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Where Heritage Meets Bioethics: Indigenous Human Remains and Genetic Prospecting

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Abstract

Background: Two issues where heritage protection law and bioethics meet and frequently conflict are the treatment of indigenous human remains and the gathering and storing of indigenous peoples' genetic information. A major source of this conflict lies in the divergent philosophies underlying indigenous peoples' worldviews, on the one hand, and the value systems upon which most national governments and the international community predicate their law-making. Among these are differences in how scientific knowledge is perceived and even how time itself is conceived, whether as a linear or a circular construct.

Methods: This article takes a human rights approach to these questions and, using this analytical approach, seeks to explore the tensions between the different value systems. This approach is based on an application of the theory and principles of human rights and through analysis of the relevant primary sources.

Results: The paper demonstrates that according greater respect to indigenous rights and to cultural values and their sense of their human and collective dignity can avoid the perpetuation of historical abuses in the fields of biological and physical anthropological research.

Conclusion: Biological and physical anthropological research on indigenous communities and heritage requires an awareness of the ethical dilemmas implicit in such work and a readiness to question the values underpinning "scientific" study. Ultimately, it is important to align the global common good of human rights with the common goods that can come from such biological and anthropological research.

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Introduction

One of the serious challenges facing international law when seeking to regulate access to and use of the heritage of indigenous peoples relates to the very different worldviews of indigenous peoples and the "international community" that makes the law. This disconnect of perspectives has, at its basis, a fundamental difference with what "heritage" itself means. For indigenous peoples, this is a much more comprehensive notion than that generally applied in international cultural heritage law (1). This problem is compounded by the very distinct understanding of time among many indigenous societies, where time is circular and not linear. Since the prevailing concept of heritage is predicated on a linear view of past-present-future, the ancestral remains buried many centuries ago do not fall into the category of protected objects while they may be for indigenous persons who are still living as members of their contemporary world. This has resulted in great controversy over museums in Europe, North America, and elsewhere which hold indigenous human remains (2, 3) that were collected by (mostly European) travellers, colonial administrators, archaeologists, anthropologists, and others over the past few centuries (4). In recent years, and in response to strong indigenous demands, a number of these remains have been returned by museums (5). For non-indigenous scientists and scientific institutions, they represent a legitimate subject of physical, anthropological, archaeological, and biological research; in fact, they are an integral part of indigenous communities, their identity, and their heritage. In that sense, their removal represents an attack not only on their history–an oral tradition told with reference to their ancestors–but against their very human and collective dignity.

More recently, the collection of genetic information from indigenous communities for research and/or commercial purposes has become controversial. This is a practice known as "bio-prospecting" in which their genetic information is regarded as a form of natural resource, akin to mineral deposits, that is subject to investigation and exploitation. The genetic codes of indigenous peoples are of particular interest to scientific researchers since many such communities have been relatively isolated from other ethnic groups and so have little genetic mixing. For indigenous communities, however, their genetic information is not viewed primarily as the subject of scientific research but as an integral part of their identity; it is not something that can be reduced to the control and ownership of others (through scientific investigation and patenting). Even research projects that make their data and findings openly accessible based on open access principles, allowing research for the common good of humankind, usually a laudable goal, [1] contribute to a sense of violation of their personal and cultural integrity. In view of the long history of different forms of domination and colonization, this is hardly surprising.

Both of these cases which relate directly to biological research in different ways, though this is more direct in the case of genetic research, raise a number of important issues; for example, "can these be treated as a form of heritage? If so, whose heritage and who should have the management of this heritage? ". This, then, raises further questions regarding heritage rights (if they can truly be called "heritage") and the respective and often conflicting rights of indigenous persons and scientific researchers and institutions. It is not clear how far a perceived common good (in gathering genetic information on indigenous populations) can be weighed against the individual and collective rights of indigenous peoples. Both issues set up an ethical and legal challenge between "modern" science, as exhibited in physical anthropology and genetics, as opposed to traditional indigenous knowledge, and customs and cosmologies.

