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"Anti-colonial Genomic Practice?" Learning from the Genographic Project and the Chacmool Conference

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I want to commend the organizers of the Chacmool Conference panel. All too often attempts to discuss the broader social and cultural dimensions of genetic studies of ancient human migrations devolve into simplistic celebrations or condemnations. It is heartening to find here an example of a conference session that managed to avoid these dangerous poles, and to grapple instead with the hard task of discerning the issues raised and not raised by genomic studies of human migrations and history. I would like to devote my commentary to exploring what might be learned from the discussions at Chacmool.

Perhaps mostly important, the Chacmool panel transcript makes very clear that what is at issue in these studies—studies exemplified in many talks at Chacmool about the National Geographic's Genographic Project—is not a clash between pro-science anthropologists, archaeologists, and geneticists on the one hand, and anti-science indigenous communities on the other.[1] Jerry Cybulski, Carrie Dan, and Sheila Greer all provided very promising examples of First Nations peoples in Canada working as scientists, or with scientists, to do human genetic variation research.[2] They made clear that members of indigenous groups are not antiscience; rather, as Debra Harry noted, they are "pro–indigenous rights."[3] The question is not how to stop genomic studies of indigenous DNA; the question is how to do this research in a manner that respects and responds to the concerns and values of the people whose genomes scientists analyze.

It is here that the hard questions begin: How do you conduct science in a way that both respects and promotes the values of indigenous peoples *and* the values of scientific inquiry? At one level, the answer to this question appears simple: first, one conducts research in a manner that respects rights of self-determination (e.g., the right of indigenous communities to decide if and how they will participate in research) and second, one provides benefits to indigenous communities. Indeed,

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as much as some indigenous rights leaders and organizers of National Geographic's Genographic Project have disagreed, they do agree on these two guiding principles. The unresolved challenges lie in determining exactly what it might mean to transform these principles into practice. I will focus on the challenges posed by the first principle: respect indigenous rights of self-determination. I break this into two parts: (1) the challenge of determining who the "self" is that determines and (2) the challenge of determining what it would mean, and what it would take, for that self to make determinations. I will begin with the first challenge: defining "the self" that determines.

As many of the speakers in the Chacmool panel made clear, in most indigenous communities the self that has the right to make decisions is not understood to be an autonomous, *individual self*, as it is in Western liberalism. Rather, it is a self that recognizes its connections to others living in the present, past, and future. It is a *collective self*.[4] By now, most who conduct research involving Indigenous peoples (including the organizers of the Genographic Project) understand this distinction between a Western liberal self and a collective self, and the need to respect both. However, much uncertainty remains on how exactly to do this.[5] The Genographic Project, for example, states in its "Ethical Framework" that "the authority to speak on behalf of any group is fundamentally local and limited."[6] The intention here is admirable: to allow people to speak for themselves, and not to let people or organizations located in distant lands speak for them. Translating this intention into practice, however, raises difficult questions. As audience member Bjorn Simonsen asked at the Chacmool meeting, when you say the local community speaks for itself, "who is that community? Are they people who turned up at that particular meeting who said, 'Yeah, this sounds like a good idea. Nice presentation.'"[7] This question about who the local community is, and who speaks for it, is more or less difficult depending on whether there is a formal governing structure, and if there is, whether indigenous peoples recognize this formal governing structure as their own or deem it a structure imposed by a colonial nation-state.

