ANNUAL REVIEWS

Annual Review of Anthropology

Ethics in Human Biology: A Historical Perspective on Present Challenges

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Annu. Rev. Anthropol. 2018. 47:263–78

The *Annual Review of Anthropology* is online at anthro.annualreviews.org

https://doi.org/10.1146/annurev-anthro-102317-045922

This article is part of a special theme on Ethics. For a list of other articles in this theme, see **http://www.annualreviews.org/doi/full/10.1146/annurev-an-47-themes**

Keywords

bioethics, human biology, informed consent, human subjects, indigeneity, refusal

Abstract

The practice of human biology requires the negotiation of a range of ethical issues, including the politics of race and indigeneity, the appropriate use of research materials, and the relationship between researchers and those people from whose bodies they seek to gain knowledge. Grounding my discussion in a history of the field, I discuss key ethical turning points that have shaped the present. These include the field's complex historical relationship to race and colonialism and the implications this relationship has for research, including the needs and desires of Indigenous peoples. This review demonstrates that human biology has been a crucible for many of the most complex ethical issues facing anthropology and allied practices of biomedicine and life science. Its future success as a field is inextricable from its practitioners' ability to adapt in ways that foster the trust and engagement of those humans whose bodies constitute the basis for their knowledge making.

INTRODUCTION

The first and most important question to ask of the ethical practice of human biology is, who does human biological knowledge serve? Answering this question will, of necessity, involve considering the needs and desires of those humans whom the biologist seeks to engage. This question has not always been the focus of human biology, and yet it provides a framework for understanding the historical origins of the present-day ethical challenges involved with making human biological knowledge.[1] This emphasis on "making knowledge" versus "doing research" acknowledges that much of the ethical innovation in the field of human biology has emerged from critical responses by Indigenous peoples, communities who have often served as important sources and subjects for the field. Indeed, certain Indigenous scholars have come to object to the word "research" itself, arguing that it does not serve the needs of Indigenous peoples who are asked to offer information to science about their private lives and, in the case of human biology, their very bodies (Deloria 1969, Smith 2012, Tuck & Yang 2012).

In emphasizing the need to begin with the question "who does human biological knowledge serve," this review offers strategies for negotiating the complexities involved with the biological study of human organisms and even for producing knowledge that is more durable because it is more precise in its aims and relevance (Haraway 1988b, Harding 2009, TallBear 2013). Some scholars have argued that science itself is compromised by an approach where Indigenous peoples are regarded primarily as objects of scientific discovery and not as contributors to the creation of knowledge (Fricker 2007, Tsosie 2012). By considering whom human biological knowledge serves, we can not only understand how and why the present-day ethical challenges facing human biology have emerged but also envision strategies for strengthening the value and integrity of future knowledge. Through a discussion of key historical examples, I explain the limitations to the bioethical approach that has been adopted by institutional review boards (IRBs). I then provide resources to aid human biologists in treating ethical practice as a central and constitutive dimension of the science of human biology.

Human biology, often encompassed under the umbrella of biological anthropology, is a heterogeneous field of inquiry that comprises expertise in genetics, epidemiology, endocrinology, infectious diseases, evolutionary biology, and sometimes primatology and medical anthropology (Little & James 2005, Lindee & Santos 2012). Human biology is distinctive because of its practitioners' abiding interest in the biological plasticity and potential of humans as well as the variability within and between human groups (Schell 1995, Ulijaszek & Huss-Ashmore 1997, Relethford 2008, Stinson et al. 2012). Writing in the 1920s, Johns Hopkins' zoologist Raymond Pearl was among the first to argue that biology—previously the study of life properties and processes in nonhuman organisms—should also look at the normal human (Pearl 1924 as cited in Little & Garruto 2009). Pearl's work opened the possibility for asking biological questions about humans' potential, in particular their "normal" life trajectory and aging process, nutrition, and evolution and adaptation to a diverse array of environments (Little 2010).