Even if it is assumed that indigenous human remains fall within the broader category of cultural heritage, the traditional approach to heritage protection for preventing its destruction or deterioration as a result of the impacts of natural processes or human interference is neither sufficient nor appropriate. This case requires focusing on human rights dimension in safeguarding cultural heritage, which has always been implicit since the adoption of the Universal Declaration of Human Rights in 1948, and was more fully recognized from the 1970s onwards in terms of the rights to develop a culture, for example (6).

Recent international policy-and law-making concerning the preservation of cultural diversity and safeguarding the intangible cultural heritage has

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1. For example, the DNA of Covid-19 was made freely available to teams searching for vaccines and other treatments by Chinese researchers in January 2020.

brought human rights issues to the forefront of heritage protection law (7). The rights associated with culture ascribed to article 27 of the International Covenant on Civil and Political Rights (ICCPR, 1966) and Article 15 of the International Covenant on Economic, Social and Cultural Rights (ICESCR, 1966) (8, 9) clearly apply to cultural heritage, as well as certain freedoms of expression and association (10). Moreover, the human rights that are specifically accorded to indigenous peoples provide a crucial legal context within which both these cases are considered.

Indigenous heritage and human rights

Since indigenous persons enjoy special rights based on the fact of being indigenous, it is important to clarify who qualify as "indigenous peoples" [1] under international law and, following this, what is "indigenous heritage". The generally accepted definition of "indigenous peoples" in the UN system was crafted in 1978 by the UN Special Rapporteur on the rights of indigenous peoples, Martinez Cobo (11). According to his definition, the main characteristics of indigenous peoples are that they are the living descendants of pre-invasion peoples in lands now dominated by others, they constitute culturally distinctive groups, their ancestral roots are much more strongly embedded in the lands in which they live (or would like to live) in comparison to more powerful groups, and they have a sense of self-identification as being indigenous. A subsequent UN Special Rapporteur, Daes, defined "indigenous heritage" in 1997 in terms that clearly point to the very specific worldview of indigenous peoples and how they perceive and relate to their heritage:

[it includes] everything that belongs to the distinct identity of a people … all those things which international law regards as the creative production of human thought and craftsmanship, such as songs, stories, scientific knowledge, and artworks. It also includes inheritances from the past and from nature, such as human remains, the natural features of the landscape, and naturally-occurring species of plants and animals with which a people has long been connected (12).

The specific inclusion in this definition of human remains as "[an inheritance] from the past", [2] makes it clear that their ancestors' human remains are an important element in their "distinct identity" and a link to their past, and that holding them elsewhere is a serious violation of rights. Beyond this, the comprehensive character of what is included as "heritage" is notable, and signals that indigenous heritage enjoys a special character that does not fit easily into the categories of classical law of heritage protection [3] (13). The holistic view espoused by Daes requires it to be seen as a single, integrated whole, pertaining to the whole community, enjoyed by that community permanently and without alienation.

In order to understand more clearly the significance of indigenous remains for modern biological research, the research on human skeletal and dental remains conducted by Skeletal Biology and Forensic Anthropology Research Group [4] can be investigated. This includes sub-fields such as biological anthropology, bio-archaeology (osteoarchaeology), and the biology of the human skeleton. Research objectives in bio-archaeology, for example, cover reconstructing ancient human life-ways, behavior, health, demography, and disease by studying human remains from archaeological contexts. Indigenous populations, in view of their ancient origins and lack of inter-mixing, provide a particularly valuable study set. However, this is against the way in which indigenous peoples view their ancestors' remains which is specific and different from most of human societies. This has important implications for how they should be treated from both an ethical and a legal viewpoint. In most cultural traditions,

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[1] With regard to the tricky international law question of what constitutes a "people" (as opposed, for example, to a minority), they are "peoples" insofar as they comprise distinct communities with a continuity of existence and identity linking back to their ancestors and pre-dating the modern States in which they now reside.

