

Human Genome Diversity Project: Impact on Indigenous Communities

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The study of genetic variation in the human species cannot be undertaken outside the cultural, political, and historical context within which scientific research has been traditionally conducted on indigenous peoples. Consideration of their rights may render the Human Genome Diversity Project, as originally articulated, intractable.

Intermediate

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Introduction

0172.1 The Human Genome Diversity Project (HGDP) was proposed as an augmentation to the Human Genome Project (HGP; Cavalli-Sforza *et al.*, 1991). Recognizing that the HGP was based on a Platonic design in which the human species was represented by a single ideal specimen (Walsh and Marks, 1986), population geneticists proposed the collection of genetic material from diverse populations of the world. In the years since that initial proposal, the project has come under intense criticism by members and advocates of indigenous peoples.

unstable and were sensitive to the statistics used, the genes analyzed, the particular populations chosen, and the demographic history of the groups.

If the HGDP had been principally interested in the structure of the contemporary human gene pool, it might have begun by sampling according to an arbitrary criterion such as geography, as one of its principal organizers, Allan Wilson, suggested at the outset. But its guiding question was the genetic relations among culturally designated groups, and so it adopted the cultural groups themselves as its organizing principle for sampling, which became the root of the controversy. 0172.4

Why the Focus on Indigenous Communities At All?

0172.2 Many of the problems faced by the HGDP were brought about by its insistence on targeting indigenous, exotic peoples rather than urban populations. If the goal was to study the human gene pool at the beginning of the twenty-first century, it was flawed, because the indigenous peoples only represent a small fraction of that gene pool. The project could be better served, notes the National Research Council's report from 1997, by collecting samples from internally diverse urban populations.

0172.3 The HGDP was structured around a single research topic: the microphylogeny of the human species – the pattern of descent of different human groups – which had been a principal research issue of the HGDP's leader, Stanford geneticist Luca Cavalli-Sforza. Using statistical analyses of the frequencies of many alleles across many populations, Cavalli-Sforza represented the similarity of human gene pools in a tree-like structure or dendrogram, which resembled the ancestry of species. But these dendrograms grossly oversimplified the historical processes affecting human populations. As a result, these depictions were

Historical and Political Context

Blood has been retrieved in the field by anthropologists since the development of serological technology early in the twentieth century. Carleton Coon was the first to retrieve blood (in 1922) from 'his people,' the Rif, in Morocco, to see whether their physical features and their blood-group features would match when allocating them racially. 0172.5

Blood remained a staple of anthropological collection even as the questions changed and race waned as the dominant anthropological paradigm. Even so, it had special problems associated with it, as Coon himself noted in the 1950s: 0172.6

Blood-letting for blood-group analysis falls into the class of blood-letting in general, and evokes the whole ideology of blood-brotherhood, the fear of injury by contagious magic, and that of ritual contamination based on the analogy of menstruation. (Coon, 1954)

Blood is never, as anthropologists have been known to say, 'just' blood. Nevertheless its collection had proceeded for decades on a small scale, sometimes 0172.7

as part of a specifically anthropological project or sometimes for medical testing, and it has been retained and ‘piggybacked’ by researchers interested in other questions. The overarching assumption here has been that once the substance is out of the person’s vein, it belongs to the researcher.

0172.8 This followed tradition in classical anthropology: the great collections of Native American skeletal materials, for example, were ‘acquired’ in the nineteenth and twentieth centuries through practices that even included grave-robbing. ‘It is most unpleasant work to steal bones from a grave,’ wrote the great anthropologist Franz Boas to his sister very early in his career, ‘but... someone has to do it.’ Ultimately the bones came under the control of museum scientists and were used to advance the careers of the many scholars who acquired them or analyzed them, often without regard for the sensibilities of the people whose relatives the bones actually comprised. It was a classic colonial enterprise, agents of a powerful state acting with little regard for the powerless.

0172.9 The situation changed dramatically with the passage of the Native American Graves Protection and Repatriation Act of 1990 (NAGPRA). This legislation was designed to acknowledge that North American Indian remains were sacred objects, no less sacred than the scientists’ relatives’ bones, and belonged not to science but to the tribes from whom they had been ‘acquired.’ This was a significant affirmation of the rights of indigenous Americans and came at precisely the same time that the HGDP was being formulated and was naively planning to collect bioanthropological objects of sacred value on a large scale.

