

**Strengths and Dangers of Developing a Market for Genome Diversity Mapping:
Considering the Literature from Indigenous Perspectives and Communities**

Context / Background of Previous Attempts to Identify Indigenous Populations for the Purpose of Genome Testing

Just in December, elders froze in South Dakota because of substandard housing. And then you look at the millions and millions of dollars that are being spent to research indigenous peoples' DNA with absolutely no regard for our lives, and maybe even no intent to ensure our survival as peoples. I honestly don't think that there is much of an interest really to make sure that we survive as who we are.¹

- Native American representative at a 1998 HGDP Stanford meeting

We are suffering and dying from type II diabetes because our pancreases can't manage the amounts of...junk food, the carbs what we consume...We are not dying from our physical inheritance. We are dying from the environments that we live in, and the conditions that we have to survive in.²

- Debra Harry, Indigenous Peoples Council on Biocolonialism

One can easily see how scientific speculation on who came from where would eventually be used to politically disenfranchise Indigenous peoples.³

- Winona LaDuke, Native American Activist

For Indigenous peoples, who are often the most marginalized and impoverished peoples of the world, the promises of benefit sharing agreements may be alluring...Before entering into a benefit sharing agreement, Indigenous peoples must understand that by entering such an agreement, they are submitting to a legal jurisdiction entirely foreign to their own systems of management and protection of natural resources and knowledge.⁴

- United Nations Permanent Forum on Indigenous Issues

Indigenous peoples who provide key material for a project have a right to share in the long term profit which accrues from that project's outcome, even if it is many years in coming. Protocols that outline these principles may be useful in helping all those involved to ensure that issues are fully discussed and understood.⁵

- Michael Dodson and Robert Williamson, University of New South Wales

If Indigenous people were interested in genetic research for a genetic question specific to their group, they do not need the HGD project to do this work. The technology and expertise is widely available to groups interested in genetic research.⁶

- Debra Harry

¹ Jenny Reardon, "Creating Participatory Subjects," in *The New Political Sociology of Science*, ed. Scott Frickel and Kelly Moore (Madison: University of Wisconsin Press: 2006), 360.

² Winona LaDuke, "Vampires in the New World," in *Recovering the Sacred* (Cambridge: South End Press, 2005), 129.

³ *Ibid.*, 123-124.

⁴ United Nations Permanent Forum on Indigenous Issues. Sixth Session, May 14-25, 2007, New York, NY. *Indigenous Peoples Council on Biocolonialism*, <http://www.ipcb.org/>

⁵ Michael Dodson and Robert Williamson, "Indigenous Peoples and the morality of the Human Genome Diversity Project," *Journal of Medical Ethics* 25 (1999): 204-8.

⁶ Debra Harry, "The Human Genome Diversity Project and its Implications for Indigenous Peoples," *GeneWatch* 20:2-3 (1996), 8-9.

In 1991, the Human Genome Diversity Project was first proposed for the purpose of sampling and archiving human genetic diversity in order to understand “who we are as a species and how we came to be.”⁷ The immediate target subjects for the study became indigenous populations. According to organizers, the genetic identities of these isolated groups were becoming threatened with increasing migration and mixing of populations. Sampling of these populations was, then of “greatest importance for understanding human evolution...[and the] valuable gene pools would need to be sampled before they ‘vanished’.”⁸ What researchers did not expect was the fierce opposition to their project by the very subjects of their study: the many different indigenous groups around the world. While the researchers claimed that the collection of samples would benefit all of humankind and curtail racism by furthering a collective knowledge of humanity’s shared past and origins, publicly claimed to be against the patenting of any of their collected samples, and welcomed collaboration from indigenous groups, the researchers’ best intentions could not convince many of their target groups that the project would be beneficial in any way, or even be, at best, harmless. Although many spokespeople for the indigenous groups agreed that HGDP organizers believed they were embarking on a just and beneficial project, their opposition was rooted in the recognition that “researchers and potential research subjects do not share the same cultural values and structural positions in society.”⁹ Of the many concerns indigenous representatives voiced, three became prominent in the ensuing discussions with HGDP organizers: 1) Indigenous groups had little to no interest in investigating ancestral origins based on genetic analysis because they already had a knowledge system in place which created their ancestral identity; 2) Many indigenous groups had no intentions of “vanishing”. They questioned why millions of dollars would be spent on researching Indigenous

⁷ Jenny Reardon, *Race to the Finish* (Princeton: Princeton University Press, 2005), 1.

⁸ *Ibid.*, 1.

⁹ Jenny Reardon, “Creating Participatory Subjects,” in *The New Political Sociology of Science*, ed. Scott Frickel and Kelly Moore (Madison: University of Wisconsin Press: 2006), 353.

DNA while many of those Indigenous populations did not even have the most basic necessities for survival; and 3) they believed that any genetic constructions of identity could undermine indigenous struggles for land, resources, rights and efforts towards self-determination that many self-identified indigenous groups have been struggling for against colonial powers. These concerns, along with many more, including individual and group consent boundaries, the sanctity of life disrupted by the extraction of DNA, potential patent piracy and commercialization DNA materials, the indeterminacy of many genetic conclusions, and the attention not paid to cultural or environmental conditions have limited the progress the Human Genetic Diversity Project hoped to have made to date and have raised questions concerning other efforts which involve the genomic testing of indigenous peoples. The HGDP is still pursuing its efforts, however, along with similar groups like the International HapMap project and others directly involved in investigating the links between individual and population genomes and health. Based, primarily, on the concerns identified from this relationship between the HGDP organizers and Indigenous groups, then, some ethical guidelines have been proposed for future genomic research that may want target Indigenous populations. These ethical guidelines are not exhaustive and welcome additional insights, especially from representatives of Indigenous peoples and from other contributors working on guidelines for individual genomic testing.