[2] It reads: "Heritage" is everything that belongs to the distinct identity of a people and which is theirs to share, if they wish, with other peoples. It includes all those things which international law regards as the creative production of human thought and craftsmanship, such as songs, stories, scientific knowledge, and artworks. It also includes inheritances from the past and from nature, such as human remains, the natural features of the landscape, and naturally-occurring species of plants and animals with which a people has long been connected.' [Emphasis added].

[3] Indigenous culture tends to separate cultural form of natural elements of heritage (as in the 1972 Convention on the Protection of the World Cultural and Natural Heritage), with the adoption of UNESCO's 2003 Intangible Heritage Convention, into "tangible" and "intangible" categories which are meaningless to indigenous peoples.

[4] In the School of Anthropology and Archaeology at Australian National University.

human remains become heritage elements and no longer the "property" of their descendants after a specified period of time, often between 100 and 150 years.

In contrast, indigenous societies typically see time in a circular manner, [1] which means that their (even very ancient) ancestors are not gone but remain with them as subjects of veneration and sanctity. Hence, access to the bodies of their dead ancestors and traditional burial grounds is integral to their religious practice and cultural identity (14). The Lagos Chief, for example, told the West African Lands Committee in 1912 that, "I conceive the land belongs to a vast family of which many are dead, few are living, and countless numbers are unborn (14) ". This view has also been upheld in the case of Hopu and Bessert v. France (15) by the Committee on International Covenant on Civil and Political Rights (CCPR); regarding a planned hotel development on traditional burial grounds of indigenous persons in Nuuroa, on the island of Tahiti, the Committee took the view that "cultural traditions should be taken into account" when defining the term "family" and that their buried ancestors remain an important part of their descendants life (15).

With regard to indigenous peoples' human rights, the ILO Convention No 169 concerning indigenous and tribal peoples (1989) is currently the only binding agreement with only 23 ratifications. In applying the provisions of this Convention, "the social, cultural, religious, and spiritual values and practices of these peoples shall be recognized and protected" and "the integrity of the values, practices, and institutions of these peoples shall be respected" (article 5 (a)), which conveys that their customs, religious, and spiritual beliefs and their practices relating to the treatment of their ancestors' human remains should be respected. Within another human rights treaty framework, the Committee on the Elimination of Racial Discrimination (CERD) has called upon States parties to recognize and respect the distinct culture of indigenous peoples and to promote its preservation as an enrichment of the State's own cultural identity (16). The United Nations Declaration on the Rights of indigenous Peoples (UNDRIP) adopted in 2007 is a significant, albeit non-binding, instrument (17). It grants indigenous peoples the right "to practice and revitalize their cultural traditions and customs" which includes "the right to maintain, protect, and develop the past, present and future manifestations of their cultures, such as archaeological and historical sites, artefacts …" (article 11). They also have the right "to maintain, control, protect, and develop their cultural heritage" which includes the "human and genetic resources" that are the subject of this paper (article 31). This would imply, inter alia, the right not to have their human remains disinterred or their genetic information gathered without their permission, based on prior complete informed consent. Museums are, as can be seen, some of the primary public institutions that hold indigenous human remains (including university museums), and ICOM Code of Ethics for Museums (2017) governs professional practices for the museums. It seems that research on human remains should be conducted in a manner that "take[s] into account the interests and beliefs of the community, ethnic or religious groups from whom the objects originated" (at 3.7). Museum activities involve a contemporary community or its heritage, the latter describing exactly the situation of indigenous descendants, "acquisitions should only be made based on informed and mutual consent" and "[r]espect for the wishes of the community involved should be paramount" (at 6.5). In recent formulations relating to implementing 2003 Convention for the Safeguarding of the Intangible Cultural Heritage (encompassing indigenous heritage), the requirement for consent is now expressed as "full, prior, informed and sustained consent" which introduces the additional criterion that the consent must not only be given freely and with sufficient information and understanding, but that this is not a one-off action and rather a sustained form of consent. This, in turn, would imply that there is an ongoing dialogue between researchers regarding indigenous subjects of research in both follow-up studies and publications. For example, Indicator 9 of the Overall Results Framework for monitoring

