International Journal of Cultural Property (2009) 16:133–140. Printed in the USA.
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doi:10.1017/S0940739109090092

Introduction

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In November 2006, a discussion thread erupted on the online discussion list of the World Archaeological Congress (WAC) concerning the National Geographic Society's Genographic Project (which is also sponsored by IBM and the Waitt Family Foundation). Initiated in 2005, the Genographic Project is designed to study human population movements in the past based on the analysis of DNA samples voluntarily contributed from people around the world. This project was also designed to move beyond the kinds of ethical and other concerns relating to indigenous rights, appropriation, and group consent (to name a few) that led to the demise of its predecessor, the Human Genome Diversity Project, which began in 1991 and continued until the late 1990s.[1] Such projects owe their origins to significant advancements in biomolecular research and technology studies, which have not only resulted in a genetic revolution in archaeology and related studies but also witnessed growing public interest in ancestry tracing through genetic means.[2]

The emails on the WAC discussion list concerning the Genographic Project seemed to call out for better information (and fewer misconceptions) about the cultural implications of this kind of research in particular and genetic testing in general. This exchange provided an interesting counterpart to the growing public interest in obtaining a $99.95 kit to trace one's ancestry. These issues also seemed to resonate with recent studies on the uses of ancient DNA (aDNA) from archaeological contexts. In all of these cases, the situation is decidedly more complex than a simple dichotomy between researchers and descendant communities, with each of those groups representing a remarkably broad array of opinions.

A host of new issues and questions considering the impact of human genetics research on descendant communities have arisen, for example:

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https://doi.org/10.1017/S0940739109090092 Published online by Cambridge University Press

DNA and blood samples now have a market value; once they are removed from an individual's body, they are considered property,[3] as is the information derived from them.

Who benefits from the extraction of these substances and how? How can we move from the right to extract and use blood or DNA samples for science to realizing the responsibility of transforming the process into benefits and improvements for people from whom samples are taken?

What assumptions have been made about how indigenous peoples will respond to genetic research? Or about groups being headed for cultural or biological extinction?

What are the impacts of human genetic research, negative and positive, on the lives of people? Where is protection needed so that harm is prevented?

What types of research methods may facilitate more equitable and collaborative relations and informed consent?

What are the questions that communities want addressed?

With such questions in mind, we decided to organize a forum titled "Decoding Implications of the Genographic Project" at the 39th Annual Chacmool Conference in 2006, held at the University of Calgary, Alberta, Canada. The theme of the 2006 conference, "Decolonizing Archaeology," seemed an apt venue. We set out with the intention of bringing individuals representing a wide range of perspectives together in one panel, primarily to inform and answer questions from those in attendance and also to record the proceedings to make them accessible to a broader audience. Our goal was to use this opportunity as a venue for an informed public discussion (*not* a debate). We were interested both in the uses of ancient human genetic information and in how genetic data about an individual's past might figure in present-day issues of cultural identity, research ethics, and intellectual property. We wanted to dispel some of the myths surrounding these studies; notions, for example, that indigenous peoples are not as "scientific" or as open to scientific studies as others. We also noted certain parallels between research pertaining to genetic data and that of human remains in archaeology in terms of community concerns, control over the process and products of research, and modes of resolution.

The panelists ranged from molecular anthropologists and biological archaeologists who work with early human skeletal remains and other sources of aDNA to heritage workers, activists, tribal archaeologists, and a bioethicist. Many different perspectives, experiences, and research interests were represented. Again, we emphasized to participants (and the audience) that this was not a debate but a discussion that strived to respect a diversity of values and viewpoints. Although we did succeed in bringing individuals representing a wide range of perspectives together respectfully in one room, perhaps the audience really benefited most from this; because those on the panel with the most divergent views still seemed to talk past one another. Nevertheless, everyone was able to share their opinions

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and have them taken seriously. In the process of organizing the panel, we learned that, in addition to trying to hear from and listen to a range of perspectives, it's important to look carefully at who really has more at stake. Although we all may like to believe that science should benefit everyone, in actuality it benefits some more than others.

