



GENETIC RESEARCH ON HUMAN MIGRATION

National Geographic's Genographic Project Advances Science but Poses Risks for Indigenous Peoples

Science versus traditional belief systems, benefits versus risks, what constitutes genuine participation in project design, what constitutes free and informed consent—these are some of the issues raised in the debate over the National Geographic Society's Genographic Project. This project, which aims to gain deeper insights into patterns of historical human migration around the world, was launched in Spring 2005 and is scheduled to span five years. It is being carried out by well-intentioned and highly qualified scientific researchers who are following accepted scientific standards for research on human subjects.

The debate over the Genographic Project has touched Cultural Survival directly. One of the project's Advisory Board members, Dr. Wade Davis, Explorer in Residence at the National

Geographic Society, is a member of Cultural Survival's Board of Directors. Cultural Survival's predominantly Indigenous Program Council, which sets programmatic policy and direction for Cultural Survival, has discussed and raised challenging questions about the benefits and risks of the project for Indigenous Peoples.

In the spirit of improving communication and collaboration between Indigenous Peoples and non-Indigenous members of global society, Cultural Survival has offered to facilitate a dialogue between the Genographic Project's leaders and our Program Council so that each can fully understand the other's purposes, interests, and concerns. Due to scheduling conflicts, that meeting will not take place until May 2006.

In the meantime, we offer the following overview of the issues to our readers. The viewpoints for and against the project are succinctly expressed in the article by Genographic Project Leader Dr. Spencer Wells, and in the article by Indigenous activists Debra Harry, Executive Director, and Le'a Malia Kanehe, Esq., of the Indigenous Peoples Council on Biocolonialism. We conclude with a synopsis of the questions and concerns raised during Cultural Survival's October 2005 Program Council meeting, which is authored by the Program Council's co-chairs, Dr. Richard Grounds (Euchee, Oklahoma, USA) and Stella Tamang (Tamang, Nepal).

—Ellen L. Lutz, Executive Director of
Cultural Survival

HOW MUCH WE HAVE TO LEARN

By Spencer Wells

Genographics Project Director

To study humankind's 60,000-year migratory journey around the world and explore our interconnectedness as a species, National Geographic, in partnership with IBM and with funding from the Waitt Family Foundation, launched the five-year Genographic Project in April 2005.

The main components of the project are field research, public participation and communication, and the legacy fund. We are focused on a true collaboration with indigenous peoples in scientific field research.

We have structured the initiative not simply to achieve our research goals, but to search for better ways of learning from indigenous peoples themselves, their groups, and those who work closely with their cultures.

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COLLECTING BLOOD TO PRESERVE CULTURE?

By Debra Harry and Le'a Malia Kanehe

Indigenous Peoples Council on Biocolonialism

The National Geographic Society is going from collecting images and stories to the more invasive practice of collecting blood from indigenous peoples around the world. In April 2005, the National Geographic Society announced its partnership with the IBM Corporation to amass the world's largest bank of indigenous blood and a database of information related to the study of human origins and migrations. This new endeavor, called the Genographic Project, intends to collect, store, and analyze 100,000 DNA samples taken from indigenous peoples.

The five-year \$40-million project, also funded by the Waitt Family Foundation of Gateway Computer fortune, purports to "help people better understand their ancient history." The

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As a not-for-profit scientific and educational organization, it's been a long time since National Geographic simply "took pictures." Teams work closely with indigenous peoples to help conserve cultures, nature, and histories, and to share their stories with a global audience.

I brought the Genographic Project idea to National Geographic because they have a broad mission to bring a practical understanding of world cultures—the value of other peoples' ways of life and worldviews—to a general audience. Our team realizes the depth and scope of the research debate and is realistic about the work ahead.

In the 1990s, as a young geneticist studying under Luca Cavalli Sforza at Stanford, I saw first-hand the passionate discussion surrounding the Human Genome Project on Diversity. This helped to shape the way I thought of my role as I began my own work. I see myself as an historian whose work with indigenous groups complements their own stories.