ANTHROPOLOGY MEETS BIOLOGY

It is important to consider the extent to which the ethical issues facing human biologists today have been shaped as much by the history of anthropology as by the history of biology (Marks 1995, Radin 2017b). Raymond Pearl, now hailed as a founding figure in human biology, was not

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[1] This perspective helps to situate the specific and valuable attention to ethics in the field and lab that has come from human biology practitioners themselves in recent years (especially Turner 2005, 2010, 2012; MacClancy & Fuentes 2013).

trained as an anthropologist. Rather, his background was in anatomy and zoology. As his vision for human biology began to be institutionalized and adopted by subsequent generations of biologists, it was without the benefit of disciplinary awareness of the fraught history of anthropology and colonialism (Marks 2008).

Whereas anthropologist Franz Boas and his students came to observe the difficult circumstances in which many of the subjects lived in their early ethnographies (Stocking 1966, 1991; Darnell 1998, 2008), it was not until the late twentieth century that anthropology began to seriously reckon with how the circumstances of their knowledge making had been shaped by colonial encounters (Wolfe 1999). Marxist anthropologists like Eric Wolf and Stanley Diamond, both students at Columbia University, where Boas had worked until his death, and others began to call for an approach to anthropology that was explicitly oriented toward alleviating the violence done to Indigenous peoples through the joint forces of capitalism and colonialism (Asad 1973, Diamond 1974, Wolf 1982, Fabian 1983). This work continued in ways that are often seen as contributing to a strained relationship between the four American anthropological subfields: biological, cultural, linguistic, and archaeological (Segal & Yanagisako 2005).

Recent historical work has shown that in the decades after the Second World War the biological and anthropological traditions of the study of the human body were admixed and recast in the purportedly more objective terms of "life science" (Smocovitis 2012). In the early 1950s, physical anthropologists had also begun to remodel understandings of human biology through studies of fossils from ancient humans and the behavior of hunting and gathering societies and primates. This work, part of what anthropologist Sherwood Washburn called "the new physical anthropology," was meant to destabilize older, essentializing ideas about race and replace them with purportedly antiracist concepts of population and plasticity (Haraway 1988a, Little & Kennedy 2010, Jackson & Depew 2017). Via the uptake of multivariate statistics and, later, techniques of molecular analysis, the shift from race to population was also meant to relegitimate the biological study of human bodies as a subject appropriate for a self-consciously ethical science (Gannett 2001, Sommer 2016).

Many of those invested in this new approach had participated in the creation of the UNESCO statements on race, which were hailed as the end of scientific racism (Barkan 1992). The statements, written in 1950 and 1951 (Montagu 1951), are often misunderstood as having declared merely that race is a social construction. A more accurate interpretation is that the statements sought to define inequality as a product of culture and not nature (Selcer 2009, Gil-Riaño 2014, Bangham 2015). In effect, the UNESCO statements preserved the race concept for use by biologists, who believed that it was necessary for work on questions of evolution and variation (Lipphardt 2010, Selcer 2012). Historians and sociologists have since observed that biological race concepts nonetheless found their way back into explanations for inequality, if they had ever been successfully disentangled in the first place (Duster 2006, Bliss 2012, Fujimura et al. 2014).

During the 1950s and 1960s, physical anthropology became biological, and human population genetics took on aspects of anthropology. Historian Donna Haraway has described how, through Washburn's efforts, "the discourses of Cold War, nuclear technology, global urbanization, ecological crisis, and sexual and racial politics. . .threatened now with intolerable rates of change and evolutionary and ideological obsolescence" were "[w]ritten into the bodies of early man and living primates" (Haraway 1988a, p. 242). Rather than leaving race behind, this reconstitution of knowledge and practice contributed to the redistribution and evolution of ideas about race in terms of population (Reardon 2005, Sommer 2008, Bangham & de Chadarevian 2014).

Amid a rise in populational thinking during the Cold War, many human biologists began to focus their attention on groups they understood to be endogamous "primitive" ancestors of their more cosmopolitan, admixed selves (Radin 2013, Santos et al. 2014). The ability to split living members of the human species into temporally and technologically distinctive populations, what human geneticist James Neel (1958) cast as "stone age" and "atomic age," was an ironic byproduct of efforts by postwar biological humanists to construct a universal human. The salvage of biological materials and information from one kind of human population, thought to be destined for extinction, would be used to ensure the salvation of another kind, who sought to maintain and optimize their own evolutionary potential (Vidal & Dias 2015, Dent & Santos 2017, Radin 2017b).

