

## Intellectual property and the ethical/legal status of human DNA: The (ir)relevance of context

## La propriété intellectuelle et le statut éthique et légal de l'ADN humain: la (non-) pertinence du contexte

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### Résumé de l'article

Il a beaucoup été question ces dernières années du statut éthique et juridique de l'ADN humain. Ce sujet est d'une grande importance et pertinence pour les communautés autochtones car la question de qui a le droit d'accès à l'ADN des individus et à son contrôle, ou à l'ADN extrait de restes humains, pourrait avoir des implications pour l'ensemble d'une communauté. Dans un autre contexte, la décision d'un individu de contribuer, par un échantillon de sang, à la recherche médicale pourrait en dire long sur l'état de santé des autres membres de la communauté. Qui a le droit de contrôler l'accès à l'ADN ou au récit d'une communauté concernant ses origines? Même si certains ont soutenu que l'ADN humain devrait être considéré comme une propriété culturelle afin de pouvoir assurer le contrôle approprié du code génétique, nous doutons de la validité de cette approche. Bien que nous reconnaissons que les contextes différents dans lesquels l'ADN est extrait et utilisé nécessitent parfois des approches particulières, nous soutenons que l'accent devrait être mis principalement sur la nature des relations établies et entretenues entre les chercheurs et les communautés de descendants, et accessoirement seulement sur le statut unique de l'ADN lui-même.

# Intellectual property and the ethical/legal status of human DNA: The (ir)relevance of context

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Daryl Pullman\*, George P. Nicholas\*\*

**Résumé:** La propriété intellectuelle et le statut éthique et légal de l'ADN humain: la (non-) pertinence du contexte

Il a beaucoup été question ces dernières années du statut éthique et juridique de l'ADN humain. Ce sujet est d'une grande importance et pertinence pour les communautés autochtones car la question de qui a le droit d'accès à l'ADN des individus et à son contrôle, ou à l'ADN extrait de restes humains, pourrait avoir des implications pour l'ensemble d'une communauté. Dans un autre contexte, la décision d'un individu de contribuer, par un échantillon de sang, à la recherche médicale pourrait en dire long sur l'état de santé des autres membres de la communauté. Qui a le droit de contrôler l'accès à l'ADN ou au récit d'une communauté concernant ses origines? Même si certains ont soutenu que l'ADN humain devrait être considéré comme une propriété culturelle afin de pouvoir assurer le contrôle approprié du code génétique, nous doutons de la validité de cette approche. Bien que nous reconnaissons que les contextes différents dans lesquels l'ADN est extrait et utilisé nécessitent parfois des approches particulières, nous soutenons que l'accent devrait être mis principalement sur la nature des relations établies et entretenues entre les chercheurs et les communautés de descendants, et accessoirement seulement sur le statut unique de l'ADN lui-même.

**Abstract:** Intellectual property and the ethical/legal status of human DNA: The (ir)relevance of context

There has been much discussion in recent years about the ethical and legal status of human DNA. This topic is of great relevance and importance to Aboriginal communities because the question of who has the right of access to and control over the DNA of individual persons, or of DNA extracted from human remains, could have implications for an entire community. In another context an individual's decision to contribute a blood sample for health research could reveal much about the health status of other members of the community. Who has the right to control access to DNA or a community's narrative of its origins? While some have argued that human DNA should be considered cultural property in order to ensure appropriate control of genetic information, we question the wisdom of this approach. Although we acknowledge that the differing contexts in which DNA is extracted and utilised could require unique approaches in

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some circumstances, we argue that emphasis should be primarily on the nature of the relationships established and maintained between researchers and descendant communities and only secondarily on the unique status of the DNA itself.

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## Introduction

DNA research offers extraordinary opportunities to learn about the biological basis of humanity, our origins, and our history in unprecedented detail. The benefits to the health sciences, history, and other realms of knowledge are enormous, especially for the original peoples of the Americas and elsewhere. We now know, for example, not only the genome of a 4,000-year-old individual from Greenland on the basis of ancient DNA (aDNA) recovered from permafrost-preserved hair (Rasmussen et al. 2010), but also the degree of genetic relatedness between eight mummified individuals from Qilakitsoq, Greenland, dating to the 15th century (Gilbert et al. 2007). At the same time, these scientific opportunities need to be balanced against a host of ethical, social, and legal dimensions of the cultural and intellectual properties of DNA and questions of access, control, and benefits from research.

There has been much discussion in recent years about the ethical and legal status of human DNA (Caulfield 2003; Hoedemaekers and Dekkers 2002; Knoppers 1997). This discussion follows, in part, an expanding debate over questions about “ownership” of the body that relate to both physical samples (from modern cells to ancient skeletal remains) and information derived from them (e.g., Boyle 1996; Charo 2006; Holm 2001; Nwabueze 2007). The “discovery” of DNA began a scientific revolution that continues to shed light on the origins and nature of humanity, at times challenging long-held opinions of what we thought we knew in these regards. It is only in recent decades, however, that serious debate has begun over its broad implications for public health, research protocols, scientific knowledge creation, product development, and property rights.