Ethical questions figure prominently here concerning the treatment of human genetic material as cultural property. However, the patenting of the human genome has been a reality for decades. In 1980, the U.S. Supreme Court ruled that live human organisms were patentable. By 2005, 20% of human genes had been patented worldwide, with the majority of patents held by private companies and universities. The issues are complex—legally, ethically, and culturally. On the one hand, in the medical sciences, researchers receive financial or other rewards for the creation of new knowledge that benefits many. On the other hand, the individuals who provided the biological samples used in that research typically have no control over, or benefits from, information derived from their own bodies.[4]

Potential uses of genetic data promise to create many challenges and opportunities that intersect with intellectual property issues in social science research and the domain of cultural heritage. Indeed, the exponential increase in situations such as this that fall within the realm of intellectual property is staggering. Googling "intellectual property" 10 years ago might have fetched 100,000 hits; today, it is well over 50 million. About 185,000 of these deal with cultural heritage issues, a number that is rising daily. This growing awareness of intellectual property issues grew out of concerns that first appeared in ethnobiology, as indigenous peoples responded to real or perceived threats to traditional knowledge and cultural patrimony. Unless those involved in the cultural heritage realm begin to take a proactive approach to these issues, they will likely to find themselves in the same situation as American archaeologists, who were complacent for centuries about so-called scientific uses of human remains until legislation was imposed.[5] Greater awareness of who is raising what concerns is a vital starting point to avoid such an outcome. We also believe that fair and equitable protocols relating to genetic information and best practices are often more effective and equitable than imposed legislated solutions.

During the conference session, the panelists identified several key issues that should be addressed when working with communities on human genetic research. These include negotiating the nature of informed consent—what a truly *informed* consent entails—as well as clarifying the ownership of samples and data. Many panelists had concerns about the potential misuse of either samples or data, and they cautioned that all potential impacts or consequences of a study should be considered, particularly any possibly negative ones. The problematic practices of the Human Genome Diversity Project in the 1990s had also created an atmosphere of mistrust and suspicion.

In general, there remains quite a bit of uncertainty, if not suspicion or skepticism, about the links among the widespread publicity of human genetic testing,

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the inflated claims of what it can reveal, and the need to promote human genome studies to sustain research funding. One broad concern regarding genetic testing in general, and the now widely available ancestry kits, in particular, is the claim that these tests will tell an individual her or his ultimate story, when all that can really be traced is one thin thread of an individual's many-stranded past. As bioethicist Daryl Pullman noted in his panel remarks, such claims, which figure prominently in the promotion of genetic testing kits, border on misrepresentation in advertising.

> Where do you really come from? And how did you get to where you live today? DNA studies suggest that all humans today descend from a group of African ancestors who—about 60,000 years ago—began a remarkable journey. Follow the journey from them to you, as written in your genes.[6]

Although human genome studies such as the Genographic Project certainly "have implications for anthropological and archaeological research" (see Wells and Schurr, this issue), they also have significant implications for indigenous peoples and other descendant communities. It's not hard to see how tenuous interpretations of an "ultimate story" could be seen as threatening (or possibly validating) by indigenous peoples who are faced with seeking to prove long-term relationships to land and resources. A very real possibility exists that courts or other legal forums will place more weight on DNA results over and above other forms of evidence when it comes to claims of cultural continuity such as oral histories, ethnographic accounts, or even archaeology (in spite of the fact that we know there are no "pure" peoples). There is the potential that genetic evidence could destabilize notions of cultural identity in ways that both disrupt or uphold identity claims that lead to decisions about land rights, political authority, access to resources, and cultural knowledge.

Both scientists and indigenous peoples (and some are both) feel that they have something to lose in such situations—scientists, their data, funding, and ability to answer research questions; indigenous peoples, their cultural integrity and sense of identity, as well as possibly losing rights to land or resources. The panelists discussed a number of safeguards that can be put in place to mitigate the potential for harm or misinterpretation. The foremost suggestions had to do with dialogue, collaboration, and accountability.