This agenda was formalized and put into practice during the decade-long International Biological Program (IBP), which yielded one of the first textbooks in the field and which was used to train an influential generation of human biologists (Radin 2013). *Human Biology: An Introduction to Human Evolution, Variation, and Growth*, published in 1964, surveyed the state of the science in topics ranging from macroevolution, human genetics, forms of biological variation in modern populations, human growth and constitution, and human ecology, and, in doing so in a single volume, linked them as relevant to the biological study of the human (Harrison et al. 1964).

The concepts presented in the textbook focused on populations perceived as being isolated, "primitive," and in danger of disappearing. Scientists simultaneously characterized these groups as having successfully endured environmental stress (of cold, altitude, and heat, respectively) only to experience new stress resulting from the disintegration of traditional cultural patterns. Although the projects of the Human Adaptability Section of the IBP were not focused exclusively on so-called primitive groups, they were a dominant feature of the enterprise. As one of the leaders of the Human Adaptability Section later recalled, "[E]mphasis was placed on the need to intensify the study of simple societies still living under 'natural' conditions. Such groups would provide object lessons of the actual adaptability achievable by man when relying largely on his biological endowment" (Collins & Weiner 1977, p. 2). The prioritization of such groups as ideal subjects for human biology, later understood by some human biologists as constituting ideal "natural experimental models" (Garruto et al. 1999), shaped circumstances from which a number of today's ethical issues have emerged.

BIOETHICS, IRBs, AND ETHICAL REGIMES

At the same time that human biology was being institutionalized in the context of the IBP, questions of ethics in the context of human subjects research were being institutionalized at American universities and sites of federal research and funding, such as the National Institutes of Health (NIH). Similar to UNESCO's efforts to redefine race after WWII, the creation of the IRB was spurred by repudiation of the actions of Nazi scientists (Annas & Grodin 1992, Heimer & Petty 2010). Yet, American medical practices also came under scrutiny. In 1966, physician Henry Beecher published a watershed report documenting a preponderance of ethical abuses in the context of American medical research (Beecher 1966). Between the testimony of physicians and scientists at the Nuremberg trials, the Declaration of Helsinki of the World Medical Association, Beecher's exposé, and revelations in the 1970s of the exploitation of African Americans by researchers at Tuskegee, scientific institutions found themselves compelled to improve structures that would mitigate, if not eliminate, research practices that exposed subjects to undue harm (Lederer & Moreno 1996, Reverby 2000, Lederer 2004).

The IRB system in place in the United States grew from a model created at the NIH in the 1950s. Starting in the 1960s, the US Surgeon General required all research institutions—universities, hospitals, and others—to get prior approval from a human-subjects review committee composed of its own members. This requirement became federal law in 1974 when Congress enacted the National Research Act. The IRB works via a mode of decision making that historian Laura Stark (2011) has described as "governing with experts," meaning that groups of individuals who have a relevant range of expertise from within the institution form committees that evaluate study designs before they are put into practice.

An important kind of expert that emerged along with the creation of the IRB and its norms was the bioethicist (Bosk 1999, Stark 2011). Bioethics was forged by life scientists, physicians, philosophers, and theologians who were responding to the ways that postwar developments in biology and medicine were creating novel ethical problems (Cooter 1995, Martensen 2001, Rothman 2003, Jonsen 2007). As a field, bioethics cohered around four key principles, all derived from Euro-American philosophical principles that reflected the values of a liberal, democratic society. Autonomy, beneficence, nonmaleficence, and justice became benchmarks of research recognized by universities and federal institutions as "ethical." Both the IRB and bioethics, separate institutions that nonetheless are often regarded as having a shared mandate, have had to contend with important limitations and criticism, including charges that they serve to minimize liability for the institutions in which research happens as opposed to providing true protections to the human subjects of research (Schrag 2010, Koch 2012, Cooper & Waldby 2014, Stark & Campbell 2014).