These discussions are of special relevance and importance to Aboriginal<sup>1</sup> communities because the question of who has rights of access to and control over the DNA of individual persons, or of DNA extracted from ancient human remains, could have implications for an entire community. An individual’s decision to contribute a blood sample for health research, for example, could reveal much about the health status of other members of the community, which could in turn lead to stigmatisation or

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<sup>1</sup> In this paper we use the terms “Aboriginal” and “Indigenous” interchangeably in referring to the first peoples of the land.

to problems in obtaining insurance. Of course these and related concerns are by no means limited to Indigenous peoples, but they may be doubly troublesome for communities that have been historically marginalised and disenfranchised with limited control over their own affairs, and where there are often serious and extensive health concerns linked to diet, lifestyle, and heredity. Likewise, a genetic discontinuity between ancient and recent populations in a region, such as one suggested by Smith et al.'s (2009) study of archaeological and modern mitochondrial DNA (mtDNA) in the Aleutian Islands, could conceivably upset land claims or otherwise cause social or economic harm.<sup>2</sup> Comparable issues emerge when DNA extracted from ancient human remains (aDNA) is used to study the origins and migration patterns of ancestral populations (Carlyle 2005). Who has the right to control access to ancient DNA and/or to control a community's narrative?

This paper explores issues raised by the right to access to and control of human DNA as it pertains to Indigenous communities. These issues emerge in two distinct contexts: health research and anthropological/archaeological research. We have worked extensively in these contexts, one (DP) as a medical ethicist who is highly involved in health-related genetic research, and the other (GN) as an archaeologist with more than two decades of experience working with First Nation's communities on issues of cultural and intellectual property. Do common ethical and legal principles apply irrespective of the context, or are the issues of access and control so distinct that different rules must apply in each context? Are distinct issues raised by the provenance of the biological materials under consideration from Indigenous peoples or their ancestors? While some have argued that the DNA of Aboriginal peoples should be considered cultural property in order to ensure appropriate control of genetic information, we question the wisdom of this approach. While acknowledging the differing contexts in which DNA is extracted and utilised could require unique approaches in some circumstances, we argue that emphasis should be primarily on the nature of the relationships established and maintained between researchers and Aboriginal communities and only secondarily on the unique status of the DNA itself.

We situate this discussion by noting first that many Indigenous peoples are not averse to genetic research, whether to address contemporary health issues or to learn from ancestral remains. Indeed, many Northern communities are actively involved in archaeological initiatives. To take just three examples:

- working with the approval of the Aleut Corporation and the Aleut/Pribilof Island Association, researchers from the University of Utah collaborated with Aleut

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<sup>2</sup> Smith et al. (2009) studied mtDNA from the remains of 86 individuals collected in archaeological contexts by Aleš Hrdlička in the 1930s. On the basis of morphological differences and age, Hrdlička postulated that continuity in the pre-Aleut population ended about AD 1000 with the arrival of people from the Alaskan mainland (*ibid.*: 409). The mtDNA data support Hrdlička's hypothesis only if the sample is divided into early and late populations, but discounts it if considered as a single population (*ibid.*: 423). The popular notion that DNA can easily resolve questions about population origins and movement in the past is not always true.

communities to study questions about genetic continuity between ancestral and modern Aleuts (O'Rourke 2009; Rubicz et al. 2003);

- on Prince of Wales Island, Alaska, DNA was recovered from 10,000-year-old human remains with the permission of the Tlingit Tribe (Kemp 2007). Over 230 Native Alaskans participated in this study; and

- the Champagne and Aishihik First Nations partnered with the British Columbia Ministry of Small Business, Tourism and Culture to recover and analyse aDNA from Kwaday Dän Ts'inchí, a 550-year-old individual found when a glacier receded in northern British Columbia (Monsalve et al. 2002). The Champagne and Aishihik were particularly interested in determining whether living descendants could be found, in part to determine this person's clan affiliation, which would be necessary for the funerary rights (Nicholas and Wylie 2009: 36).

Such projects point to the success of collaborative ventures, in stark contrast to the often-contentious relationships that have occurred between researchers and descendant communities at the intersection of science, politics, and religion. Consider the well-known case of Kennewick Man (e.g., Burke et al. 2008; Thomas 2000) and others (Nicholas et al. 2008). Legitimate concerns have also been raised over the collection and use of genetic information of Indigenous peoples, as evidenced by reactions to the highly controversial Human Genome Diversity Project (Reardon 2005),<sup>3</sup> which we discuss below.