The Genographic Project involves DNA sampling of 100,000 indigenous and traditional peoples, as well as an equal number of non-indigenous. We have a duty to explain, and explain comprehensively. That is what we have been doing, and are doing now, in each of the research regions we are setting up.

Chairman Michael "Tender Heart" Markley of the Seaconke Wampanoag tribe publicly shares that his group is behind the project "100 percent" and wants to learn more about their story. Jecinaldo Barbosa Cabral, a Brazilian Amazon indigenous leader, stated in *Tierra America* (April 27, 2005), "We aren't opposed to the Genographic Project. But if the indigenous community is not aware of it, then there cannot be agreement about it."

Outside of explaining the project to individual indigenous groups around the world, we seek ongoing input from broader groups like Cultural Survival, the UN Permanent Forum on Indigenous Issues, and the Indigenous Peoples' Council on Biocolonialism. And we are very clear that the thousands of indigenous groups all over the world do not wish to be represented by a single group.

This is what we are and what we are not:

- The Genographic Project is studying the human migratory journey; there is no medical research in the Genographic Project.

- Genetic data will not be patented from any results of the project. We are not collecting clinical data, nor are we examining markers that have any known medical relevance. This is data that will tell us about historical migration patterns.

- Due to sensitive ethical issues around ancient DNA testing, we will be guided by regional authorities in approaching descendants for access and with fully informed consent.

- All the information belongs to the global community and will be released, with indigenous collaboration and approval, into the public domain.

- The Genographic Project is designed with strict, independently approved, technical protocols that assure privacy and the anonymity of all participants. We are seeking special approval to share details of these protocols with those who request them from the regional ethical review committees responsible for overseeing the Genographic Project in each of the international research centers. All applicable laws concerning genetic sampling and fieldwork will be followed, and necessary permits obtained prior to any field sampling.

- Unquestionably, indigenous communities need to become aware of all the implications of any voluntary genetic research project local to them. No group is the same, which is why we designed the Project's research centers to be local to their areas and led by experienced field researchers who are inspired by the communities with whom they work. For example, at the University of Witwaterstrand, African researcher Himla Soodyall was recently bestowed the President's Award by President Thabo Mbeki for her work in human genetics with indigenous communities.

- Researchers explain the project fully, with supporting materials, to the approved collaborators and representatives in their area. They explain the project again to the individuals who volunteer to take part. Participation must be agreed upon through both group and individual written consent. Consent will be guided by the group's preference and the collaborator's experience, using translation where necessary. Researchers explain in advance what will be done with samples and what the information could be when it comes back from the lab. And they explain that we do not intend to replace peoples' stories, but simply add to them.

- In keeping with the scale and spirit of The Genographic Project, we are developing a Legacy Fund to benefit indigenous peoples. Funded from the international sale of the participation kits, the Legacy Fund focuses on educational and cultural programs to assist indigenous communities dealing with the forces of modernization and globalization. Early enthusiasm for the kits has already raised more than \$850,000 for this program. Kits include cheek swabs that are mailed anonymously and tracked with confidential identification numbers online.

- Finally, this is an initiative that will actively involve the public. We want everyone interested to understand the goals, methods, and results. As we have always done, we will support groups in communicating their stories and promoting preservation of their languages and cultures.

What we learn will be continually released into the public domain over the life of the project, and people can go back as we "put the leaves on the branches" to reanalyze, query, and learn more. Over time we are going to create an open-access, interactive, virtual "atlas" of human history.

Today, it's easier than ever to move around our planet; globalization, wars, and environmental disasters only cause more movement. What we lose is the context in which genetic diversity arose. Every two weeks, a language is lost, taking with it irreplaceable knowledge. Between 50 to 90 percent of the 6,000 languages in the world today face extinction, likely over the next century.

The search for our origins has always been bigger than any one group's particular effort to create a snapshot. No one is offering a cure for disease. We are not trying to change peoples' beliefs. The Genographic Project has never been about a single tangible "benefit" to humankind's family, but to tell the story of the whole family.

Collaboratively, working across our viewpoints and expertise, it just might lead to us thinking and learning about each other in new ways. Despite our differences, the human family is closer than we think. We are all learning how much we have to learn.