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1. Writing of the Inuit peoples on Kodiak Island (Canada), Pullar noted that: "to indigenous people, time is circular. Those ancestors who may have died hundreds of years ago are still part of the circle. They are still members of the group of people living today. They may have passed to another world but they remain full members of the group. G.L. Pullar, "the Qikertarmuit and the scientist: fifty years of clashing world views", 1995 UBC Law Rev. Special Issue 119: 125. Similarly, the Dreamtime of Aboriginal peoples in Australia has a circular rather than linear perspective on time.

and evaluating the 2003 Convention which relates to "research and documentation, including scientific, technical, and artistic studies" includes an Assessment Factor that makes reference to the "free, prior, sustained, and informed consent" of the bearers of this heritage when they participate in such studies, including the "dissemination of research findings and scientific, technical, and artistic studies" . [1]

Bio-prospecting

The great increase in genetic research, including such mass observation projects as the Scotland's DNA project in 2012 (18), has raised a number of ethical concerns, including the fear that they might be used to support eugenic theories or that private companies might exploit their findings in an inappropriate commercial manner. A large number of patents have been granted for human DNA findings over the past 20-25 years with the involvement of numerous private corporations, especially multinational companies. Genetic data from indigenous populations are particularly valuable since they are believed to constitute unusually distinct populations (19).

Indigenous populations have applied the term "bio-prospecting" to the gathering of data related to genetic research in their communities, which they regard as a form of genetic piracy or theft. [2] The ancestral memory of Native American indigenous peoples of a European invasion that was close to genocide [3] has greatly added to this suspicion. Indigenous people regard this interest in their genes (as much as the biological resources of their biodiverse territories) as simply a new form of appropriation and colonization. In addition to this, there is an ethical objection based on concerns over conducting this kind of human research and how informed consent can be secured. A particularly egregious case is the genetic research conducted by Arizona State University on the Havasupai Tribe in the early 1990s. The tribe members consented to collaborate in this research as they were informed that the project is related to diabetes. In 2004, however, they initiated a lawsuit against the university on the ground that their samples were used for research (inquiry into schizophrenia, inbreeding, and migration theories) [4] (20) which they had not consented to. This is significant since most ethical guidelines for such research requires free, prior, and informed consent by the subjects of scientific research.

Another case of interest is the Genographic Project conducted by the National Geographic Society with IBM in 2005-10 for the collection and analysis of DNA blood samples from over 100,000 indigenous people. This was described as "the world's largest study of its kind in the field of anthropological genetics" and the project organizers stated that there would be no medical research involved and no patenting of the genetic data from the project. An indigenous group that has effectively articulated opposition to this project is the indigenous Peoples Council on Bio-colonialism (IPCB) which was established in 1993. The IPBC fights against what it sees as bio-piracy–either biological resources in indigenous territories or indigenous genetic codes–and advocated for non-collaboration with the Genographic Project. One statement made by ICPB is particularly relevant to this article: "Many indigenous peoples regard their bodies, hair, and blood as sacred elements, and consider scientific research on these materials a vi-

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[1] Overall Results Framework for the Convention for the Safeguarding of the Intangible Cultural Heritage, contained in the Basic Texts of the 2003 Convention available online at: https://ich.unesco.org/en/basic-texts-00503 (accessed 01-04-2012). Assessment Factor 9.3 reads: "Practitioners and bearers of ICH participate in the management, implementation and dissemination of research findings and scientific, technical and artistic studies, all done with their free, prior, sustained and informed consent".

[2] Indeed, several Native American tribes have passed laws prohibiting bio-prospecting on their territories. In 1998, the Confederated Salish and Kootenai tribes adopted a resolution that severely restricted genetic research on their reservation in Montana. This resolution declared: "Scientific research and genetic exploitation of indigenous peoples represents the greatest threat to American Indians since the European colonization of the Americas".

[3] In addition to the associated violence, the importation of hitherto unknown diseases led to the death of huge numbers of indigenous Americans with the arrival of European invaders in the 15th and 16th centuries BCE.

