Doc., Minist. Health, Wellington, N.Z.
65. Natl. Health Med. Res. Counc. 2018. *Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders*. Canberra: Commonw. Aust.
66. Natl. Health Med. Res. Counc., Aust. Res. Counc., Univ. Aust. 2018. *National Statement on Ethical Conduct in Human Research: 2007 (Updated 2018)*. Canberra: Commonw. Australia
67. Natl. Hum. Genome Res. Inst. 1996. Report of the International Strategy Meeting on Human Genome Sequencing held at the Princess Hotel, Southampton, Bermuda, on 25th–28th February 1996. Available from Duke Univ. Libr., Durham, NC. <http://hdl.handle.net/10161/7715>
68. Need AC, Goldstein DB. 2009. Next generation disparities in human genomics: concerns and remedies. *Trends Genet.* 25:489–94
69. Nordling L. 2017. San people of Africa draft code of ethics for researchers. *Science*, Mar. 17. <https://doi.org/10.1126/science.aal0933>
70. Pacheco CM, Daley SM, Brown T, Filippi M, Greiner KA, Daley CM. 2013. Moving forward: breaking the cycle of mistrust between American Indians and researchers. *Am. J. Public Health* 103:2152–59
71. Pearson CR, Parker M, Fisher CB, Moreno C. 2014. Capacity building from the inside out: development and evaluation of a CITI ethics certification training module for American Indian and Alaska Native community researchers. *J. Empir. Res. Hum. Res. Ethics* 9:46–57
72. Peters AA, Coulthart MB, Oger JFF, Waters DJ, Crandall KA, Baumgartner AA. 2000. HTLV Type I/II in British Columbia Amerindians: a seroprevalence study and sequence characterization of an HTLV type IIa isolate. *AIDS Res. Hum. Retrovir.* 16:883–92
73. Petit C. 1998. Trying to study tribes while respecting their cultures: Hopi Indian geneticist can see both sides. *SFGate*, Feb. 19. <https://www.sfgate.com/news/article/Trying-to-Study-Tribes-While-Respecting-Their-3012825.php>
74. Popejoy AB, Fullerton SM. 2016. Genomics is failing on diversity. *Nature* 538:161–64
75. Rainie SC, Rodriguez-Lonebear D, Martinez A. 2017. *Policy Brief: Data Governance for Native Nation Rebuilding (Version 2)*. [http://usindigenousdata.arizona.edu/sites/usindigenousdata/files/spotlight/files/policy\\_brief\\_data\\_governance\\_for\\_native\\_nation\\_rebuilding\\_v0.5\\_1.pdf](http://usindigenousdata.arizona.edu/sites/usindigenousdata/files/spotlight/files/policy_brief_data_governance_for_native_nation_rebuilding_v0.5_1.pdf)
76. Reardon J. 2005. *Race to the Finish: Identity and Governance in an Age of Genomics*. Princeton, NJ: Princeton Univ. Press
77. Reardon J. 2009. “Anti-colonial genomic practice?” Learning from the Genographic Project and the Chacmool Conference. *Int. J. Cult. Property* 16:205
78. Roberts L. 1991. A genetic survey of vanishing peoples. *Science* 252:1614–17
79. Rochford TS. 2012. Ten reasons why genetics does not explain health disparities between Māori and non-Māori. *New Genet. Soc.* 31:99–110
80. Rubin P. 2004. Indian givers. *Phoenix New Times*, May 27. <https://www.phoenixnewtimes.com/news/indian-givers-6428347>
81. Rural Adv. Found. Int. 1993. *Patents, indigenous peoples, and human genetic diversity*. RAFI Commun., Rural Adv. Found. Int., Ottawa, Can.
82. Sahota PC. 2014. Body fragmentation: Native American community members’ views on specimen disposition in biomedical/genetics research. *AJOB Empir. Bioethics* 5:19–30
83. Schuster SC, Miller W, Ratan A, Tomsho LP, Giardine B, et al. 2010. Complete Khoisan and Bantu genomes from southern Africa. *Nature* 463:943–47
84. Sharp RR, Foster MW. 2002. Analysis of research guidelines on the collection and use of human biological materials from American Indian and Alaskan Native communities. *Jurimetrics* 42:165–86

6.22 Garrison et al.

Review in Advance first posted on  
March 20, 2019. (Changes may  
still occur before final publication.)