Human biology is a uniquely global science, which means that it involves people from multiple cultures and institutions. Bioethics and IRBs primarily seek to address problems within institutions but have difficulty managing ethical questions that transcend specific times and places. A more capacious framework is the "ethical regime," a term that draws attention to the "specific biotechnology policies and styles" of bureaucratic structures and systems developed largely within state and academic research institutions to facilitate scientific and biomedical research (Ong & Chen 2010, p. 4). Attention to variations in ethical regimes can help human biologists recognize when they may encounter challenges in attempting to extend a framework developed in one culture to another (Radin & Kowal 2015).

Perhaps the most troubling limitation to IRBs and bioethics as guides for ethical practice in human biology is that these systems do not emerge from the values for ethical engagement set by the communities with whom researchers seek to make knowledge. This is a problem precisely because, as Stark's ethnography of IRBs has shown, the review system encourages its board members to think of human subjects (a legal category invented in the 1960s) as "analogues of specific, tangible people whom they know in their daily lives" (Stark 2011, p. 15). Because human biologists often seek to understand the biology of those who are culturally and ecologically quite different from themselves, this strategy is less effective and may even contribute to research that is less and not more ethical. For this reason, some Indigenous groups and the Indian Health Service of the United States have developed their own comprehensive guidelines and systems of ethical approval and oversight (e.g., Brugge & Missaghian 2006, Sahota 2007, Taniguchi et al. 2012, Nordling 2017).[2] However, such locally innovated ethical regimes are generally unable to reach outside the physical territory of the tribe (or Indian Health Service facilities) to affect lab research conducted elsewhere using materials collected at specific fieldsites (Radin & Kowal 2015).

CONSENT AND COMMODIFICATION

These aforementioned limitations may be understood best in terms of the doctrine of "informed consent," which emerged from bioethics and the IRB as a key technology for ensuring that bioethical principles were being satisfied in the research encounter (Hoeyer & Hogle 2014). In the most

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[2] The research ethics protocols and guidelines of First Nations communities, including Nuu-Chah-Nulth are available at **http://www.fnehin.ca/site.php/research_guidelines/**. The National Congress of American Indians Policy Research Center website provides a Tribal Research Regulation Toolkit at **http://www.ncaiprc.org/research-regulation**. The National Congress of American Indians Policy Research Center website has created the American Indian and Alaska Native Genetics Resource Center (**http://genetics.ncai.org**). Beyond North America, see the recently published San Code of Research Ethics (**http://trust-project.eu/wp-content/uploads/2017/03/San-Code-of-RESEARCH-Ethics-Booklet-final.pdf**).

fundamental sense, informed consent requires the persons designing the research to describe what they understand to be the risks and benefits associated with the proposed investigation. Even as human biologists strive to do so, for the reasons I have already stated—the variability of values across place and time—their efforts to conduct research in accordance with the Euro-American ethical regimes of their home institutions have repeatedly put them at odds with members of Indigenous communities.

The inadequacies of the practice of informed consent were made powerfully evident to human biologists in the early 1990s when a group of population geneticists proposed to sample and archive Indigenous genetic variation around the world (M'Charek 2005, Reardon 2005). This effort, known as the Human Genome Diversity Project (HGDP), was in many ways a rearticulation of the goals of the Human Adaptability Section of the IBP, which had also been motivated by a global stocktaking effort (Santos 2002). Whereas the questions motivating scientists remained relatively consistent between the 1960s and the 1990s, profound transformations in social and economic life contributed to a redefinition of what it meant to participate in research (Reardon 2005, Kowal et al. 2013).

After the HGDP was announced in 1991, activists and members of Indigenous groups responded with concern about how scientists were going to use the knowledge they would acquire in the context of their research (Friedlaender 1996, Hayden 1996, Dukepoo 1998). In particular, new genomic technologies were receiving media attention for their ability to, among other things, transform cellular components of blood into "immortal" cell lines, capable of producing infinite amounts of valuable DNA (Franklin & Lock 2003, Landecker 2007). Those who expressed concern pointed to the long history of neglect and exploitation of Indigenous peoples. Anxieties about "colonial bioprospecting" and "biopiracy" were articulated at the 1992 Rio Conference on Biodiversity and circulated widely via the newly woven World Wide Web (Lock 1994, Haraway 1997). Concerns about the commodification of the body in the context of research on human biology became entangled with debates over informed consent (Wu 2000, Wald 2005). How could they be certain, they asked, that scientists were not looking to make money from their bodies?