[4] The last, migration studies, is particularly unacceptable to indigenous peoples since it is designed to demonstrate their origins (based on the theory of migration from somewhere else) which is wholly antagonistic to their view of being the first inhabitants of their lands. Arizona State University (ASU) agreed to pay $700,000 to 41 members of the Havasupai tribe in 2010 to settle legal claims that researchers improperly used tribe members' blood samples in genetic research.

olation of their cultural and ethical mandates". In this statement, then, the twin issues of indigenous human remains and genetic information are addressed together, and the sacred and untouchable quality of both is emphasized.

In addition to the aforementioned issues, the question as to who benefits from the research is a further ethical concern. The companies which own patents over the genetic data they collect are seeking commercial gain from using these data, whether for pharmaceutical or other research purposes. In 2015, within the framework of UNESCO's 2003 Convention on Safeguarding of the Intangible Cultural Heritage, a series of Ethical Principles (21) were adopted by the intergovernmental committee of that treaty. Among the twelve principles, Principle 7 states that "communities, groups, and individuals who create intangible cultural heritage should benefit from the protection of the moral and material interests resulting from such heritage" and "particularly from its use, research… [by] others". This would suggest that indigenous communities should benefit from the exploitation of their own genetic information, which could be seen as a form of heritage created by them.

Of course, there will be individual members of and groups within indigenous populations who are enthusiastic to cooperate with these genetic research projects, and it cannot be assumed that organizations such as ICPB speak for all indigenous persons. However, they do articulate an oppositional worldview that it is important to recognize and respect when such projects are proposed. This is particularly true since most ethical protocols governing scientific research projects focus on individual consent, while many indigenous groups regard their culture and dignity as collective and seeking individual consent is therefore not a valid approach. Moreover, genetic research if allied with migration theories could be used to challenge indigenous claims to control their ancestral territories and natural resources that are important for mining, logging, and other non-indigenous commercial activities. Lastly, the legacy of racist attitudes towards indigenous peoples around the world (in the Americas, the Pacific region, Africa, India, and elsewhere) cannot be ignored which has underpinned scientific research on human remains and may still be an unspoken bias legitimizing genetic research while ignoring indigenous values concerning cultural integrity and sacredness.

Ethical dilemmas

Scientific versus indigenous values: Indigenous claims for the restitution of human remains have frequently centered on artefacts that are accorded "scientific" value by the disciplines of archaeology and physical anthropology. There are numerous examples of such indigenous artefacts held in museums and institutions in Europe, North America and they are symbolic of a conflict between different value systems, whereas for indigenous cultures, they embody important spiritual and cultural values while they also hold a value for scientific research (22). Legislation that guarantees respect for the former may well prevent their collection and scientific investigation. In this sense, the rights and collective dignity (good) of the indigenous population are set against a public good/interest associated with scientific research findings. When the Smithsonian Institution returned the skeletal remains of approximately 1,000 indigenous people to Kodiak Island after eight years of request from their Inuit descendants, the debate reflected a fundamental difference of perspective between the scientific community and the Inuit over the value of these human remains. Most legislative systems uphold the values of modern science and ignore the principles enshrined in indigenous customary law; this approach is the main focus of this paper which needs to be challenged.

Where a common interest, such as forensic research or advances in medical knowledge is identified, for example, disinterment becomes acceptable. [1] As a response to the strong resentment felt by many indigenous peoples towards archaeological fieldwork that disturbs the burials of their prehistoric ancestors (23). The Native American Graves Protection and Repatriation Act (1991) in the United States is an important development. It incorporates indigenous values and it has handed control to Indian tribes over several ritual and cultural objects previously held in US museums as well as over grave sites. A similar approach found in the code of conduct of the UK Museums Association (2015) requires museums and their staff to "dispose of human remains with sensitivity and respect for the beliefs of the communities of origin" and demands that they "recognize the humanity of

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1. For example, the disinterment of the bodies of whalers from the Arctic Circle permafrost who died in 1918 from the influenza pandemic in order to derive information on the genetic code of the virus.