All of the participants emphasized the need for dialogue among interested parties (or stakeholders), including more open and honest two-way conversation regarding what genetic testing can and cannot reveal, as well as the potential benefits and consequences at the community level. There also seemed to be consensus that these studies should be conducted collaboratively, that is, in partnership, with full transparency, often *under the direction* of the local community, and not simply using what passes as the standard model of informed consent or consultation. Those most affected by the study should be involved in decision making, including negotiations about the study's implementation in the community, its interpretation, and how (or whether) it should be presented to the public. The importance

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of long-term relationships and the need for greater reciprocity in research relationships was another critical point.[7]

As the panelists indicated, it is clear that indigenous perspectives are not anti-science, but strongly concerned with a human rights aspect that looks at the implications of research beyond its scientific value.[8] Debra Harry (this issue) notes that for Native peoples, tribal or indigenous identity is much more than genetics, and there is much more at stake. As Sheila Greer, Debra Harry, Jerome (Jerry) Cybulski, and Carrie Dan all express, while First Nations and other Indigenous peoples recognize that DNA research can have value for them, they want to be able to set some of the terms of engagement.

After having been dispossessed of so much, there is growing concern among indigenous peoples about maintaining at least some degree of sovereignty over their own genetic resources. For Debra Harry, ethical guidelines are not enough to protect the rights of indigenous peoples in these matters. She advocates a legal regime that would both protect genetic resources and enforce accountability on the part of researchers and scientists, with attention to the power differentials among researchers and those from whom they collect data. Harry also suggests that global protocols are unlikely to work; instead, indigenous communities need to have the opportunity to respond individually to the issues presented by DNA testing, based on their own cultural lenses and particular situations. What is most important is that community members voice their concerns and have them taken seriously, make their own decisions, and are aware of what the consequences might be (or not be).

But a related question is whether intellectual property law or cultural property law is really the appropriate framework for this. Are the issues more about ownership and patents or about having some control over the design, implementation, and results of research? As Kim TallBear notes (this issue), "in our knowledge society, to govern and shape research and its structures can be a form of anticolonial practice." One approach that is becoming more and more common is for tribes or communities to establish their own review boards that regulate research and outline protocols for a more mutually beneficial research partnership. The Indigenous People's Council on Biocolonialism, which Harry directs, has developed a framework for approving a research agenda that can be adapted by a particular community to assert a collective cultural right over genetic data, traditional knowledge, or other products of research.

This, in turn, raises additional questions regarding the rights of the individual within a collective and how that collective is defined. This is an issue that runs up against the current narrow interpretations of intellectual property, and one likely to become more significant and salient in the years ahead. As Jonathan Marks (this issue) mentions, these issues require the field of anthropological genetics (as well as many other disciplines, we would add) to confront its past and the challenges of renegotiating research relationships.

New technologies yield new knowledge, but they also give rise to new challenges. This is very true in the realm of genetic studies where the information that

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can be gleaned from an ancient human bone fragment or modern cheek swab is astounding. There is always a delay between the introduction of these technologies and the realization of the impacts they may have. In the case of human genetic studies, these impacts include not only a better understanding of the story of humanity but also concerns about cultural identity, traditional knowledge, and community well-being. These issues and many more are thoughtfully discussed in the pages that follow. We believe that they offer important insights on the cultural implications of human genetic research, as well as generate new ethical and legal questions to pursue further.

ACKNOWLEDGMENTS FROM THE CO-EDITORS

The Chacmool panel session was sponsored by the World Archaeological Congress and the project on Intellectual Property Issues and Cultural Heritage: Theory, Practice, Policy, Ethics (IPinCH).[9] This special section of *IJCP* was prepared under the auspices of IPinCH, an international collaboration of archaeologists, indigenous communities, lawyers, heritage workers, ethicists and others, funded by the Major Collaborative Research Initiative program of Canada's Social Science and Humanities Research Council. IPinCH activities include creating a clearinghouse for information on intellectual property issues in cultural heritage, supporting community-based studies on these issues, assisting agencies and organizations in identifying good practices, and sharing how others have resolved these issues ethically and equitably. The views expressed here are our own and do not necessarily represent those of other members of the IPinCH project, its partners, or funders. We thank Lucie McNeil, Gregory Carr, Lindi Conover, Sarah Cavanaugh, Joe Watkins, and Alec Barker for their assistance at various stages, and especially all of the panel participants and commentators for their willingness to share their perspectives, knowledge, and experiences with the broad audience they deserve.