HGDP scientists were stunned by the strong criticisms facing their proposed research. They insisted that they were not oriented toward the commercial applications of the nascent biotech industry. Nor had they anticipated the influence of an emerging pan-Indigenous community that cast science as an enemy rather than an ally (Niezen 2003). The leaders of the HGDP quickly regrouped and attempted to address these concerns. They developed what was called a model ethical protocol designed to address the different social structures that characterized Indigenous communities, namely the inadequacy of a culture of consent focused on individuals in a liberal, democratic society or what would be understood in bioethical terms as the principle of "autonomy" (Reardon 2001, 2005).

The resulting innovation was a doctrine of group consent, which was intended to account for Indigenous communities' collective concerns about the implications of participation in the HGDP. Geneticist-turned-science-studies scholar Jenny Reardon has diagnosed the derailment of the HGDP as the result of a failure to innovate social protections appropriate to the new science in question (Reardon 2001, 2005). The anger and mistrust resulting from the fact that these scientists had designed an ambitious research project that required participation from Indigenous groups without adequately considering the perspectives of members of those groups was difficult to overcome, and the project was halted. In the meantime, more than 1,500 cell lines collected from groups who did agree to participate in the project persist as part of a panel at La Fondation Jean-Dausset Centre d'Etude du Polymorphisme Humain (CEPH) in Paris. The cell lines were gathered from various laboratories by the HGDP and CEPH and frozen using liquid nitrogen "to provide unlimited supplies of DNA for studies of sequence diversity and history of modern human populations" (Cavalli-Sforza 2005).

The furor over the HGDP was exacerbated by a related controversy that helps to make clear the complexities and inadequacies of using informed consent as a marker of ethical research. In the early 1990s, anthropologist Carol Jenkins, in collaboration with other human biologists at the NIH, found that a member of a group called the Hagahai, who live in the New Guinea highlands, possessed a viral gene associated with HIV called HTLV-1. It was the virus that existed within human somatic cells that had become of interest to scientists. At NIH director Bernadette Healy's behest, government-funded scientists were required to file for patents on any discoveries that could conceivably be put to commercial use, even if that use had not yet been defined (Lock 2001, Weir et al. 2004). This mandate was reinforced by the Supreme Court of California, which ruled in 1990 that a person had no right to any share of the financial profits of anything that is developed using his or her "discarded" body parts [*Moore v. Regents of the University of California* (1990), Wald 2005]. Jenkins filed for the patent in accordance with these rules. However, Jenkins reportedly sought informed consent from the Hagahai and told them about the patent at the time of application. Furthermore, she agreed to donate her own portion of any royalties to the community (Hirsch & Strathern 2004).

Upon learning of the patent filing, a group that was unaffiliated with the Hagahai, known as Rural Advancement Foundation International (RAFI), accused Jenkins of attempting to patent Indigenous genes. RAFI's efforts catapulted the Hagahai, along with scientists who worked with them, to the center of nascent discontent over biocolonialism and biopiracy that also surrounded the HGDP (Radin 2017b). The patent was ultimately dropped; however, it led to a watershed special issue of the periodical *Cultural Survival Quarterly*, which brought together human biologists and Indigenous representatives to address the subject of human gene patenting (Friedlaender 1996).

The commentaries in the *Cultural Survival Quarterly* issue made clear that concerns about patenting were inextricable from understandings of the negative, enduring impact of colonialism and capitalism on Indigenous lifeways. They also pointed to the inadequacies of informed consent. Solomon Islander and Indigenous activist Ruth Liloqula's contribution centered on how genomic techniques of human resource extraction not only were oriented toward benefitting the biotech industry but also privileged certain forms of ancestry making over others. There was, in her view, a fundamental lack of alignment in the interests of those who wished to collect and use Indigenous blood to answer questions that did not appear to serve the individual(s) from whom it had been extracted (Liloqula 1996).

