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Author(s): Joseph S. Alper and Jon Beckwith
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THE HUMAN GENOME DIVERSITY PROJECT*

Racism: A Central Problem for the Human Genome Diversity Project

Joseph S. Alper University of Massachusetts—Boston, USA
Jon Beckwith Harvard Medical School, USA

Before any scientific project involving human subjects is initiated in the United States, an institutional review board must examine the potential benefits and risks of that project. Evaluations that indicate significant risks can either be cited to put into effect greater precautions in the design of the project or to halt the endeavor altogether.

The Human Genome Diversity Project (HGDP) is an undertaking of great scientific interest. Its primary purpose is to catalog the genetic similarities and differences among populations. It will provide detailed information about the frequency distribution of different markers in different groups and establish a genetic family tree relating the various population groups. Its findings will provide the peoples of the earth with a tremendous font of knowledge about their history, interconnections, and aspects of their cultures. This information will be broadly useful for those who study the "history and geography of populations," to quote from the title of the book on this subject by Cavalli-Sforza, the leader of the project (Cavalli-Sforza, Menozzi, and Piazza, 1994). Scientists will use this information to trace the migration of groups and to establish the relationship among languages based on the genetic relationships among the groups that speak these languages. Those who study human population genetics will be provided with rich material for their research. Such a project reinforces our humanness by continuing the age-old quest for human self-knowledge. From that perspective, this project reflects some of the highest aspirations of our species and is a benefit to society.

However, some of the proposed benefits of the HGDP are highly dubious. In his *PLS* article, David Resnik suggests that the HGDP will help "particularly" those indigenous populations being studied (1999:17). We question this claim. This benefit would presumably arise out of knowledge gained about the genetics of various diseases in different populations. But, the HGDP concentrates on genome-wide comparisons among population groups, in order to achieve its goals of understanding the histories of peoples and their migrations. This is not an efficient way to learn about the specifics of different disease patterns or etiologies among these groups and any such information would arise more by chance than by design. Rather, if a major goal were really to improve the health of ethnic minorities and

Joseph S. Alper is Professor of Chemistry at the University of Massachusetts—Boston, Boston MA 02125, USA. His published papers have dealt with many aspects of the social implications of human genetics: human sociobiology, behavioral genetics, genetic discrimination, genetic screening and testing, and the applicability of the Americans with Disabilities Act to genetic conditions. For the past 15 years, he has been a member of the Boston-based Genetic Screening Study Group. **Jon Beckwith**, American Cancer Society Research Professor of Microbiology and Molecular Genetics at Harvard Medical School, Boston, MA 02115, USA, was a member of the Working Group on Ethical, Legal, and Social Implications of the Human Genome Project and a member of the Genetic Screening Study Group. His articles on social implications of genetics have appeared in journals such as *BioScience*, *The Philosophical Forum*, *Cahiers de Psychologie Cognitive, Science and Engineering Ethics*, *Social Science and Medicine*, *Journal of Law, Medicine and Ethics*, and the *American Journal of Human Genetics*.

**Editor's Note*: The March 1999 issue of *Politics and the Life Sciences* carried an article by David B. Resnik entitled "The Human Genome Diversity Project: Ethical Problems and Solutions" (Volume 18, Number 1, pp. 15-23). Since the article addresses an important contemporary issue, we invited commentaries from a wide variety of knowledgeable scholars, scientists, and public policy analysts from around the world. The essays we received, together with a response from Resnik, are presented here as a symposium on the ethical problems and solutions associated with the Human Genome Diversity Project.

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indigenous populations, then a *direct* attempt to define the genetic and, at least as importantly, the environmental factors associated with the particular diseases plaguing these peoples would be required.

Moreover, even if genetic information about specific diseases were obtained from the HGDP, it is not clear that this knowledge would be of significant benefit to the indigenous populations. It is widely recognized that, despite the public promises of imminent cures and treatments deriving from new genetic knowledge, surprisingly little progress has been made in turning this information into benefits to people's health. We have no doubt that some future gene discovery work will lead to such cures and treatments, but, by that time, many of these indigenous groups may no longer be extant. Furthermore, the history of transferring health advances to the poorer peoples of the world does not give cause for optimism.