ENDNOTES

1. There is no clear date for the demise of the Human Genome Diversity Project. In a timeline, Reardon (*Race to the Finish*, p. 177) stated, "In April 2004, Cavalli-Sforza writes in a letter to *Nature* that cites the CEPH collection as evidence that the Diversity Project is an active and successful project. Calls for continued financial and political support of the project." On the other hand, Wells (*Deep Ancestry*, p. 172) noted, "Although a few samples were collected under the auspices of the HGDP, for the most part it had closed shop by the late 1990s, killed by opposition to its many flaws." For more information on the Human Genome Diversity Project, see Cavalli-Sforza, "The Human Genome Diversity Project"; M'charek, *The Human Genome Diversity Project*; O'Rourke, "Anthropological Genetics in the Genomic Era"; Reardon, *Race to the Finish* and "Race Without Salvation"; Zilinskas and Balint, *The Human Genome Project and Minority Communities*. For more information on the Genographic Project, see Wells, *Deep Ancestry*, and also the project's web site (www.genographic.com), which provides information on all aspects of the project, including its goals, methods, ethics, and an archive of press releases.

https://doi.org/10.1017/S0940739109090092 Published online by Cambridge University Press

2. See Wells and Read, *The Journey of Man*. An Internet search on "ancestry testing" will yield dozens of companies offering "genealogical" readings by means of a DNA swab kit.

3. This has parallels to how the copyright of traditional practices, knowledge, and stories automatically belonged to the anthropologist who extracted them and wrote them down.

4. We are referring here to the well-known case of John Moore, who unsuccessfully sought an ownership interest in a patent related to a cell line derived from his spleen. See Boyle, *Shamans, Software, and Spleens*; and also von der Ropp and Taubman, "Bioethics and Patent Law."

5. Such legislation includes the National Museum of the American Indian (NMAI) Act of 1989 (Public Law 101–185) and the Native American Graves Protection and Repatriation Act (NAGPRA) of 1990 (Public Law 101–601).

6. Genographic Project, "A Landmark Study of the Human Journey" (www.genographic.com). The last sentence of this quote has since been removed from the Web site.

7. This is a theme that reverberates throughout not only cultural heritage studies but also in human-oriented research and development in general. Instead of simply following the maxim "do no harm," an alternative avenue is to employ the "precautionary principle," which errs on the side of caution in promoting proactive measures to prevent potential damage or harm that could possibly result from research or its outcomes. See Bannister, "Indigenous Knowledge and Traditional Plant Resources," 295. Another compelling approach is that based on "virtue ethics," as described by Colwell-Chanthaphonh and Ferguson, "Virtue Ethics and the Practice of History."

8. This is evident in a growing number of instances in North America and in other places where indigenous communities are not only working with archaeologists and others in the study of ancient human remains, but sometimes even directing the work themselves. Panel participant Sheila Greer has been closely involved with research related to *Kwädày Dän Ts'ìnchi* (Long Ago Person Found), an individual whose centuries-old remains were found at the edge of a glacier in northern British Columbia. See Beattie et al., "The Kwädày Dän Ts'ìnchi Discovery," 2000. Champagne and Aishihik First Nations worked collaboratively with provincial agencies and archaeologists on studies of *Kwädày Dän Ts'ìnchi* and his belongings. They also initiated a community DNA study to see if living relatives of the deceased could be identified, in part to ensure proper, clan-based burial rights. Seventeen relatives were identified, 15 of whom are members of the Wolf Clan. As reported in Langdon, "Scientists link 17 living people to an aboriginal man found in glacier."

9. For more information about the IPinCH Project, see http://cgi.sfu.ca/~ipinch/cgi-bin/.

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