However, even in the best of circumstances where a formal governing structure does exist that is recognized as legitimate by Indigenous peoples, resource shortages and the complexity of contemporary issues have led these local communities to network with regional and international governance efforts. A recent report of the Indigenous Community Governance Project (ICGP), for example, found that indigenous community organizations are often "overloaded" and "underfunded." The resulting struggle of small, local organizations to sustain their service and administrative capacities leads "to federal and regionally dispersed forms of governance."[8] This finding is consistent with what I have found in my fieldwork and interviews with members of indigenous groups responsible for responding to requests for DNA. Many who work with or are on governing bodies that review research for First Nations in Canada or tribes in the United States report that these bodies often depend on volunteer labor and, as Sheila Greer noted at Chacmool, are so "taxed" that they do not have the resources needed to gather all the information they need to ade-

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quately review genomic studies.[9] This is one reason why some Indigenous peoples have sought to work together to create regional and international infrastructures—such as the United Nations Permanent Forum on Indigenous Issues (UNPFII), and the Indigenous Peoples Council on Biocolonialism (IPCB)—that can do this work.[10]

The result is a network of organizations that span local, regional, and international levels. Scientists who seek to study the DNA of Indigenous peoples must navigate what ICGP has called these emergent and complex "networks of leadership and authority."[11] Understandably, these scientists often encounter problems. Networks raise fundamental questions of governance: What nodes in the "networks of leadership and authority" must scientists pay attention to? What criteria should they use to decide? There are no settled answers, and genome scientists should not be blamed for doing wrong when no clear rights and wrongs exist. Conversely, though, these same scientists understandably create problems and provoke antagonism if they act as if they have all the right answers.[12]

In addition to these questions about the definition of the self—questions partially created by the pressures of colonialism, globalization, and the complexity of an increasingly technoscientific world—efforts to respect indigenous rights of "self-determination" also create challenging questions about what it would take for indigenous peoples to "determine" if they want to participate in this kind of genomic research. Most efforts to answer these questions draw upon the Enlightenment notion that human beings can best make determinations when enlightened by information and knowledge. In the language of dominant discourses of biomedical ethics, this is the practice of informed consent. By now there have been many questions raised about how an Indigenous person could ever be in the position to truly give informed consent to do genomic research. These questions normally turn on questions about whether Indigenous peoples can understand what genomics entails. I suggest, however, that the more important questions hinge on whether genome scientists themselves understand what genomics entails. Organizers of the Genographic Project, for example, state that their initiative primarily entails a "nonpolitical" quest for knowledge about the human past.[13] The result will be greater stores of information and rationality that will help human beings overcome their irrational prejudices.[14] Like organizers of the Human Genome Diversity Project, they deny their involvement in anything that might tarnish their Enlightenment goals: patents, racism, and political struggles over sovereignty and group membership.[15] Indeed, some organizers of the Genographic Project cast as either irrational or uninformed those who suggest their project raises issues of politics and power, such as threats to indigenous rights of self-determination.[16]

In the face of Genographic Project organizers' apparent resistance to recognize their initiative's entanglement in complicated questions about how power and capital (economic and cultural) form in a genomic age, it now falls upon indigenous groups to answer the many unresolved questions. These questions are not easy to address. Let me provide one example.[17] Genographic organizers state that they will not allow any patenting of the data generated by the project. I believe them.

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However, as the project's FAQ document explains, "Family Tree DNA [a genetic ancestry company] does have access to some of the DNA and data to assist in the analytical research."[18] This raises the following questions: Will access to these data enable Family Tree DNA to develop a new generation of ancestry tests that they can then sell?[19] In such a case, as Genographic promises, the data would not be patented, but could a new genetic ancestry test be patented? Will Family Tree DNA be able to go back to indigenous groups to ask them if they can perform further tests on their DNA? Finally, who will profit economically from the films made about the Genographic Project?[20] In other words, although the Genographic Project might not, strictly speaking, produce profits, will it spin off profit-generating products, such as films and genetic tests? If the answer is yes, should this be part of the information provided to indigenous groups as they make their decisions? The Chacmool Conference provided a much-needed space in which these questions could be raised, and approaches to answering them discussed.