HEALING OR HARMING?

Following the controversies surrounding the HGDP and Jenkins's research with the Hagahai, in 2000, journalist Patrick Tierney published a book, now largely discredited, that accused a team of researchers working in the 1960s of knowingly exacerbating a measles epidemic among members of an Indigenous group called the Yanomami in order to observe the "natural history" of the disease in a so-called virgin soil population (Tierney 2000). The charges made against these researchers, including James Neel who had recently died, and Napoleon Chagnon, a cultural anthropologist, rocked the anthropological profession (Fischer 2001). The American Anthropological Association as well as the American Society of Human Genetics established inquests to determine what, exactly, had happened and what it meant for research (Borofsky 2005). Although investigations exonerated Neel, demonstrating that rather than exacerbating the epidemic his team had actively worked to curtail it, important and enduring questions were raised about scientists' obligations to intervene and aid the very humans they attempted to enroll as research subjects (Salzano & Hurtado 2004).

Human biologists had long considered their ability to provide acute medical care in the field as a benefit for the Indigenous people they sought to enroll in their studies. During the IBP, for example, it was common practice to treat ailments encountered in the field (Radin 2017b). Today, the desire to help improve the health circumstances of a community whose members are participating in research often derives from well-intentioned humanitarian values that seek to improve access to care (Redfield 2005, Dent 2016). Yet, the practice of using the promise of health care as an incentive to participate in research can create undue pressure on an individual or community (Petryna 2005) without providing longer-term solutions that emphasize self-determination (Stevenson 2014).

These concerns scale up to the structures of international research partnerships, which are often uneven. Major North American and European universities and medical centers have been incentivized by funding structures and the demands of academic publishing to prioritize the perpetuation of their own research agendas, which may come at the cost of material improvements to the life circumstances of those whose bodies form the basis of investigators' research (Crane 2010, 2013; Birn 2014).

Many of the chronic health issues facing Indigenous communities have been linked to settler colonialism, including the creation of the reservation system in the United States and broader forces of industrialization around the world (Stephens & Herring 2011). Human biologists have long lent their expertise to the study of these phenomena among Indigenous communities but not without controversy. A recent and widely publicized example involved the Havasupai, an Indigenous community living in the North American Southwest, who willingly engaged researchers from Arizona State University to help them understand why they were suffering from disproportionately high rates of diabetes and hypertension. Tribal leaders granted consent to researchers to collect health-related data, including blood samples. Years later, with no relief from these health conditions, Havasupai learned that these blood samples were being reused for studies that had nothing to do with diabetes. These included studies of the group's ancestors' migratory history, which, they charged in a lawsuit raised against Arizona State University, could potentially jeopardize their land claims and tribal sovereignty [*Havasupai Tribe v. Arizona Board of Regents* (2008)]. Ultimately, the tribe reached a financial settlement and won the right to reclaim their blood from the university (Kowal et al. 2013) if not the ability to make human biological knowledge on their own terms (Garrison 2013).

COLLECTING, RETURNING, AND REUSING

The question of how to manage the preserved body parts of human biological research subjects brings together all the ethical questions previously discussed, making it an especially charged nexus of a range of the ethical issues in human biology today (e.g., Kowal 2013, Kowal et al 2013). It continues in projects as high profile as National Geographic's Genographic Project (TallBear 2007, Malhi 2009), itself a continuation of the agendas articulated first in the IBP in the 1960s and then the HGDP in the 1990s, as well as in a wide range of human biology projects taking place around the world. The Havasupai case is far from the only instance in which calls for repatriation of research objects—previously associated primarily with artifacts and bones—are being extended to preserved human tissues extracted in the course of human biological work. Indeed, the logic of repatriation, formalized into law in the 1990s with the Native American Graves and Repatriation Act (NAGPRA), has served to begin reversing the flow of materials out of the laboratories and museums of anthropology in ways that have destabilized human biologists' practices (Rose et al. 1996, Kirsch 2011, Kakaliouras 2012).

