International Journal of Cultural Property (2009) 16:213–217. Printed in the USA.
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doi:10.1017/S094073910909016X

Commentary on Implications of the Genographic Project

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First, I would like to thank George Nicholas and Julie Hollowell for inviting me to comment on this important panel discussion. Second, I would like to thank all the panelists for their articulate and highly stimulating discussion, which deftly illustrates the range of cultural, historical, and political complexities that inform not only the Genographic Project but also research conducted with Indigenous peoples and indigenous communities more generally.

I was first contacted about the Genographic Project by a journalist on the eve of its launch in 2005. At the time I was based at the Smithsonian Institution in Washington, DC, where I was working on a range of intellectual property and indigenous knowledge problems arising from the long-term historical study, documentation, and collection of Indigenous peoples' knowledge. In seeking my commentary, the journalist asked that I address the potential intellectual property dimensions of the project. In my review, however, I became more and more concerned about the ethical issues—in particular, how such research had been conceived and presented, to what extent Indigenous peoples were being produced as "objects" of research; where, if at all, indigenous perspectives were being counted and incorporated into its development and operation; and how Indigenous peoples would derive direct benefit from a project of this nature. While there were clearly major intellectual property issues that would arise—namely, who would own the DNA "data" once collected, who would own the genetic database that was to be compiled, who would benefit from its inevitable and eventual commercialization, and who would be able to access it in the future—I was so struck by the lack of clear guidelines or conditions for determining consent and the absence of background discussion with Indigenous peoples about the possibilities and limitations of the Genographic Project that I focused on these issues in my commentary. The subsequent newspaper publication resulted in a tirade of hate mail that I have never before, or ever since, received.[1] Most of this mail

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https://doi.org/10.1017/S094073910909016X Published online by Cambridge University Press

argued that indigenous peoples had absolutely no right to be asserting ownership or control over the data or process of such an important research project. I noted with interest the repetition of words like "humanity" and notions of science as unquestionable "public goods."

The Genographic Project is more than a scientific attempt to resolve genetic issues concerning the origins of human diversity. It is a project about the politics of life itself. This is why it is mobilizing a range of historical and highly political tensions around such topics as the production of scientific truth; the complex relationships between persons, DNA, and identity; the responsibilities of researchers when working with Indigenous peoples and communities; indigenous rights to control, develop, and derive benefit from any research in which they are participating; and the ownership and future access to genetic databases.

The most serious problem facing the Genographic Project is that it proceeds without adequately addressing its own politics. That is, it presumes that there is no real problem with making Indigenous peoples and communities research objects, that the information garnered will be of benefit to all, and that there is no reason to be concerned about what might happen to this collected genetic material in the future. It is on this point that my greatest concerns about the Genographic Project lie.

In a recent first publication, the Genographic Project Public Participation Mitochondrial DNA Database was announced.[2] This database is now the largest mtDNA database ever collected and comprises some 78,950 samples. The database itself has an Open Source license (which is a copyright license) in order to make it available to the scientific community and the general "public." With the creation of this database, however, new questions of ownership emerge that the project can no longer afford to ignore.

The collection, collation, and long-term storage of genetic material in databases is an area of intense debate and concern within legal and medical communities. Critical concerns revolve around ownership, control, and access to the genetic material. Additionally, there are further questions in relation to what level of privacy protection should be provided to genetic information derived from DNA and tissue samples. These concerns arise precisely because genetic data, like any medical data, are highly sensitive, as they may reveal several levels of personal information—about the individual and his or her relatives. While the potential value of this kind of information is high, how that information is used and by whom remains unpredictable.

Certainly there are distinctions between a database that contains the genetic information obtained from the analysis of DNA or tissue and those databases that contain the actual tissue or DNA samples. Nevertheless, both kinds of databases are sensitive and can pose threats to privacy. As Bregman-Eschet explained, "Genetic databases [pose threats to privacy] via the accumulation of genetic information in one electronic form and DNA banks do so by allowing for the possibility of making endless amounts of DNA copies for different uses from one single sample."[3] The Genographic Project database is the former of these two, though we

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must also presume the existence of the second kind of database—the one that contains the actual tissue or DNA samples and that makes the first kind of database possible.

Despite increasing concern, there are currently no uniform laws relating to the regulation of genetic databases and biobanks in a majority of countries, including the United States, the United Kingdom, Canada, South Africa, and Australia. Indeed, only Estonia and Iceland have enacted specific legislation.[4] Although the database framework itself is protected under copyright law, the actual content remains unprotected. This is where fundamental concerns for ownership, control, consent, benefit sharing, and access arise. With no legal controls, "the general approach in the law across different jurisdictions is that control of the DNA samples rests with the controller of the genetic database."[5] In the context of the Genographic Project, whose primary target groups are indigenous peoples, this issue of ownership and control is significant. With the changing value of genetic information, resolution of these issues now constitutes one of the core responsibilities of the Genographic Project researchers and organizers.

For more than seven years I have worked on ownership, access, and control of indigenous cultural material (such as photographs, sound recordings, and films) found in repositories around the world.[6] In every instance, the value of that material has changed over time and, correspondingly, so too have the interested parties seeking access.[7] In too many cases, Indigenous peoples have not had access to material that relates to themselves, their family, or community.[8] As recording and documentation had been conducted by others, Indigenous peoples were not the "authors" and therefore not the copyright holders of that material. This has meant that Indigenous peoples have had little, if any, legal rights in this material. The point is that these same issues of ownership, control, and consent continue to persist within the Genographic Project. With no legal guidelines or legislative frameworks that govern the status or the future of this genetic material, the Genographic Project is operating in a legal no-man's land. The most obvious danger here is that this ambiguous status tends to benefit those parties who control and can access the information, and as history illustrates, this has seldom been indigenous peoples.

In addition to concerns for ownership and control of genetic databases, other equally pertinent questions remain: for example, what will happen at the end of the project? Will both databases be destroyed? Given their unpredictable value and utility, this is highly unlikely, so where will they end up—in private or public hands? Who will be able to access them? What legal options will be available if there is disclosure of individual or group identity? What safeguards are in place for the potential commercialization and further distribution of this genetic information? Can informed consent really have been given when it is not possible to foresee all the research uses of the genetic material?

Given the historical practices of studying Indigenous peoples, collecting information, and taking that information away, the targeted use of indigenous research

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subjects in areas of science and genetic research that lack clear legislative protections for the research subjects is not acceptable. The Genographic Project has an obligation and a responsibility to address these questions before it proceeds any further.

ENDNOTES

1. "Genographic Project aims to tell us where we came from." *USA Today*, April 12, 2005.
2. Behar et al., "The Genographic Project Public Participation Mitochondrial DNA Database."
3. Bregman-Eschet, "Genetic Databases and Biobanks."
4. Gibbons et al., "Governing Genetic Databases."
5. Kaye et al., "Population Genetic Databases."
6. Anderson, *Indigenous Knowledge and Intellectual Property*; Anderson and Bowrey, "The Imaginary Politics of Access to Knowledge"; Anderson, "Practicing Reality"; Anderson, "Access and Control of Indigenous Knowledge in Libraries and Archives"; Anderson and Koch, "The Politics of Context."
7. For example, in Australia from 1993 onward, state governments, mining companies, and agricultural interests all began accessing archives of indigenous collections in order to respond to increasing litigation around land rights and native title.
8. See Kinnane and Marsh, "Ghost Files."

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