Many organizers of genomic studies of early human history and many indigenous people share a similar goal: conducting genomic research in a manner that respects Indigenous peoples and their rights. Sharing this common goal is a first essential step toward addressing centuries of unequal and sometimes oppressive relations between anthropologists and geneticists, on the one hand, and the indigenous peoples whom they have sought to study, on the other. However, moving closer to this goal requires recognition that the goal has not yet been met. Despite the similarity of our genes, we are not yet all one (nor do I think it should be our goal to become all one). Furthermore, we cannot and should not act as if we are.[21] Consequential power differentials and historical structures of inequality continue to separate many genome scientists from many of the indigenous people they seek to study. For any productive dialogue to take place, the specificity of these power relations—in particular, the specificity of the ways in which genomics shapes and is shaped by them—must be addressed. This, in turn, will require stepping back from the fear that recognizing difficult questions about power and authority will automatically lead to condemnation, a repeat of the Human Genome Diversity Project debacle.[22] The panel held at the Chacmool Conference demonstrates that there is no direct link between genomic studies of Indigenous peoples and accusations of racism; instead, there are many openings for developing anticolonial genomic practices. My hope is that organizers of current genomic studies of the human past will take advantage of these openings. Here, in these creative spaces, lie the hope and the new possibilities of genomic studies of human variation.

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sarily reflect the views of the National Science Foundation. I would also like to thank Emma Frau, Donald Smith and Kate O'Riordan for their helpful feedback on this piece.

ENDNOTES

1. For a description of the Genographic Project, see ⟨https://www3.nationalgeographic.com/genographic/⟩ accessed 25 November 2008.

2. Jerry Cybulski is a biological anthropologist who works for the Canadian Museum of Civilization who "collaborates" with First Nations in British Columbia in mtDNA research aimed at revealing early population histories in Canada. Carrie Dan is from the Kamloops Indian Band and is also an archaeologist. She works in the Secwepemc territory as both a community member and a researcher, conducting genetic studies on repatriated ancestral remains. The aim of these studies is to link these remains with those living today who might responsibly care for them. Sheila Greer is an anthropologist who is employed by the Yukon-based Champagne and Aishihik First Nations. She has worked with those First Nations across the southern Yukon and adjacent southeast Alaska that have "voluntarily chosen" to participate in the Community DNA study, a study, like Dan's, that seeks to find the living ancestors of ancestral remains so that these people's living ancestors might responsibly care for these remains. For more details, see transcript of the Chacmool panel discussion published in this volume.

3. Specifically, Debra Harry stated, "I want to reiterate that we're not being antiscience or antiresearch. There's nothing wrong with research. There's nothing wrong with sound scientific inquiry. But we are definitely pro–human rights and pro–indigenous rights, so we're looking at these research projects from that context." Harry is executive director of the Indigenous Peoples Council on Biocolonialism (IPCB). For more information on the IPCB, see http://www.ipcb.org (accessed 25 November 2008).

4. As Sheila Greer noted, "I remind the audience that indigenous societies are collectivist ones, where there really are no individuals, but rather citizens connected through a complex web of very strong social relationships." Jerry Cybulski emphasized that the decisions in the First Nations in Canada with which he works are "community decisions." See Chacmool panel discussion transcript in this issue.

5. In addition to the problem that I describe here of how to define the who speaks for indigenous people, genomics also raises the problem that Daryl Pullman raised at Chacmool: It is not always clear that an indigenous community is the only collectivity that can claim a right to own and control genetic material. As Pullman noted, "Yes, but you can ratchet that [claim that ancient DNA belongs to the whole indigenous community] up—the literature talks about the human genome belonging to all of us as well, to all of humanity, while at the same time, communities want to exercise a degree of control over it."

6. The Genographic Project's Ethical Framework can be downloaded at https://www3.nationalgeographic.com/genographic/?fs=www5.nationalgeographic.com/ by clicking on "Read the Ethical Framework" (accessed 25 November 2008).

7. See Chacmool panel transcript in this issue.

8. ICGP, *Further Key Insights*, p. 2; ICGP, *Ten Key Messages*, p. 3. The ICGP is supported by the Australian Government, Reconciliation Australia, and the Australian National University. I want to thank Simon Longstaff for informing me about the work of the ICGP.