all people" in all their actions. In this wording, an appreciation of the human rights dimension of these questions can be clearly seen. Moreover, museums should take into account "the interests of actual or cultural descendants [and] the strength of the claimants' relationship with the items". Principle 5 [1] of the aforementioned Ethical Principles for UNESCO's 2003 Convention is also of relevance here. It states that "[c]ustomary practices governing access to intangible cultural heritage should be fully respected". This suggests that not only ritual objects, including the remains of their ancestors but also related cultural practices and their original burial places should be respected. This would preclude any disinterment of indigenous human remains for any purpose, including research that could be beneficial for society in general, without the full, prior, informed, and irrevocable consent of the descendant community members.

However, dilemmas remain; for instance, if archaeological examination of human bones is conducted to trace diseases such as arthritis or leprosy and improve their method of treatment, where does the ethical imperative lie? Equally, if studying genetic data from contemporary indigenous persons can help to understand our biology better, whose interests are paramount? The study of indigenous human remains may even help us to understand human bio-cultural adaptation and may provide guidance as to how threat posed by current zoonotic diseases such as Covid-19 can be confronted (24).

With regard to research projects that collect indigenous genetic data, both the Genographic Project (mentioned above) and the Human Genome Diversity Project (HGDP), another large genetic project gathering indigenous genetic information, were explicitly predicated on the notion of a global common good. Designers of the latter project stated that all of the information gathered belongs to the global community and that the genetic data will be released (anonymously and as aggregate data) into the public domain. This approach, however, is based on a number of assumptions which are not in keeping with the indigenous worldview; the first of these is that the "global public good" is an ethical value that can override indigenous ownership of one's own heritage and/or genetic information. A second assumption is that outsiders (here, the scientific community and commercial interests) have a form of knowledge and understanding that is superior to indigenous traditional knowledge and beliefs. Inherent in this is a direct opposition between the principles of open knowledge and research (of the international scientific community) and the strong desire of indigenous peoples to safeguard what is sacred to them. Hence, it also pits traditional knowledge, a cultural practice in itself, against "scientific" knowledge. The HGDP has been accused of racism, commercialization, exploitation, and cultural imperialism as well, and more importantly of applying a faulty process of securing informed consent (25).

Formally seeking consent for research on human bodies is not a new phenomenon and dates back to at least the late 19th century in Europe. Despite this, some research subjects have been deemed more worthy of giving consent than others (26). Similarly, black and minority communities in the US and Europe have been subjected to medical and/or biological studies and even interventions without their consent. A celebrated and egregious example of this is research conducted in the US on African Americans from poor communities who were infected with syphilis, from 1932 until 1972. Over this forty-year period, the researchers did not treat these participants with penicillin, a highly effective treatment (27).

In addition to clear failures to seek consent, the issue of how far the consent sought is informed is crucial and the requirement for translating consent forms into the subjects' language (or providing effective interpretation) are obviously necessary. However, seeing the issue of 'translation' simply as a linguistic one misses an important point, namely that this process may hinge on information being provided in cultural terms that are meaningful to the subjects (28). Where this is particularly problematic, similar to the process of gathering indigenous genetic information, the cultural terms and understanding of the research community and those of the indigenous populations can be so far removed from each other that mutual misunderstanding is likely to occur if this is not handled with extreme sensitivity. For example, if the focus of

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1. It reads: "access of communities, groups and individuals to the instruments, objects, artefacts, cultural and natural spaces and places of memory whose existence is necessary for expressing the intangible cultural heritage should be ensured, including in situations of armed conflict. Customary practices governing access to intangible cultural heritage should be fully respected, even where these may limit broader public access".

consent is mainly placed on risk, then important questions about the sanctity of the information, customary rules governing access to it, and the dignity of the indigenous subjects (in their own terms) may well be ignored. This tells us that the whole process of seeking consent from indigenous communities can only work properly if it is conducted through close consultation with them from the design of the consent form, through information-sharing and securing consent, to evaluation of the process. This is also the only way to move from the model of "doing research on, not with indigenous people, with little regard to local cultural protocols and languages and without seeking consent from communities" (26).