Dr. Spencer Wells is Project Director of The Genographic Project and an Explorer-in-Residence at the National Geographic Society.

project's research protocol for the North American region was approved by the University of Pennsylvania's Social and Behavioral Sciences Institutional Review Board (IRB). The protocol asks, among other questions, whether Europeans could have migrated to the Americas thousands of years ago, who were the aboriginal inhabitants of North Africa and whether the Berbers are their direct descendents, and who were the aboriginal inhabitants of Indonesia.

The Genographic Project has established ten regional centers around the world that will be responsible for taking DNA samples from 100 participants from each of 1,000 indigenous groups. The sample collections will be maintained at these regional centers in perpetuity for future research on human history.

The project also intends to analyze so-called "ancient DNA," or the genetic material extracted from the remains of ancestors. In order to obtain genetic material from ancient human remains, scientists must crush, scrape, and otherwise desecrate some portion of the remains. The study of ancient remains is a highly sensitive and emotional issue for indigenous peoples and one that cuts to the heart of the debates around scientific racism.

The Genographic Project is reminiscent of the failed Human Genome Diversity Project (HGDP) of the 1990s, which was found unsuitable for US federal funding due to intractable bioethical problems. Although the Genographic Project has tried to distance itself from the HGDP, both projects share similar goals and intellectual leadership. The main significant difference is that the Genographic Project has secured private funding, and thus does not have to undergo the same depth of public scrutiny. The absence of federal oversight raises the level of risk, leaving indigenous peoples with fewer mechanisms for accountability.

The plight of the HGDP is well documented. The issues that plagued it, such as the genetic reification of cultural/ethnic groups, group and individual informed consent, storage and security of genetic samples and data, intellectual property issues, false notions of "disappearing cultures," and prioritizing the saving of blood over the people themselves, are all present in the Genographic Project. Yet, the Genographic Project has only minimally addressed those concerns and seems to base its ethics solely on the notion of individual informed consent, which was found to be insufficient in the case of the HGDP. As the U.S. National Research Council Committee on Human Genome Diversity noted in a 1997 report:

"Consent alone cannot justify research on populations that will not be able to benefit from it because such research violates basic principles of social justice and equality. Research subjects can make a gift to researchers or humanity, but the validity of such a gift in the context of studying genetic diversity, especially of isolated populations, is too problematic to provide the sole justification for the research."

Unless the risk-benefit ratio favors the populations to be studied, the research protocol is not ready for ethical review.

But review of the research protocol for the Genographic Project by the Indigenous Peoples Council on Biocolonialism (IPCBI) indicates that the project fails to address many key ethical issues that were raised in the context of the HGDP, as well as questions regarding the collective and human rights of indigenous peoples.

In the context of the anticipated "extinction" of cultural diversity due to current economic and social pressures, the Genographic Project asserts one of the primary benefits is to protect cultural diversity. The collection of blood from indigenous peoples may be interesting for scientific inquiry, but the IPCBI does not believe it will perpetuate or protect indigenous cultures.

Specific language in the consent form states, "it is possible that some of the findings that result from this study may contradict an oral, written, or other tradition held by you or by members of your group." Indigenous knowledge systems and oral histories are the foundation of cultural diversity. Although the outcomes of this project may indeed contradict indigenous knowledge, the findings themselves can only be speculative at best, since this type of research is not definitive. The discounting of indigenous historical knowledge goes beyond just a difference of opinion. A claim that challenges the "indigeness" or "aboriginality" of certain indigenous peoples could pose serious political threats.

Indigenous peoples' rights are based, in part, on being the original inhabitants of their territories. Governments have a long history of trying to divest indigenous peoples of their land rights and undermine their cultural integrity, by any means necessary. Despite the speculative nature of genetic research on human histories, the findings of the Genographic Project will carry the weight of science, which could be used to trump indigenous peoples' unique political status and rights.

If the Genographic Project will not benefit indigenous peoples, who will it benefit? National Geographic has said it considers the bank and database a "scientific legacy" for future generations of researchers. It will create new media for distribution through their various outlets that undoubtedly will generate new sources of revenue. The scientists will advance their academic careers. IBM will firmly establish itself as a leader in bioinformatics. National Geographic, IBM, and individual scientists will be the beneficiaries, all at the expense of indigenous peoples.