9. Specifically, Sheila Greer explained at Chacmool, "the capacity of the indigenous government, organization, or other body is often taxed as far as the ability of their staff—or consultants engaged as advisors—to make sure their interests are adequately recognized or protected. Financial resources affect the situation significantly. When it comes to research and studies, my personal experience tells me that 'he who pays the piper calls the tune.' I cannot speak strongly enough about the importance of First Nations or other indigenous organizations having their own resources—resources that are

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independent of any process that may compromise their ability to act in their own best interest or as representatives of their peoples." My own fieldwork confirms Sheila Greer's observation. See Reardon, *Race to the Finish*; Author's Fieldwork Notes from the meeting "For Tribes: How to Build and Sustain a Tribal Institutional Review Board," 11 July 2005.

10. The IPCB, Cultural Survival, the United Nations Permanent Forum on Indigenous Issues (UNPFII), and the Council for Responsible Genetics precisely worry about the material conditions that make research review and "informed consent" possible. Genographic scientists collect samples in some of the most remote places on earth, places reached only through flying on some of "the most dangerous flights in the world," and places not yet materially connected to emerging indigenous networks of knowledge about the material and social practices of genomics (See https://www3.nationalgeographic.com/genographic/pi/balanovska_notes.html accessed 25 November 2008). In such conditions, they ask, what would it mean to give "informed consent"? People in these places are "informed" about the Genographic Project by Genographic scientists, interested parties who "inform" on some things and not others. IPCB and other indigenous right groups have tried to make these questions about the material conditions of consent visible. These questions transform the problem of informed consent from one of an *individual's capacities to understand genomics*, to one of the *capacity of institutions that support genomic research to produce effective and accountable knowledges about this research*. I address this issue in more detail later in this commentary. For debates on what it means to "inform" as they played out in the Human Genome Diversity Project, see Reardon, *Race to the Finish*, pp. 106–113.

11. See ICGP, *Ten Key Messages*, p. 4.

12. Convinced of the rightness of their own framework for addressing questions about the constitution of authority within Indigenous communities, Genographic Project organizers did not send out their "Ethical Framework" for review. One person authored this "Ethical Framework," and because of the project organizers' confidence in the position put forward in this framework, the organizers sought no formal review of this document. See interview of project organizer by author, 25 September 2007. Many problems resulted. Most notably, Genographic researchers failed to consult and gain the review of indigenous governance bodies at critical moments: at the inception of the idea to the Project, during the writing of the "Ethical Framework," and before seeking to collect samples in Alaska. This has generated much ill will and opposition. It also resulted in violations of research codes. In particular, Genographic researchers failed to gain the necessary approval of the Alaska Area Institutional Review Board before collecting samples in Alaska. As a result, Genographic researchers had to send back these samples and start the collection process over again. See Harmon, "DNA Gatherers Hit Snag: Tribes Don't Trust Them," *New York Times* (December 10, 2006).

In a positive development, it does appear that the Project's failure to obtain the approval of the Alaska Area Indian Health Service Institutional Review Board, and the subsequent suspension of the Project in North America, did sensitize Project leadership to some of the complexities of defining authorities who speak for Indigenous groups in the area of research regulation (See Harmon, "Seeking Ancestry in DNA Ties Uncovered by Tests," *New York Times*. ⟨http://www.nytimes.com/2006/04/12/us/12genes.html⟩ (April 12, 2006) accessed 25 November 2008; and interview of project organizer by author, 26 November 2007). It would appear that this has created an opening for indigenous leaders to now work with project leadership to develop positive collaborations.

13. In much of National Geographic's current literature, they describe the Genographic Project as a "non-medical, *non-political*, non-profit and non-commercial" initiative [emphasis added]. See, for example, ⟨https://www3.nationalgeographic.com/genographic/silk_route_announcement.html⟩ accessed 25 November 2008.