Another issue that is of great importance to many indigenous populations involved in research relates to the control and use of research findings after the fieldwork is completed. Similar to the case of the Arizona State University study described above, indigenous genetic information has been used for research objectives (e.g., concerning migration studies) without subjects' agreement. In a study conducted in Hawaii, indigenous community members refused to consent to use of their biological samples in future studies. The researchers assumed (probably correct) that this refusal was linked with cultural beliefs relating to desecration of body parts (29). This illustrates the need for a thorough understanding of cultural beliefs and practices. In Fitzpatrick's literature review, only one out of 56 relevant research publications evaluated both community preferences for method of delivery of information and their understanding of the information presented when seeking consent for research with an indigenous population (30). This was one out of five research studies on indigenous communities in which the need for "involvement of local indigenous people in seeking consent, establishing good relationships between researchers and potential participants, cultural competence, and clear communication using plain language with visual cues" were all recognized. Even with the best of intentions, outside researchers still generally fail to address the issue of consent effectively. Fitzpatrick shows current national and international guidelines for seeking consent from indigenous populations and refers to the item "respect for indigenous culture". This is covered in most cases, while the item "research team includes local indigenous community members" is not universally included and "Indigenous members on research ethics/advisory board" is even less well covered. This would suggest, then, that respect for indigenous cultures can be a box-ticking exercise without any real effect, and that the actions that will really make a difference here, in particular local indigenous community members on the ethics/advisory board, are not so well accepted or adopted. This is hardly surprising since "respecting" someone else's culture is a fairly passive action that does not cede any real power, while including indigenous members on an advisory board does imply ceding some power to the community studied.

A further problem with many guidelines is that the way in which they are couched allows for much greater or lesser engagement with indigenous subjects over the matter of consent [1]. For example, the re-use of data gathered in a research study that was consented to is often left as a grey area and this is a serious challenge to indigenous communities' rights over how their biological information is used in the future. [2] This brings us back to the notion of "sustainable" consent, in other words that consent is not a one-off action that then has an effect in perpetuity but is, rather, an ongoing process of dialogue with the studied community. If this latter approach is taken, then the danger of biological data gathered from indigenous peoples being used for subsequent research objectives that they do not agree to is greatly reduced. The other point about ethical guidelines in general–beyond the obvious fact that they are usually developed by scientific institutions or at a global level–is that it can be dangerous to assume that what works for one indigenous population will work for all. This reminds us of the need for a fundamental principle of establishing a meaningful dialogue with the community that fits their cultural terms. However, this raises a further challenge which is how to ensure that the

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[1] The following example is given in Fitzpatrick's work op.cit n.66 at p. 30: "the research ethics committee shall endeavour to protect the integrity of our Indigenous Knowledge, our culture and the members of the Six Nations from harm or abuse".

[2] In the aforementioned 1990 study by Arizona State University, blood samples were collected from the Havasupai tribes for diabetes research. These samples were subsequently re-used for other research purposes without the community's knowledge. Mello and Wolf op.cit. n. 41.

representation from the community is fully representative of the views of all members; this is a particularly tricky issue and just reminds us of the importance of the quality of dialogue.

Conclusion

The treatment of indigenous human remains and genetic information in relation to their human rights, [1] in particular the notion of their collective human dignity was addressed in this article. Moreover, an investigation was made to determine whether the understanding of "heritage" as applied in international law is one that responds appropriately to indigenous understandings and sensitivities.

In fact, there is a great gap of understanding between an indigenous world view that is holistic and in which the "circle of life" predominates, and the idea of modern scientific research conducted for the public (and even global) good. This has led to tensions and to the treatment of indigenous human remains and their genetic information in ways that are antipathetic to the indigenous sense of what is sacred and even their sense of human dignity. As a consequence, much of international heritage protection law–which is predicated on a non-indigenous understanding of "heritage" as well as one that validates modern scientific viewpoints–has generally failed to protect indigenous peoples against violations of their dignity, spirituality, and bodily integrity caused by scientific research on their ancestral human remains and their DNA.