Although health, archaeology, and anthropology represent distinct research contexts for possible issues related to the ethical and legal status of human DNA, these contexts have significantly overlapped in a number of recent well-documented cases. Perhaps the two best-known ones—the Nuuchahnulth community from Vancouver Island in British Columbia (Dalton 2002), and the Havasupai tribe of Arizona (Dalton 2004)—highlight the potential problematic of research. In both examples, genetic researchers approached the Aboriginal communities ostensibly to conduct health-related research on a particularly prevalent medical condition (rheumatoid arthritis for the Nuuchahnulth, and type 2 diabetes for the Havasupai). In each case the communities were willing participants in the proposed medical research as they were anxious to gain insights into these devastating conditions. However, in both cases the blood samples were later used for research that went well beyond the scope of what the participants had initially agreed to, including anthropological studies.

Such cases have prompted some to argue that “tribes should assert their sovereignty by developing and adopting tribal laws that will control research proposed within reservation boundaries and will protect their cultural property [...]” (Harry and Kanahe 2006a: 29). “Cultural property” is then defined rather expansively to include

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<sup>3</sup> For a broad discussion on issues relating to the Genographic Project, which succeeded this project, see panel discussion and commentary in Hollowell and Nicholas (2009). Also see discussions on this and other topics by the Indigenous Peoples Council on Biocolonialism (IPCB n.d.).

not only songs, artifacts, sacred sites, and traditional medicines, but also ancestral remains and human genetic materials.<sup>4</sup> But what would it mean to treat human genetic material as “cultural property” over which some descendant group could claim a sovereign right? Is it appropriate to treat the genetic materials of Indigenous peoples, whether extracted from ancestral remains or from living donors, as on par with traditional songs, medicines, sacred sites, and artifacts? Conversely, is genetic material unique such that special laws and practices must be invoked in order to protect and treat it appropriately?

Much is at stake in how these questions are answered, as failure to provide adequate protections could result in widespread abuses such as those of the Nuu-chah-nulth and the Havasupai. Indeed, those who argue for special protections for Indigenous genetic materials often invoke these examples as if they are the norm rather than the exception. While no one argues that what happened in these instances is appropriate or acceptable, these are in fact exceptional cases that fail to represent the vast majority of health, archaeological, and anthropological research that is conducted usefully and appropriately in Indigenous communities (e.g., Nicholas et al. 2008).<sup>5</sup> We must guard against citing the exception in order to set the rule. Overly restrictive practices with regard to access and control of genetic samples could deprive Indigenous communities of the benefits of valuable health research even as it deprives all of humankind of certain aspects of the human story we all share.

In what follows we explore the ethical and legal status of human DNA and consider some of the proposed approaches to managing it both legally and morally. In particular, we consider the question of “genetic exceptionalism,” the idea that genetic material and the information it contains is in some sense unique such that it requires laws and procedures designed specifically to address its exceptional nature and characteristics. Our intent is to offer a nuanced discussion that explores the complexity of the issues while providing insights on how to manage them.

### **Genetic exceptionalism and the (ir)relevance of context**

The advent of the Human Genome Project<sup>6</sup> in the 1990s heralded a new era for humankind in which science would ostensibly reveal ever more detailed information about our biological origins, help to explain our current situations as far as our health, social, and perhaps even economic status are concerned, and provide predictive insights

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<sup>4</sup> While aDNA is usually extracted from human skeletal remains, which many Indigenous peoples hold sacrosanct, it can also be obtained from hair, which may be considered less problematic and yet still hold substantial information. For example, 4,000-year old, permafrost-preserved hair from Greenland suggests the ancestral Saqqaq population had a stronger association with Siberian populations than with New World groups (Rasmussen et al. 2010).

<sup>5</sup> Some controversial and highly sensationalised cases, such as the charges of gross scientific and ethical misconduct (indeed, genocide) leveled against James Neel’s and Napoleon Chagnon’s Yanomami research program (see Dreger 2011), are difficult to fully evaluate.

<sup>6</sup> Not to be confused with the Human Genome Diversity Project, based at Stanford University.

into our future prospects (Rifkin 1998). However, even as the Human Genome Project was moving toward completion in 2003, ethicists, legal experts, and social scientists were scrambling to assess the broader ethical, legal, and social implications (ELSI) of the genomics era.<sup>7</sup> So daunting were the prospects of genetic exploitation and other untoward effects of the anticipated explosion of genetic information and its various applications that the United Nations Educational, Scientific and Cultural Organization (UNESCO) was prompted to issue a *Universal Declaration of the Human Genome and Human Rights* (UNESCO 1997). While many in the ELSI community rushed to address these issues and to develop policies to govern access to and control of genetic information, others argued against such “genetic exceptionalism” (Gostin and Hodge 1999; Lemmens 2000; Suter 2001). This second group maintained there is nothing unique about genetic information that requires special legislative or policy protection. While they granted that genetic information can be personal, sensitive, familial, or potentially discriminating, the same can be said of other sensitive information not drawn from genetic sources. Rather than developing new legislative mechanisms and policy initiatives directed at the supposed exceptional nature of human genetic materials, we should simply apply the laws and policies already in place to protect individual privacy, to limit unjustified discrimination, to protect economic interests, and so forth.