For instance, Tierney's accusations against the actions of researchers working in the 1960s have arguably been overshadowed by his publication of the confirmed fact that ~3,000 blood samples collected in the context of that fieldwork persisted in North American freezers. It was not long before Yanomami leaders and allies began to demand that the blood be returned. Toto Yanomami, a member of the community, argued that "Yanomami don't. . .take blood to study and later keep [it] in the refrigerator. . . . The doctors have already examined this blood; they've already researched this blood. . . . So we want to take all of this blood that's left over" (quoted in Borofsky 2005, p. 64). This argument was a sharp critique of the open-ended horizon of a biomedical research program that preserved human remains without specific ideas about who would benefit or how to distribute such potential benefits (Radin 2017b).

Calls for the return of the blood to the Yanomami deeply unsettled members of the scientific community. Some saw repatriation as a form of loss of collections that belong to "mankind's patrimony" (Froment 2011, p. 196). Such claims participate in a narrative of human relations that perpetuates assumptions that Indigenous bodies provided a baseline for the history of a universal Western man without considering that Indigenous forms of knowledge provide different means for understanding the order of nature and ways of establishing kinship (Reardon & TallBear 2012). Whereas scientists regarded these blood samples as forms of latent life containing untapped epistemic potential, those Indigenous peoples who sought to reclaim the samples regarded the blood as a form of incomplete death of their ancestors (Kowal & Radin 2015). It took until 2015 for the Yanomami blood samples to be returned, when community members gathered where they live to return them to the earth.

Amid this controversy, in 2000, Oxford University Professor of Biological Anthropology Ryk Ward agreed to give back the 883 blood samples he had collected from the Nuu-Chah-Nulth, a First Nations community in Canada. He had made the collection in the 1980s in conjunction with research on rheumatic diseases, which disproportionately affected the group. When members learned that Ward had also used the blood for research unrelated to the health questions but instead to questions of ancestry, they demanded that it be returned. In this case, the blood was ultimately returned to researchers at the University of British Columbia, where a Nuu-Chah-Nulth research committee was created to regulate the use of the samples (Garrison 2013).

The case of the Havasupai, along with the widely publicized story of Henrietta Lacks (Skloot 2010)—an African American woman whose cervical cancer cells transformed biomedical research—has generated a number of alternative perspectives on the appropriate use of tissue in human biology research, including attention to the minimization of "cultural harm" to those whose bodies provide the basis of knowledge (Tsosie 2007). Some have proposed the concept of "DNA on loan," which is designed to ensure ongoing communication between those using the biological substance and those from whom they were extracted (Arbour & Cook 2006). Still others, in attempting to address the complexities involved with the reuse of materials, have argued that what is required is a form of tiered consent in which those whose tissues are being collected can agree to different degrees of reuse (Mello & Wolf 2010).

These various approaches to the appropriate use and reuse of blood, DNA, and other body parts are being tested in our current big data Information Age (Reardon 2017). Institutions such as the NIH, which are funded by US taxpayer dollars, have a mandate to make the products of their research freely available, in keeping with democratic values of openness and transparency (Leonelli 2016). Yet, as James et al. (2014) have argued, "while broad access to data may lead to benefits for populations underrepresented in genetic studies, such as indigenous groups, tribes have ownership interest in their data" (p. 820). Thus, questions of property, ownership, and benefit should be imagined to relate not only to flesh, but also to data. This emerging data sovereignty movement will have implications for how human biological data is stored, circulated, and reused (Garrison 2017) and may even contribute to a reimagining of the ethics that guide the politics of non-Indigenous data economies beyond human biology (Radin 2017a).