Therefore, for taking an ethical and human rights-oriented approach to these questions, the assumptions underpinning both the applicable international law as well as scientific research agendas should be examined. In the current pandemic crisis associated with Covid-19, this is even more essential since the stakes are far higher for the health and future of our shared humanity. It is imperative to continue in our pursuit of a global common good through biological and anthropological research while protecting indigenous rights and interests. When addressing these issues, it should be considered that ethical positions are not absolute but that they are culture-specific and that "globally accepted" principles do not necessarily respond to the needs and belief systems of all peoples and societies. The tensions that have been drawn out in this article between "scientific" values, including those which most legal systems are based on, and indigenous knowledge and customary practices demonstrate this clearly. In order to ensure that these two positions can be better reconciled, for the good of everyone, biological research conducted on indigenous populations–be it on their skeletal remains or genetic data–must be conducted with their full, prior, informed, and irrevocable consent and ethical guidelines which involve them as equal and active partners and not as passive research subjects should be applied.

Conflict of Interest

The author declares no conflict of interest.

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[1] This includes rights of minorities as expressed in Article 27 of the ICCPR and the rights of indigenous peoples as expressed in ILO Convention Concerning Indigenous and Tribal Peoples in Independent Countries (No.169, 1989) and the UN Declaration on the Rights of indigenous Peoples (as agreed by members of the Working Group on Indigenous Populations on its 11th session, 1993).

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مجله ایرانی حقوق و اخلاق زیست پزشکی

مقالهٔ پژوهشی

محل تلاقی میراث با اخلاق زیستی: بقایای بومی بشر و کاوش ژنتیکی

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چکیده

مقدمه: جای که دو موضوعی حقوق حمایت از میراث و اخلاق زیستی با یکدیگر برخورد می‌کنند و اغلب با یکدیگر در تعارض هستند، نحوه تلقی بقایای بومی انسان‌ها و جمع‌آوری و ذخیره اطلاعات ژنتیکی مردمان بومی است. منبع اصلی این تعارض مبانی فلسفی متمایز نهفته در جهان‌بینی مردمان بومی، از یک سو، و نظام‌های ارزشی است که براساس آنها اکثر دولت‌های ملی و جامعه بین‌المللی قانون‌گذاری می‌کنند. در این میان در نحوه درک دانش علمی و حتی نحوه تصور خود زمان، چه به صورت یک ساختار خطی یا دایره‌ای تفاوت‌هایی وجود دارد.

روش‌ها: این مقاله نسبت به این مسائل رویکرد حقوق بشری را اتخاذ کرده و با استفاده از این رویکرد تحلیلی، به دنبال کشف تنش بین سیستم‌های ارزشی متفاوت است. این رویکرد مبتنی بر کاربرد نظریه و اصول حقوق بشر و از طریق تحلیل منابع اولیه مربوطه است.

نتایج: این مقاله نشان می‌دهد که احترام بیشتر به حقوق بومیان و ارزش‌های فرهنگی و احساس کرامت انسانی و جمعی بیشتر آنها می‌تواند از تداوم سوءاستفاده‌های تاریخی در زمینه تحقیقات انسان شناختی بیولوژیکی و فیزیکی جلوگیری کند.

نتیجه‌گیری: تحقیقات انسان شناختی بیولوژیکی و فیزیکی در مورد جوامع و میراث بومی مستلزم آگاهی از معضلات اخلاقی نهفته در کارهای از این دست و آمادگی برای زیر سال بردن ارزش‌های مبنایی مطالعه «علمی» است. در نهایت، مهم است که منافع جهانی حقوق بشر را با خیر مشترکی که از چنین تحقیقات بیولوژیکی و مردم شناسی حاصل می‌شود، همسو کنیم.

واژه‌های کلیدی:

کاوش ژنتیکی، تلاقی میراث و اخلاق زیستی

نحوهٔ استناد به مقاله:

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