0172.10 A second significant political context involved widespread rumors within indigenous communities, who were finally beginning to get attention, of ‘white people’ plotting to steal the body parts, bodies, or simply blood of indigenous people. In some cases they were right, as an international trade in body organs later developed. Perhaps it is not surprising that a prominent paleontologist was abducted from an archaeological site in East Africa at gunpoint by local people, who believed mistakenly that he wanted to steal the blood from their babies.

0172.11 A third political context involved the development of ‘biocolonialism’ by agribusiness. Availing themselves of ‘knowledge freely given by indigenous people, large agricultural corporations were making considerable profits in which the people whose knowledge they needed were not sharing. In addition, patent law concerning biotechnology strongly favors scientists, as the unsuccessful cases of John Moore (Greely, 1998) and the descendants of Henrietta Lacks (Jackson, 2001) showed – neither was permitted to share in the profits made from cell lines derived from their bodies.

In the case of the blood of indigenous people, the National Institutes of Health applied for patents for cell lines derived ultimately from the blood of a Hagahai (Papua New Guinea), a Solomon Islander, and a Guaymí (Panama). This seems to recreate the scenario of the rapacious North American capitalist, looting not merely the land or artifacts or knowledge of tribal people, but now their very blood.

Group Consent

Since the HGDP was conceptualized around human 0172.12 groups, each individual sample is only interesting to the extent that it is a representative of that group. Consequently the idea of ‘group consent’ was devised as a means of securing not only the voluntary participation of the particular blood donor, but also the voluntary participation of the polity represented by the donor.

While introducing group consent was an admirable 0172.13 step in principle, it raised a significant number of ancillary issues, centering on the idea of representation: Which blood samples represent which peoples? After all, human groups are fluid and organized hierarchically. Is group consent relevant to someone who is a ‘Chiricahua Apache,’ an ‘Apache,’ an ‘Athapaskan,’ and an ‘American Indian’ simultaneously? If the Northern Paiutes decide not to participate in a study and the Southern Paiutes decide to participate as Paiute representatives, are the rights of the Northern Paiutes thereby violated? If the Hopi decline to participate in a genetic study, can geneticists be prevented from soliciting samples from acculturated Hopis living outside their reservation?

Further, the solicitation of permission from a 0172.14 political entity representing the people raises the problem of possible coercion. If the leaders agree to participate, does an individual still have free rein to refuse, or can the leaders now simply act as agents for the scientists and subtly compel compliance? And more specifically, does everyone in the decision-making complex understand fully what the scientists want, why they want it, and what they plan to do? For people who do not share scientific comprehensions of blood, cells, deoxyribonucleic acid (DNA), identity, life, illness, and medical genetics, the elicitation of full informed consent would seem to necessitate the development of a crash course in local biological idioms.

Ultimately, the issue of group consent would also 0172.15 serve to reify these groups genetically as units of nature, when they are in fact units of social, political, and historical manufacture. Perhaps the best statement about the problem of relating human group-assignment to the reality of identity is given by the late

Frank Dukepoo (Dukepoo, 1998, p. 242), a Native American geneticist:

I call myself a 'full-blood' American Indian of Hopi and Laguna heritage. While constructing my own pedigree, I found this is far from the truth: my father (a 'Hopi') is a mixture of Hopi, Ute, Paiute, Tewa and Navajo; my mother, on the other hand, (a 'Laguna') is a mixture of Laguna, Acoma, Isleta, Zuni and Spanish. Members of other tribes share similar admixture histories as our ancestors raided, traded or kidnapped to ensure survival of their numbers. As it is reasonably safe to surmise the same situation for members of other ethnic groups, what would 'diversity' research reveal?

Pragmatic Concerns

0172.16 In an early attempt to muster interest for the HGDP, its advocates used arguments from 'salvage anthropology' – the impending loss of these peoples, an argument familiar to anthropologists since the middle of the nineteenth century. However, it sounds very cynical to ask for blood from people who are on the brink of extinction. A native of the Solomon Islands wrote:

The project has very little interest in helping these people to survive, or in addressing the social, the economical, the political, and the exploitation issues that endanger these indigenous groups of people. (Liloqula, 1996)

0172.17 Moreover, some groups were simply experiencing the normal historic forces of merging, splitting, reconstituting, and forging new identities; they were 'endangered' only as bound genetic entities.