BETWEEN REFUSAL AND PARTICIPATION

Although controversies surrounding the HGDP and the advent of NAGPRA, along with the emergence of vibrant fields of Native History and Indigenous Studies, have helped human biologists reevaluate how their well-intentioned interventions might be construed otherwise (Schroeder et al. 2006), it should not be taken as a given that Indigenous peoples will or should want to work with non-Indigenous scientists. Human biologists, and anthropologists more broadly, have all encountered instances of what Sherry Ortner (1995) identified as refusal. One facet of this refusal is a phenomenon known as "research fatigue"—a feeling of exhaustion about being subjects of inquiry (Clark 2008, Crane 2010). This position can grow out of a desire to avoid what has been referred to as voyeurism, where researchers seek to learn lessons from the study of communities but fail to improve conditions or consider the points of view of community members (Gilchrist 1997).

More recently, Indigenous anthropologists have offered their own theorization of refusal. Refusal, in this register, is not the same as nonparticipation. It is a form of opting-out that is a rejection not only of a specific research project but of the enduring colonial logics that continue to animate science. It is a position that seeks to promote different but equally valuable kinds of knowledge (Benjamin 2016). The concept of refusal might appear perverse to a scientific culture that values openness. However, Mohawk anthropologist Audra Simpson has pointed out that the political theory that is used to uphold ideas of openness, such as those advanced by John Locke, which promote shared standards of truth and justice in an intellectual commons, was itself derived from the violent enclosure of land and alienation of Indigenous peoples from their modes of governance (Simpson 2007, 2014).

Some scholars have argued, however, that Indigenous peoples have simply demanded what all research participants should want. According to this view, it is Indigenous peoples' heightened sensitivity to material and epistemic injury, rather than their cultural or epistemological differences, that has come to drive Indigenous-specific research guidelines. As a recent review of ethical guidelines for Indigenous genetic research argued, "Indigenous groups are most vulnerable to research exploitation and harm; therefore, identifying principles that work for Indigenous people will lead to best practices for all populations" (Taniguchi et al. 2012). In this view, all research participants should have control over how their bodily data are used in the future and should be offered the chance to contribute to the research design (e.g., Allen 2011, Kaye et al. 2012). Yet, Stephen Epstein (2007) has shown, in his sociology of medical inclusion, that bringing more diverse subjects into the research enterprise has not been adequate to address social inequalities.

An encouraging horizon for the negotiation of ethical issues in human biology, between refusal and participation, is coming from programs that seek to train Indigenous scholars in human biological techniques (Mahli & Bader 2015).[3] Although not all of the individuals who enroll in such programs—which are still few and far between—may become practitioners, there is enormous potential to reduce "epistemic injustice" (Tsosie 2012) by providing Indigenous peoples with the opportunity and resources to create forms of human biological knowledge that flow directly from their own values, needs, and desires. Non-Indigenous human biologists have much to learn from the ways in which Indigenous peoples approach the field, and these kinds of encounters may create still new possibilities for remaining attentive to the ever-emerging ethical and epistemological challenges inherent to seeking to understand what it means to be human.

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[3] An exemplary model is the Summer Institute for Indigenous Genomics, currently run out of the Carl R. Woese Institute for Genomic Biology at the University of Illinois (**https://sing.igb.illinois.edu**).

CONCLUSION

In this historical review of ethical issues in human biology, I have demonstrated how Indigenous peoples' refusal to simply accept the terms upon which researchers have sought to engage them has in many cases led to better approaches to making knowledge (Simpson 2016). By dint of non-Indigenous human biologists' ambitious desire to understand the human body as a biocultural phenomenon, they will always be faced with deeply challenging ethical issues (Goodman & Leatherman 1998, McInnes 2011). Yet, by reconceiving of their project as an expansive one of "making knowledge with" versus "doing research on," a project in which ethical innovation can be regarded as central as technical innovation, human biologists are exquisitely well positioned to become leaders in the project of diagnosing and even healing systemic harms that hinder science from fulfilling its own best potentials.

DISCLOSURE STATEMENT

The author is not aware of any affiliations, memberships, funding, or financial holdings that might be perceived as affecting the objectivity of this review.

ACKNOWLEDGMENTS

The ideas presented in this article are the result of a decade of collaboration with Emma Kowal and are offered in the spirit of continued conversation with our Indigenous colleagues working at the intersections of anthropology, history, and STS. Rosanna Dent and anonymous reviewers provided valuable feedback while Elizabeth Karron contributed research assistance and editorial support.

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