85. Simmonds S. 2015. *A framework for Māori review of research in district health boards*. Rep., Auckland Waitemata Dist. Health Boards and Cap. Coast Dist. Health Board, Wellington, N.Z.
86. SING Aotearoa. 2018. Summer internship for Indigenous Genomics Aotearoa. *SING Aotearoa*. <https://www.singaotearoa.nz>
87. TallBear K. 2007. Narratives of race and indigeneity in the Genographic Project. *J. Law Med. Ethics* 35:412–24
88. TallBear K. 2009. Commentary. *Int. J. Cult. Property* 16:189–92
89. Taniguchi NK, Taualii M, Maddock J. 2012. A comparative analysis of indigenous research guidelines to inform genomic research in indigenous communities. *Int. Indig. Policy J.* 3(1):6
90. Taualii M, Davis EL, Braun KL, Tsark JU, Brown N, et al. 2014. Native Hawaiian views on biobanking. *J. Cancer Educ.* 29:570–76
91. Te Mana Raraunga. 2018. *Principles of Māori data sovereignty*. Brief 1, Te Mana Raraunga. Available at <https://www.temanararaunga.maori.nz/new-page-2>
92. TELUS. 2018. Mshkikiiniikwe: building the northern biobank. *YouTube*, July 10. <https://www.youtube.com/watch?reload=9&v=BI6Kc8zPw6c>
93. Tupara H. 2012. Ethics and health research: decision making in Aotearoa New Zealand. *A7OB Prim. Res.* 3:40–52
94. UN Gen. Assem. 2008. *United Nations declaration on the rights of indigenous peoples*. Decl. A/RES/61/295, UN, New York
95. US Indig. Data Sovereignty Netw. 2019. About us. *US Indigenous Data Sovereignty Network*. <http://usindigenousdata.arizona.edu/about-us-0>
96. Wade L. 2018. Bridging the gap. *Science* 361:1304–7
97. Walter M, Lovett R, Bodkin Andrews G, Lee V. 2018. *Indigenous data sovereignty briefing paper 1*. Brief. Pap. 1, Miam nayri Wingara Data Sover. Group and Aust. Indig. Gov. Inst., Acton, Aust.
98. Ward RH, Frazier BL, Dew-Jager K, Pääbo S. 1991. Extensive mitochondrial diversity within a single Amerindian tribe. *PNAS* 88:8720–24
99. Ward RH, Redd A, Valencia D, Frazier B, Pääbo S. 1993. Genetic and linguistic differentiation in the Americas. *PNAS* 90:10663–67
100. Ward T. 2011. The right to free, prior, and informed consent: indigenous peoples' participation rights within international law. *J. Hum. Rights* 10:54–84
101. Warren-Mears V. 2012. *Principles and models for data sharing agreements with American Indian/Alaska Native communities*. Pap., Natl. Congr. Am. Indians, Washington, DC. <http://genetics.ncai.org/files/Principles%20and%20Models%20for%20Data%20Sharing%20Agreements.pdf>
102. West KM, Hopkins SE, Hopper KJ, Mohatt GV, Boyer BB. 2013. Found in translation: decoding local understandings of genetics and heredity in a Yup'ik Eskimo community. *Public Underst. Sci.* 22:80–90
103. Winickoff DE. 2008. *From benefit sharing to power sharing: partnership governance in population genomics research*. Work. Pap., Univ. Calif., Berkeley
104. Wiwchar D. 2000. Genetic researcher uses Nuu-chah-nulth blood for unapproved studies in genetic anthropology. *Ha-Sbilth-Sa*, Sept. 21. <https://hashilthsa.com/archive/news/2013-07-22/genetic-researcher-uses-nuu-chah-nulth-blood-unapproved-studies-genetic-anth>
105. Wiwchar D. 2004. Nuu-chah-nulth blood returns to west coast. *Ha-Sbilth-Sa* 31(25), Dec. 16, pp. 1, 3