14. For Genographic Project director Spencer Well's argument that genomics undermines divisive social theories of race, see, for example, ⟨http://harvardmagazine.com/2008/05/race-in-a-genetic-world.html⟩ accessed 25 November 2008.

15. Interview of Genographic Project organizer, October 19, 2007. See also Small, "First Soldier of the Gene Wars" and ⟨https://www3.nationalgeographic.com/genographic/faqs_results.html⟩ accessed 25 November 2008. For an account of the Diversity Project organizers efforts to disavow of any connection to patents and racism, see Reardon, *Race to the Finish*, pp. 92–96 and 108–112.

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16. Specifically, a central organizer of the Genographic Project stated, "I honestly don't see these results being misused in that way [to threaten indigenous rights]. There may be concerns about that, and I understand that there are concerns about that from some groups, but I honestly think if you evaluate those concerns rationally that there's no real basis for them." See interview of project organizer by author, conducted October 19, 2007. The implied message here is that those who critique the Genographic Project for posing threats to indigenous rights of self-determination do so not on rational grounds. In so doing, this Genographic Project organizer participates in a growing discursive formation that positions as irrational any concerns that do not fall in line with the "rationalism" of the biosciences. See Haran et al., *Human Cloning and the Media*, p. 152. Evidence that genomics might be used in struggles over indigenous rights includes the U.S. Department of Interior's attempt to use genetic tests in the Kennewick Man case to attempt to establish the cultural affiliation of the 9000-year-old remains found in 1996 in Washington state. The remains were found within the historical land base of tribes including the Confederated Tribes of the Umatilla Indian Reservation, the Colville Confederated Tribes, the Wanapum Band, the Yakama Nation, and the Nez Perce Tribe, and these tribes sought immediate reburial of the remains. Genetic tests were invoked in an effort to oppose the tribes' claims to the remains and were viewed by many as an effort to undermine rights granted to tribes under the Native American Graves Protection and Repatriation Act. See TallBear, "DNA, Blood, and Racializing the Tribe." In 2000, a state representative in Vermont proposed a bill to establish procedures and standards for using DNA tests to establish the identity of an individual as Native American (General Assembly of the State of Vermont, *House Bill 809: An Act Relating to DNA Testing and Native Americans*; TallBear, "DNA, Blood, and Racializing the Tribe"). More recently it has become clear that despite what the state or national governments might or might not do, some individuals will use genetic tests as a way to claim a racial or ethnic identity for the purposes of claiming state benefits. See Harmon, "Seeking Ancestry in DNA Ties."

17. Among other difficult questions usefully explored at the Chacmool Conference were questions about the meaning and effectiveness of research subjects' "ownership" of "their DNA," about the status of DNA as "cultural property," about the definition of the subject who has the right to govern genomics, and about the place and legitimacy of collective rights in liberal systems of governing genomics.

18. See ⟨https://www3.nationalgeographic.com/genographic/faqs_privacy.html⟩.

19. One main organizer of the Genographic Project did observe that "companies probably do make use of this data at some point to design [anthropological] tests" (Interview of Genographic organizer by author, 19 October 2007).

20. The National Geographic Society created a for-profit arm in 1996, National Geographic Ventures. Since then the Society has created several other for-profit arms, including National Geographic Channels International (NGCI). *Journey of Man* and the other films made about the Genographic Project (four are planned) are broadcast on NGCI channels.

21. Reportedly, dialogue at a meeting between National Geographic, Cultural Survival, and the IPCB broke down when National Geographic leadership departed from a dialogue procedure agreed to in advance that had been designed to address differences among the people invited to the meeting. Instead of two circles and a speaking structure that gave National Geographic a chance to present its case, National Geographic leadership reportedly invited everyone to join the same circle and gave up its platform to speak. This "we can all get along" approach provided no way to address the questions of power at play in the meeting, and, predictably, the meeting broke down (interview of meeting participant by author, 14 December 2007).

22. For an account of the controversies and problems generated by efforts to organize the Human Genome Diversity Project, see Reardon, *Race to the Finish*.

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