In addition, we do not agree with Resnik's contention that the HGDP will contribute substantially to the study of the human genome as a whole. First, as Resnik himself notes, human beings share more than 99% of their DNA. Second, most of the total genetic variation in the human population occurs within any single group. Intragroup genetic variance is much larger than intergroup variance. Sampling U.S. residents alone with their enormous range of ethnic and racial backgrounds would probably encompass the vast bulk of human variation. It would be hard to justify the cost of the HGDP if its goal were merely to obtain the remaining small amount of genetic variance not accounted for by sampling only U.S. and/or European residents.

Resnik is well aware of the risks associated with the HGDP. He presents a clear summary of the problems involving gene patenting, exploitation, culture, and informed consent. He is also well aware of the problems resulting from racism, including "discrimination, stigma, racial stereotyping, genocide, and eugenics" (1999:16), but argues that "the HGDP study design is not *itself* racist" (1999:17; italics in original). In this response, we argue that because the aim of the HGDP is to define genetic differences and similarities among peoples, the potential for racism *is* inherent in the study design of the project. Racism is the central problem facing the HGDP, and all the other problems Resnik discusses are exacerbated by it. In view of the sorry history of racist uses of genetics, we believe that it will require unprecedented efforts on the part of all researchers involved in the HGDP if racism is not to negate all of the expected achievements of the project.

The HGDP, the Genetics of Groups, and Racism

Concerns about the Human Genome Project, in some ways the parent of the HGDP, have centered on the possible harm to *individuals* from the availability and dissemination of genetic information about them. Controversy about the HGDP arises because of the fear that *entire groups* of people may be adversely affected.

The HGDP employs a methodology common in science: it exploits differences in some observable phenomenon in order to understand the mechanism underlying that phenomenon. For example, geneticists generate or select for mutations in a gene associated with some trait. They then study the phenotypic differences in that trait arising from these mutations as a means of understanding the genetics and biology of that trait. In the case of genetic studies of disease, the researcher will look at genetic differences between individuals who have the disease and those who do not. The goal is to understand the genetics of the disease rather than the genetic variation among the individuals, per se. However, unlike this sort of study, the HGDP is not concerned with the genetics of any particular trait. Instead, its focus is on an overall comparison of the genomes of groups. The particular groups chosen for study are selected as those likely to have the least genetic variation among members of that group because of their relative geographical or social isolation. In everyday parlance, we use the adjectives "ethnic" or "racial" to describe such groups.

Concentrating attention on genetic differences among groups has the obvious danger of providing fodder for those who promote racist politics and ideology. Racists use such information, whether real or imagined, to explain and justify social hierarchies and discrimination. As Resnik emphasizes, the HGDP is not inherently racist, and researchers involved in the project, including its leader, Dr. Luca Cavalli-Sforza, are known for their anti-racist views (Cavalli-Sforza, 1997). Nevertheless, if a single-mindedly racist group of scientists were to design a study to provide evidence for the truth of their ideology, it would not be surprising to find that their methodology closely resembled that employed by the HGDP.

If this analysis is correct, the HGDP is quite different from other scientific projects that have unintended social consequences. In most of these projects, the consequences are what might be called "by-products" of the primary purpose of the study. The Human Genome Project, for example, has supported research that has facilitated the development of genetic tests for a wide variety of human illnesses. While the incentive for support of such projects has been to improve human health and to provide aid in reproductive decisions, these tests can also be used for discriminatory purposes.

Because of widespread reports of individuals unable to obtain health insurance or even jobs because of such tests (Beckwith and Alper, 1998), some women at high risk for breast cancer refused genetic tests that might have been beneficial (Kolata, 1997). By means of appropriate government policies and legislation, these adverse consequences can be cordoned off from the desired applications of the research. However, because the focus of the HGDP is on the ethnic groups themselves, it seems to us that many of the possible deleterious applications of the primary information that the HGDP will provide cannot be so easily isolated or controlled.