Ethical Guidelines for Future Genomic Research involving Indigenous Peoples

- 1. Any research project that is seeking the participation of Indigenous subjects should include subjects in the full planning, implementation and analysis of the project, from the actual planning stages to the publication of results.**
- 2. Definitions of group consent, essential for many indigenous peoples who regard culture and property (including biological property) as belonging to a group or tribe rather than an individual, should be understood and negotiated in partnership with the subject group. Scientists need to respect the cultural values of the group and to “accept answers that they may not like. If the result of such negotiations is that research does not proceed, so be it.”¹⁰**
- 3. Any research which is agreed upon which seeks to establish the evolutionary history or geographic of subject groups should:**
 - A) Recognize the limitations of genetic analysis in establishing ancestral conclusions;¹¹**
 - B) Recognize other forms of knowledge establishing Indigenous identity, such as cultural affiliation or oral history, as equally determinative. Thus, any legal action involving Indigenous peoples and their rights to self-determination (including land and resource issues) should give Indigenous groups involved the option of determining their ancestral identity culturally or biologically (a comparison of adoptive vs. natural parental rights might suitable for establishing status of identity). Both forms of knowledge need to be recognized as distinct forms of knowledge, neither being more valid than the other.**
- 4. Any Indigenous peoples who provide genetic or other material for the purposes of research should receives agreed upon shares in any profit that may accrue as the result of such material, including profits accrued by other researchers who borrow or share the material. While this guideline “represents a breach in principle that all participation in research is strictly voluntary and not dependent on remuneration, in this context the group that has been previously disadvantaged receives the benefit as a people.”¹²**
- 5. With respect to the above guideline, any genetic or biological material provided to researchers should remain the sole property of the donating Indigenous peoples, giving them the right to choose with whom the material is shared with. This is in conjunction with the United Nations Permanent Forum on Indigenous Issues, Sixth Session, 2007, which concluded that Indigenous peoples’ rights with “are not limited to Indigenous knowledge...[including] genetic resources that originate in [their] territories, lands and waters whether or not associated directly with Indigenous knowledge.”¹³**
- 6. If there is not a mutually shared interest in the result of the genetic research, and if no profit is expected from the research, researchers should provide agreed upon resources, aid,**

¹⁰ Dodson, 205.

¹¹ Deborah A. Bolnick, “The Science and Business of Genetic Ancestry Testing,” *Science* 318 (19 October 2007): 399-400.

¹² Dodson, 208.

¹³ United Nations Permanent Forum on Indigenous Issues

training or additional research opportunities to the Indigenous peoples involved in order to contribute in a comparable manner to the interests of the Indigenous group in way that the Indigenous group is participating in the interest of the researchers.

7. With respect to the above guideline, researchers should make an concerted and sincere effort to build a relationship with the Indigenous community before research begins and maintain a relationship with the community after the research concludes.

8. When genetic sampling of Indigenous peoples is conducted for the purposes of health-related research, researchers should co-ordinate their efforts in such a way that genetic research is always conducted in partnership with other researchers who are investigating environmental or social conditions of similar health-related conditions.

Projects Which Could Be In The Interest Of Both Indigenous Peoples and Genetic Researchers (Health-Related Issues)

Genetic research can beneficially impact Indigenous communities. Collaboration with researchers, activists and policy-makers who are working with Individual Genome-Mapping efforts should be pursued, to both contribute insight from Indigenous perspectives and to receive insight from other participants working in the field of individual genomics. Health-related research is one area from which Indigenous groups could benefit, but the same caution should be exercised with regards to data interpretation and ownership as was with the HGDP so that Indigenous interests are not compromised. And equal, if not more, resources should be available for Indigenous communities than genetic resources in order to access basic health-care resources such as clean water, adequate nutrition, and medicines available for tuberculosis, malaria or other common illnesses.

Diabetes, however, prevalent in Indigenous communities worldwide, is one health-related condition that could benefit from further genetic research. Some researchers have concluded that there “is at present no consistent evidence to suggest that minority populations are especially genetically susceptible....Genetic research into complex disease demands careful attention to key environmental, social, and genetic risk factors operating within and between groups.”¹⁴ Others have included that there is a strong genetic basis for the disease and, because Indigenous peoples have a much higher rate of Type 2 diabetes than non-Indigenous peoples, genetic research into this complex disease should focus on Indigenous communities.

One example of such research is being conducted by Joanne Shaw out of the University of Queensland. The organization of her project may be helpful as a model for other health-related research involving Indigenous communities. In a 2002 news release, it did not specify the

¹⁴ Yin C. Paradies, Michael J. Montoya and Stephanie M. Fullerton, “Racialized Genetics and the Study of Complex Diseases,” *Perspectives in Biology and Medicine* 50, no. 2 (Spring 2007): 203-27.

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arrangement made with the involved communities regarding data and genetic-material ownership, or participants' involvement in research design. It does describe Shaw, however, as modeling some of the other guidelines presented above. Besides her research on the genetic components of Type II diabetes, she also has a second project, the development of a Diabetes education program which emphasizes the roles that physical activity, family and community support play in disease progression. She has also been working with the involved communities at their local Indigenous Health Center for six years previous to her current Diabetes research. Her efforts, then, model the importance of building and maintaining relationships with research participants and investing in other projects which directly benefit the community.¹⁵

¹⁵ "Indigenous Communities to Help in Diabetes Battle," Faculty of Health Sciences, University of Queensland, Australia (November 7, 2002) <http://www.uq.edu.au/news/?article=3851>

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Other Resources

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