The question of genetic exceptionalism is particularly relevant to Indigenous communities as it has implications for how we think about genetic information derived from blood samples of Indigenous peoples or from DNA extracted from ancestral remains. Is there something unique about DNA drawn from human ancestral remains that warrants exceptional consideration and policy protections? Before turning to that question, it is worth noting a few general observations about the genetic exceptionalism debate. First, the literature on genetic exceptionalism has arisen almost exclusively in human health and closely related contexts; little if any of this discussion is directed at issues in bioarchaeology *per se*. So even if the arguments against exceptionalism prove convincing in the context of human health, there may be unique contextual dimensions of bioarchaeology and anthropology that warrant exceptional policies and protections for Indigenous communities. Second, even within the human health context there is no consensus on the question of exceptionalism. The already extensive literature on the status of genetic information and the appropriate manner in which to manage it continues to expand, implying that many in the ELSI community are convinced that exceptional measures are indeed required. Finally, numerous consensus statements (Caulfield et al. 2008), policy initiatives (GRPI 2004), and legislative measures (GINA 2008) have been developed ostensibly to address the exceptional nature of genetic information.

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<sup>7</sup> ELSI is the acronym used in the United States to refer to studies of the ethical, legal, and social implications of genetics and genomics. In Canada, the acronyms GELS and GE<sup>3</sup>LS are used, the former to refer to “genetics, ethical, legal and social issues” and the latter with the superscript “3” to include economic and environmental concerns as well.

Central to the discussion of genetic exceptionalism is the legal status of human DNA in domestic and international law. Despite more than a quarter century of legal wrangling and international negotiation through such bodies as the World Intellectual Property Organization (WIPO) and the Convention on Biological Diversity (CBD), this status remains an open question (Hoedemaekers and Dekkers 2002). Canadian legal scholar Moe Litman (1997) captures some of the legal complexity underlying the ongoing discussions and debates. Legal taxonomy, he notes, is not an objective or technical exercise that aims to capture some intrinsic quality or characteristic of the objects under its purview. Rather, it is a purposive and normative process that is rooted in value judgments. The law considers something to be “property” (intellectual, cultural, personal, or otherwise) not because of something intrinsic to the object that identifies it as property *per se*, but because labelling it as property and subjecting it to the requirements of property law might best effectuate a broad range of social, cultural, psychological, or economic goals. As such, the legal character of human genetic material will vary depending on the context and the purposes for which it is being characterised. It might be regarded as private property in one context and communal property in another. In some cases it might be equated with a person, or information, or some combination of all of the above. In short, in law human genetic material is *sui generis*, or legally unique because of the exceptional social implications it carries. Litman (1997: 31) concludes by stating: “It is my view that human genetic material is best classified as a flexible legal hybrid with the character of a number of traditional juristic categories, including property and person.”

The variable legal status of human DNA suggests that how it is interpreted and managed is very context-dependent. Hence, as genetic tests for a wide variety of health conditions have become more readily available, concerns have arisen that genetic testing might be required as a precondition of insurance or employment, or that insurers might otherwise access and use this information to deny coverage to certain individuals or groups. A recent genetic study amongst Greenland Inuit, for example, suggests that this population may be at increased risk for cardiovascular disease and type 2 diabetes. (Johansen et al. 2009) It is such concerns that prompted the United States government to pass into law the *Genetic Information Non-discrimination Act* (GINA 2008), which regulates the manner in which genetic tests can be performed and how genetic information can be utilised or shared. Some in Canada have lobbied for similar legislation on the assumption that Canadians are also at risk.<sup>8</sup> However the Canadian context is quite different from that of the United States such that it is highly unlikely that Canada currently requires similar legislation (Pullman and Lemmens 2010). A key contextual difference is that Canada has a national health plan that provides everyone with basic medical insurance. In the United States the vast majority of citizens receive their health insurance through their employers. Subsequently, those employers who fund the insurance plans of their employees thus have an incentive to avoid hiring those more susceptible to certain health conditions. If employers were permitted to require genetic testing as a precondition of employment, that information could be used to discriminate against individuals deemed at higher risk. By denying employment to

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<sup>8</sup> See CCGF-CCEG (n.d.).



those at genetic risk, those individuals (and their families) would be denied basic health insurance as well. GINA thus treats genetic information as exceptional and prohibits employers from requiring genetic testing or otherwise requesting genetic information as a precondition of employment. No such exceptional treatment of genetic information is currently necessary in Canada, however, as adequate systems to protect against discrimination and for the provision of basic health insurance are already in place. While American DNA does not differ intrinsically from Canadian DNA, differing social, political, and economic realities dictate different policies on genetic discrimination in the respective jurisdictions.