0172.18 Participation in the benefits of modern health care often requires allowing blood to be drawn. Some insecurity naturally arises about the fate of that blood – a highly symbolically charged substance – once its diagnostic purpose has been served.

On one occasion, when Cavalli-Sforza was taking blood from schoolchildren in a rural region of the Central African Republic, he was confronted by an angry farmer brandishing an ax. Recalls the scientist, 'I remember him saying, "If you take the blood of the children, I'll take yours". He was worried that we might want to do some magic with the blood'. (Subramanian, 1995, p. 54)

0172.19 Rather than musing over the ignorance of the ax-wielding farmer, a contemporary reader should instead recognize unfulfilled obligations of disclosure to the participants here. A strong fear of the magic in blood makes it very unlikely that these people could have given their fully informed consent to this research.

0172.20 The existence of such ideologies about the power of blood could in principle be circumvented by

stipulating that the blood, once drawn, can be used only for the medical purpose specified and must then be destroyed. That is commonly the case now with some North American Indian groups, but there is unfortunately no way to enforce it. Blood from indigenous peoples has been a valuable scientific commodity, traded between laboratories and researchers, for different projects, establishing a network of relationships, obligations, and coauthorships (Anderson, 2000). The prospect of such a scientific tradition abruptly ceasing is quite unlikely, regardless of the agreements made with tribes, who may also have cynical views on Euroamerican people living up to their agreements at all.

The question of genetic exploitation is of para- 0172.21 mount importance. If there is economic value in the blood of indigenous people (as the interest of biotechnology companies might suggest), then what is a fair price? The HGDP's insistence that there are no financial considerations was forcefully undermined by the patent applications, which did not involve the HGDP itself but were obviously relevant. Consequently any adequate concept of disclosure and voluntary informed consent would necessitate the scientist explaining to participants that there are financial stakes, through which the researcher could get wealthy without precedent for the subject sharing in that wealth!

Since the HGDP's initial interest was to formulate 0172.22 and answer questions of microevolution, another issue is raised, calling attention to science's role in authoritatively contradicting people's ideas of their folk history and identity. One could legitimately ask why anyone would wish to participate in a project designed to undermine their own ideas of who they are and where they came from.

In any case, medical value, which came to be 0172.23 emphasized a few years after the project's inception, would be difficult to establish, as there have not been any plans for collecting detailed medical, phenotype, and life-history data to associate with the genotypes. A study of the genetic etiology of diabetes, for example, would require knowledge of which DNA samples actually came from people who were diabetic. But those samples could then not be used for a study of the genetics of schizophrenia, because there would be no information about which samples came from schizophrenics. Thus the HGDP samples could only be of exceedingly limited medical use.

The Iceland genome project, on the other hand, in 0172.24 which the national government cooperated with a private biotechnology company, combining full medical records with blood samples in the hopes of sharing in the wealth, calls attention to the economic incentive: a desire to commodify the body and the bioinformation associated with it.

0172.25 A final salutary goal promoted by the HGDP involved delegitimizing group hatreds by demonstrating the nonexistence of race. Unfortunately, this is unlikely; group hatreds are rarely rooted in biological difference or biological knowledge, and race has long been known to exert a profound impact upon modern lives as a very real set of social categories and statuses.

0172.26 But some geneticists have gone so far as to promise a genetic test to determine tribal membership and Native American identity, a false and patently impossible goal, given that tribal membership is a political status, and that there is a history of mixed races (Shelton and Marks, 2001). Ultimately, the impact of the HGDP has been to reinforce many communities' worst fears about the avarice of wealthy nations and the residual colonial attitudes of science, appearing more as an instrument for their exploitation than as a fulfillment of the Baconian promise of a better life for all.

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Further Reading

Glossary

- Biocolonialism.** Political relationship in which economically developed nations or corporations acquire the environmental knowledge or biological resources of indigenous peoples cheaply and transform them for profit, without distributing the gains equitably among those peoples.
- Dendrogram.** Bifurcating, tree-like diagram indicating relationships among things.
- Hegemony.** Political dominance; authority supported by power.

Microphylogeny. Recent biological history of closely related populations.

Race. Formerly, a large natural division of the human species; now, since such groups are recognized as illusory, the term is generally used to designate a politically meaningful category into which people may be allocated on the basis of some aspect of ancestry.

Salvage anthropology. Research on indigenous peoples requiring immediate action due to the impending destruction of those peoples or their ways of life.

Keywords

indigenous, population, society, diversity, variation