The question that indigenous people need to ask themselves before deciding to participate is whether this research is designed to answer the questions they are concerned about, and whether the benefits of participation outweigh the risks. For most indigenous people, given the opportunity to hear the full depth of the issues, the answer would be an absolute "no."

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GENOGRAPHIC PROJECT DISCUSSION AT CULTURAL SURVIVAL

In October 2005, Cultural Survival's Program Council met to discuss the issues presented by the recently initiated Genographic Project sponsored by National Geographic and private financial backers. The primary goal of this five-year project is to employ extensive DNA sampling to develop a comprehensive history of the peopling of the planet—showing relationships between historic and contemporary groups and their transmigration patterns. Indigenous and other isolated groups form the core populations who have been targeted to make this study possible.

The Program Council—a rich and diverse representation of Indigenous and non-Indigenous experts working with Indigenous Peoples from around the world—includes members with close-up exposure to the issues. Vincent Nmehielle, a Nigerian lawyer, worked with earlier African genomic research; Jean Jackson, chair of the Anthropology Department at the Massachusetts Institute of Technology, witnessed the impact of the Human Genome Diversity Project (HGDP) on Indigenous Peoples in Colombia; and Richard Grounds is a member of the Yuchi (Euchee) community in Oklahoma, the first Indigenous group contacted for participation in the HGDP in North America.

The discussion among Program Council members and participating Cultural Survival staff and board members was insightful and intense. There was a desire to be fair to the issues and a concern to continue a positive working relationship with the National Geographic Society. However, as the Program Council reminded itself, the first responsibility of Cultural Survival is advocacy and support for Indigenous Peoples. Underlying the exchange was a deep awareness of the divide that separates the diverse Indigenous worlds from the non-Indigenous world—a divide marked by radically different world views, by disparate positions in the political and economic spheres, and by contrasting experiences with western military, educational, and scientific institutions. The power differences represented by these inequities raise the ethical and moral responsibilities of any project involving the DNA of Indigenous Peoples to the highest levels.

The questions that were voiced by Program Council members during our exchange centered on the benefits and risks of the Genographic Project to Indigenous Peoples. How do Indigenous Peoples benefit from this research? If it is difficult to identify any significant benefits to Indigenous communities

based on the science itself, is the Legacy Fund to support Indigenous educational and cultural initiatives an equitable exchange? Can the fairness of that exchange be measured by the percentage of the project's funding that will go toward Indigenous concerns?

And what of the risks for Indigenous Peoples? Since Indigenous Peoples have their own cosmology, ceremonies, songs, and stories that provide satisfactory explanations of their past origins and migrations, why not trust and respect Indigenous knowledge and wisdom? Are not the findings likely to create a clash with traditional understandings and traditional beliefs? Is it acceptable to inject western constructions of descent, migration, and inheritance into Indigenous communities?

What are the guarantees against the improper use of the data? This is of particular concern, since Indigenous communities will likely not have the resources for legal remedies against violations of the agreed limited use of their DNA or blood samples. Will the specimens be destroyed? Who will own the products of the research? Is it even possible to guarantee compliance with the agreed usages into the distant future?

Given the limitations of access to information by isolated groups and the challenges of language differences, how will Indigenous Peoples be effectively informed about the project, both prior to deciding about participation and regarding any results? Will Indigenous communities have the means to prevent the remains of their ancestors from being disturbed and studied?

At what levels and to what extent have the conceiving, design, and execution of the project been truly collaborative with Indigenous communities given the critical importance to the project of Indigenous Peoples in terms of access to their life-matter?

The Program Council welcomes Spencer Wells' expressed interest in seeking ongoing input from Cultural Survival, and we look forward to the forthcoming dialogue with leaders of the Genographic Project.

Stella Tamang (Tamang, Nepal) and Dr. Richard Grounds (Euchee, Oklahoma) are co-chairs of the Cultural Survival Program Council.