Keeping in mind, then, the flexible legal status of human DNA, and recognising the relevance of context (historical, social, cultural, political, or otherwise) when considering how to think about and manage the acquisition and sharing of genetic information, we return to the status of the DNA of Indigenous peoples. Is there something unique about their DNA that requires exceptional protections? The obvious answer from a straightforward biological perspective is “no.” Human DNA is human DNA, irrespective of the source. The DNA of any two individuals drawn from all human beings is more than 99% identical, and human populations are seldom demarcated by precise genetic boundaries (Jorde and Wooding 2004). If we are to list the characteristics that identify any individual as belonging to a given ethnic or cultural group, we should be careful not to weight the genetic component too heavily. In particular, we must be careful not to conflate biology with culture (Armelagos and Goodman 1998; Juengst 1998a).

Even though there is nothing biologically unique about Indigenous peoples *per se*, particular historical and cultural considerations may warrant exceptional treatment of their DNA after all. The long and sordid history of colonial oppression and exploitation of Indigenous peoples around the globe has understandably contributed to a concern that the genetics era would lead to biocolonialism. Such concerns spawned the United Nations Environmental Programme’s *Convention on Biodiversity* (CBD) in 1993, and later the Indigenous People’s Council on Biocolonialism (IPCB). The purpose of the latter group is “to assist indigenous peoples in the protection of their genetic resources, indigenous knowledge, cultural and human rights from the negative effects of biotechnology” (IPCB n.d.) Although both the CBD and the IPCB suggest genetic materials deserve special attention, each has a very different approach to the status of human genetic materials. While the CBD sets out to define principles for the use of genetic resources from plants, animals, fungi, and microorganisms, it treats human DNA as in some sense exceptional and thus purposely *excludes* it from its purview. The IPCB, on the other hand, expressly *includes* human genetic materials as worthy of its attention, putting it on par with other objects of cultural property, including songs, artifacts, sacred sites, and traditional medicines (Harry and Kanehe 2006a) Thus, it may be said that the IPCB does not view the DNA of Indigenous peoples as exceptional in

this respect, as it is not singled out for unique treatment. Instead, genetic material is included in a long list of objects identified as “cultural property.”<sup>9</sup>

It is worth dwelling briefly on these differing approaches to the treatment of human DNA, as it could prove instructive with regard to the notion of cultural property and when and how that category can and should apply. Consider first the CBD, the key international document for conserving and utilising biological diversity. Early attempts to negotiate international agreements on plant genetic resources began from the assumption that such resources were the heritage of all humankind and as such should be available without restriction. However, at the time the CBD was negotiated in the early 1990s, it became apparent that the “common heritage” doctrine would fail to protect the economic interests of countries and farming communities that provided the genetic resources that were then used in the development of elite varieties of plants and animals. If such genetic resources are deemed the common heritage of humanity, then no group can assert a claim of intellectual or cultural property over them. Thus, the CBD started from the principle that parties have sovereign rights over their genetic resources rather than from the common heritage principle. Insofar as a group can claim a sovereign right it can negotiate terms of access to those resources, and, when appropriate, fair compensation through economic benefit-sharing agreements (see Robinson 2010).

Although the CBD recognises sovereign rights over plant and non-human genetic resources, it purposely excludes human DNA from its purview. This is because to have a sovereign right implies proprietary control such that rights holders can do as they please with the entities involved, including selling or otherwise trading these commodities in the marketplace. Many find such notions of ownership and potential commodification of human DNA objectionable, particularly in countries that have experienced slavery and trafficking in human body parts (e.g., Dickenson 2004). For this reason, the CBD does not include human DNA as an object over which groups or countries can assert sovereign rights,<sup>10</sup> and the Human Genome Organization continues to assert the “common heritage” doctrine when referring to the status of human genetic materials (HUGO 2000).

Inasmuch as the IPCB purports to treat the DNA of Indigenous peoples as cultural property over which they can assert sovereign rights, it has a different approach to the status of human DNA from that of the CBD and HUGO. Just as we noted earlier that the differing social and political circumstances of Canada and the United States dictate differing approaches to the issue of genetic discrimination, it could be argued that the unique circumstances of Indigenous peoples dictate that a property rights regime is the most appropriate means by which to assert some sovereign control over Aboriginal genetic materials (Harry and Kanehe 2006a). As such, the claim need not be that there

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<sup>9</sup> The term “property” may itself be culturally problematic, in terms of conceptions of what may be owned or possessed, and what constitutes “identity.” In addition, some societies may have no division between tangible and intangible property or heritage.

<sup>10</sup> For a fuller discussion of these and related points see Pullman and Arbour (2009).

is something intrinsically different about the DNA of Indigenous peoples *per se*, but rather that the historical and cultural context justifies a unique approach.

### **Human DNA and the ambiguity of culture**

While we do not deny that the historical and cultural circumstances of Indigenous peoples are indeed unique, we nevertheless believe there are strong arguments against treating the DNA of Indigenous peoples as cultural property. The first reason arises from the notorious difficulty with identifying cultural boundaries and establishing strict criteria by which to determine who is in and who is outside any particular cultural group. Culture as such is a rich and amorphous notion, and cultural identity could be established primarily on the basis of geographic location, language, clothing, diet, religious belief, music, or some combination of these or any number of other contingent variables. In an increasingly multicultural society, people move rather effortlessly between “cultural groups,” borrowing and assimilating as they go. Depending on the circumstances, it may be advantageous to affiliate more closely with one particular group, or to distance oneself from another. The variable nature and somewhat porous boundaries of cultural identity make such cultural variation and variability possible, and some might even argue, desirable. Indeed the historically flexible and often accommodating nature of tribal membership, particularly in response to the disruptive events of colonisation, has led to major predicaments today regarding tribal recognition and land claims. One prominent example is the Mashpee Tribe of Massachusetts’ 32-year effort to obtain federal recognition (see Clifford 1988). Recent DNA studies reveal that the mixed ancestry of the contemporary communities is embedded within the Mashpee identity (Zhadanov et al. 2010).

The problem with including human genetic material under the rubric of “cultural property” is not that it makes it difficult to identify the constituents of the cultural group to whom this property is supposed to belong, but rather that it threatens to make cultural identity biologically precise (e.g., Zhadanov et al. 2010). For if human DNA is claimed as cultural property, it assumes that cultural identity can be established from a particular subset of genetic markers. The problem with this assumption is that it flies in the face of what we know about human genetic variability. As noted previously, human populations are seldom demarcated by precise genetic boundaries. Thus, when population geneticists study the genetic differences among self-identified socio-cultural groups, they consistently find that such differences are small when compared to the genetic differences within the groups themselves. This means that a village or small tribe is likely to have the same extent of genetic variation among individuals as does the entire world (Cavalli-Sforza 1993 in Juengst 1998a). Genetic sub-groups as such are determined by the number and type of genetic loci compared. If the number of loci is expanded, the boundaries of the sub-group will grow. Alternatively, when fewer loci are compared the genetic community shrinks accordingly.

Those who argue for inclusion of the DNA of Indigenous peoples as another protected type of cultural property do so out of concerns about biocolonialism and worries about cultural appropriation (Harry and Kanehe 2006a, 2006b). We share these concerns but worry that when culture is reduced to biology the primary danger is not the cultural appropriation of genetic materials, but rather what has been termed elsewhere as “the genetic appropriation of culture” (Pullman and Arbour 2009). “Culture” is largely an existential category; while any given culture may include a wide array of rituals, distinct clothing and diet, traditional songs, stories, and a wide variety of other artifacts, practices, and beliefs, for the most part such entities gain their status as cultural objects through the lived experiences of the people who develop and use them. Those who, in turn, identify with a cultural group establish that identity through their lived experience with these various cultural practices and objects. The process of cultural identity is thus both dynamic and reciprocal, and to some degree ever in flux. Human biology, by comparison, aims to be more or less static and precise. Although epigenetic factors (gene/environment interactions) are recognised as important determinants in the manner in which various genes express themselves, the primary unit of measurement is still the genetic marker. To elevate this biological entity to the status of cultural object threatens to reduce culture to biology through the process of genetic ancestry tracing. For example, while the Finns are linguistically and culturally linked to the Saami people of Scandinavia, “when genetic diversity is studied using mitochondrial as well as nuclear genetic markers, [...] the Finns fall into a largely homogeneous gene pool that includes speakers of Indo-European languages, whereas the Saami show signs of [...] a long and independent history” (Sajanitila et al. 1996 in Juengst 1998a: 191). Establishing cultural identity on the basis of genetic ancestry thus has the potential to either corroborate or disrupt identity claims of individuals or groups. As Elliott and Brodwin (2002: 1041) note, “Given the imprimatur of science carried by genetics, those disruptions may be hard to repair.”

In sum, representatives of the IPCB are to be commended for actively pursuing measures to ensure that Indigenous peoples are prepared to establish and assert their sovereignty over their cultural property, including songs, artifacts, sacred sites, traditional medicines, and indigenous knowledge about such medicines, as well as non-human genetic materials and ancestral remains (Harry and Kanehe 2006a). All such objects, practices, and traditions can be subject to property rights claims by self-identified cultural groups, including the members of Indigenous communities. However, we suggest that the IPCB is short-sighted to include human DNA as another item on the list of entities described as “cultural property.” To do so reduces culture to biology, thus making all of the other beliefs, practices, and traditions that together inform a rich notion of cultural identity, contingent on a somewhat arbitrarily defined list of genetic markers that might then be invoked to determine who is in or out as far as the cultural community is concerned.

Is there something exceptional about human DNA, including that of Indigenous peoples? The answer is both “yes” and “no,” depending on the context in which the question is asked. For questions about cultural property, human DNA is exceptional when compared to other non-human genetic materials in that the latter can be described

as cultural property and be subjected to the dictates and strictures of property law, while the former should not be so described. This distinction is recognised by the Convention on Biological Diversity, the Human Genome Organization, and other international bodies that describe human DNA as the “heritage of humanity.” We human beings have much more in common genetically than we have differences. While we should celebrate the cultural beliefs, practices, and traditions that establish our social and cultural identities, when it comes to human biology we should concentrate on the overwhelming similarities between all peoples rather than dwelling upon genetic differences. As philosopher Eric Juengst (1998b) has warned, “No matter how great the potential of population genomics to show us our interconnections, if it begins by describing our differences then it inevitably will produce scientific wedges to hammer into the social cracks that already divide us.”

In the context of human research, however, human DNA need not be treated as exceptional insofar as the requirements of research ethics are concerned. That is, no special rules need be prescribed in order to ensure that genetic research is conducted appropriately, whether in Indigenous communities or elsewhere or whether carried out by health researchers, archaeologists, anthropologists, or other interested parties or groups in either the public or private sectors. Rather, the common principles of research ethics should apply to all research on human subjects whether it includes human DNA or not. At the same time, any such research initiatives are well served by full and equal collaborations between researchers and descendant communities, including research direction, community participation, and benefit sharing (see Nicholas et al. 2010).<sup>11</sup>

### **Research cultures in Indigenous communities**

We opened this discussion by referencing two recent notorious examples of genetic research that have been conducted in Indigenous communities and on genetic materials extracted from them, and that have been universally condemned as inappropriate not only by Aboriginal commentators but also by non-Indigenous researchers and research ethicists. The cases of both the Nuuchah-nulth and the Havasupai began as health-related genetic studies with the understanding and consent of the communities involved. In both cases the genetic samples willingly donated by the research participants were later used in other research projects, including anthropological research, unbeknownst to the original participants and hence without their consent.

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<sup>11</sup> Such an approach is central to the Intellectual Property Issues in Cultural Heritage (IPinCH) project, which is exemplified by the community-based heritage research projects being undertaken. One of these studies, “The Journey Home—Guiding Intangible Knowledge Production in the Analysis of Ancestral Remains,” is a collaboration between the Stó:lo Research and Resource Management Centre and the University of British Columbia that seeks to develop protocols for research on ancestral human remains (see <http://www.sfu.ca/ipinch/node/660>).

Cases like these have galvanised the health research ethics community to develop research guidelines for vulnerable populations, and Aboriginal communities in particular. While some have singled out genetic research as requiring special attention (Emerson et al. 2011; Goering et al. 2008), others have developed more general guidelines that include genetics research as one type of research amongst others (CIHR 2008). Central to either approach is respect for the individuals and communities who are the focus of the research, as manifested in an emphasis on “community based participatory research” in which community members are collaborative partners rather than as mere research subjects (CIHR 2008; Goering et al. 2008). This view entails building relationships with communities and with research participants. Such an approach should animate *all* human subjects research regardless of whether it is health-related, genetic, or otherwise, and whether it involves Aboriginal communities or any other vulnerable populations.

In a recent article, Goering et al. (2008) refer to the kinds of research practices that resulted in the untoward experiences of the Nuu-chah-nulth and the Havasupai as “standard practices,” and advocate for community-based participatory research practices. These latter they term “transformed practices,” which “[...] take seriously the perspectives of the often marginalized communities in which they [i.e. health researchers] work” (Goering et al. 2008: 44). It is worth dwelling briefly on the nature of the so-called *standard* health research practices that yielded the results experienced by the Nuu-chah-nulth and the Havasupai, as well as the nature and extent of the transformation the authors advocate for research ethics with vulnerable populations.

Both these research projects began as health-related research initiated by geneticists who appeared to have only a limited prior relationship with the Nuu-chah-nulth and the Havasupai. Had either project been initiated as an archaeological or anthropological study, however, the outcomes might have been different. For just as various ethnic or cultural groups develop traditions, values, and practices that are distinctive of their communities, various academic groups—including health researchers, archaeologists, anthropologists, and other social scientists—develop practices that are distinctive of their professional cultures as well. Many archaeologists and anthropologists have an extensive history of working closely with the communities in which they conduct their studies, and have thus developed a research culture that emphasises cultural sensitivity and relationship building. This is not to suggest that the history of archaeological and anthropological research is untainted by questionable research practices, but rather that the longer history of community-based research common to those disciplines has led to a more community-oriented research culture. Thus, well before CIHR developed its guidelines for health research with Aboriginal peoples that emphasised the need for relationship building, the American Anthropology Association *Code of Ethics* directed its members to “consult actively with affected individuals or group(s) with the goal of developing relationships that can be beneficial to all parties [...]” (AAA 1998). Such an ethic evolved out of a long history of working closely with and in communities in which the research was conducted. Developing respectful relationships was not only ethically appropriate but also essential to successful research practices within those communities.

In contrast to the community-based approach that has guided archaeological and anthropological research in recent decades, the paradigm for health research has been the randomised clinical trial (RCT), long considered the “gold standard” for clinical health research (Cartright 2007). An RCT is by definition impersonal, as research subjects and researchers are often blinded as to who is receiving active treatment within the trial or is part of a control or placebo group. Research subjects, as such, are not individuals, but rather part of an aggregated, anonymised, statistically significant sample. This anonymity carries over to the manner in which research results are managed. Inasmuch as the result applies not to any particular individual but rather to the impersonal statistical sample as a whole, it is not only inappropriate but indeed unethical to apply research results to an individual patient before the trial has been completed. So even if a clinician/researcher believes her patient is in an active group and is thus faring better, she would not know to which group of the study her patient had been assigned and hence should not draw clinical conclusions.

This long established practice of treating research subjects as anonymous participants and separating research results from clinical practice has become part of the professional research culture of health research. It is this research paradigm based on the RCT that informs the “standard practice” that Goering et al. (2008) aim to replace with “transformed,” community-based practices. Indeed, the advent of genetic research has prompted many to reconsider the relevance of the RCT paradigm to this area of research, as genetics is by definition familial if not community-based. Thus a research result drawn from a single individual could have immediate clinical relevance for that individual and his or her family. As such, it would be unethical to treat this information as a “research result” and to refuse to share it with at-risk individuals (Pullman and Hodgkinson 2006).

Different areas of research develop distinct cultural practices, some of which are difficult to alter. While this point does not justify the kind of untoward research experiences endured by the Nuu-chah-nulth and the Havasupai at the hands of health researchers, it may help to explain how this kind of situation could arise. Because health researchers have been trained in a culture that treats the research subject as a somewhat anonymous participant within a larger research endeavour that purposely sets out to separate research from day-to-day clinical practice, they see little need or value in developing relationships with the community, or in reporting results that have no particular clinical relevance to the subject. With the advent of the genetics era, however, health researchers are rethinking the standard RCT-based paradigm and advocating transformative practices that recognise the values, perspectives, and inputs of those who participate in research. It is no surprise then that it is genetic researchers who are leading this transformation of the research culture and practice in health care.

## Conclusion

While the medical and scientific communities and the public benefit from genetic research, not all parties are willing partners or equal beneficiaries. This is especially the case with Indigenous peoples. For them, the question as to individual (or family) rights vs. public benefit is far more than an academic exercise. Indeed, because of their historical circumstances and the nature of their worldview, unauthorised or unwelcome use of their biological or cultural heritage can cause real harm, including threats to identity, well-being, and even claims to the land (e.g., Nicholas et al. 2008: 239).

In light of this history, these and related concerns are acknowledged by the Indigenous People's Council on Biocolonialism in their approach to protecting the genetic materials of Aboriginal communities. Nevertheless, we have argued that including genetic material within the category of cultural and intellectual property (Harry and Kanehe 2006a, 2006b) is not effective, and indeed may be problematic if it leads to the conflation of culture with biology. Certainly, the IPCB's approach may be effective as a stopgap measure in the absence of other provisions. But the means to a more meaningful and effective approach in genetic research is to change the research process itself, which has long favoured the researcher's interests.

There is today a transformation underway in both the health and social sciences, with new types of relationships being established between communities and researchers (e.g., Denzin et al. 2008; Liamputtong 2008). Where the communities are Indigenous peoples, this change has often been in response to the legacy of colonialism and its continuing effects on modern communities, including very limited benefit from research conducted on their lands and sometimes even on their members. Goering et al. (2008: 44) call for "transformed practices," recognising that "a profound disconnect exists between common academic research practices and legitimate community expectations, and justice requires that this gap be bridged. Our contention is that research practice needs to be more sensitive to the needs of marginalized communities [...]."

These issues are being addressed in our respective fields. By virtue of their lived experiences, many archaeologists and anthropologists already engage in transformed practices, incorporating community-based participatory research (amongst other approaches) into their research. Health-based researchers are moving in similar directions (e.g., CIHR 2008<sup>12</sup>) as they seek to be more sensitive to the historical circumstances of the Indigenous peoples with whom they work. While not adopting a property regime *per se* with regard to the status of human DNA, the guidelines rely extensively on the notion of "DNA on loan" (Arbour and Cook 2006), which aims to establish a degree of control by Indigenous communities over the biological samples they donate for health or other research. This notion functions not as a legal category,

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<sup>12</sup> While developed initially by the Canadian Institutes of Health Research to govern health research in Aboriginal communities, the guidelines are now incorporated into the newly revised second edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (CIHR et al. 2010) that governs all human research funded by the three major granting agencies in Canada.



however, but much more informally as an ethical principle to guide the interactions between Aboriginal communities and researchers as they continue to negotiate the terms of their relationships.

The genetics and genomics era in human research continues to hold great promise for advancing our knowledge and understanding on a variety of fronts. Given the history of colonial oppression experienced by Indigenous peoples, it would be prudent and understandable to take a cautionary approach to the question of how to protect and manage cultural knowledge and heritage in general, and human genetic resources in particular. As we have argued here, the cultural tensions are not just a matter of Indigenous versus non-Indigenous communities, but involve evolving research cultures such as those in archaeology and anthropology and in the health field as well. Given this ongoing dynamic process the question of context will continue to be relevant to our understanding of the various issues that arise in this regard, and to the development of policies and procedures to address and manage them.

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