Racists concentrate on those differences among groups that they believe reflect essential characteristics of people, such as their behavior and aptitudes. Today, this essentialist perspective is bolstered by the perception, promoted by the popular media and even by some scientists (Nelkin and Lindee, 1995; Beckwith, 1997), that these characteristics are substantially explained by people's genetic makeup. Thus, those making racist arguments often use the fact that there exist genetic differences among different racial and ethnic groups to explain, for example, differential performance by these groups on IQ tests.

We do not fear the finding of genetic markers that correlate with differences in such characteristics among groups. In view of the complexity of behavioral traits such as intelligence, any findings of this sort will contribute little to explaining the differences in those traits among groups. Rather, our concern is based on a long history of flawed scientific studies of the genetics of human behavior and on the misrepresentation of the genetic knowledge we have acquired about human behavior (Kevles, 1985; Billings, Beckwith and Alper, 1992; Alper and Beckwith, 1993). Even contemporary scholars making racist genetic arguments have repeatedly cited flawed research and have perpetuated the fundamental mistake of genetic determinism, namely, that a heritable trait is impervious to changes in the social or physical environment (Lewontin, 1976; Alper and Beckwith, 1993).

In view of this history, we anticipate that discoveries arising from the HGDP will be misinterpreted and misused to bolster racist theories of group differences. The HGDP will be searching for both the genetic similarities and genetic differences among groups. Clearly, the project will be of no interest if no differences are found. But they certainly will be found. Consequently, we would argue that the major factor that distinguishes the HGDP from a racist project is the use that is to be made of this knowledge. HGDP researchers can use the information to learn about human history and geography; scientific racists can use this information to justify their theories that certain groups are superior to others. Some scientific racists might even conduct research in an attempt to correlate the specific genetic differences found by the HGDP with group differences in those traits they believe to be important for ranking the races.

Should the HGDP Be Supported?

A promising avenue of research should not be abandoned solely because the results can be misused (Beckwith, 1997). In the case of the HGDP, the knowledge that will be obtained promises to be fascinating and of fundamental intellectual interest. However, as we have argued, the chances that this knowledge will be of material benefit to the indigenous peoples being studied are highly questionable. We are strongly in favor of research whose major impetus is an intellectual one. Nevertheless, given that the only certain benefits are purely abstract, any likely negative consequences of such a project require extremely careful scrutiny. The potential danger that information from the HGDP will be used to fuel racism, arguably one of the most pernicious evils facing the world today, mandates such scrutiny. As a result, we are not as sanguine as Resnik in believing that simply acknowledging past and future "explosions" will enable the HGDP to "navigate through the minefield of scientific racism" (1999:18).

Geneticists Confront Racism

The history of the role of geneticists in confronting misuse of their science does not inspire confidence that the racist uses of the HGDP will be prevented (Ludmerer, 1972; Allen, 1975; Beckwith, 1993; Beckwith, 1997). For many years, a small number of geneticists, including Cavalli-Sforza himself, have used already-existing genetic knowledge to argue against racist ideas. In Cavalli-Sforza's words, "races do not exist. There is such a remarkable continuity in the variation from place to place that it is practically impossible to define races, except in very approximate ways" (Cavalli-Sforza, 1997). In addition, these geneticists have pointed out that there is greater genetic variation within groups than there is among groups. Other geneticists have exposed the flaws and misrepresentations of studies claiming a genetic basis for IQ score differences among groups (Beckwith, 1999). In fact, it is argued that knowledge obtained by the HGDP will only strengthen these anti-racist arguments. But, if these arguments, already based on substantial scientific evidence, have not yet carried the day, why should we expect that the strengthened arguments using the new information generated by the HGDP will prevent that same information from being successfully employed by racists?

We can imagine at least two explanations for the failure to effectively counter the racist claims. First, only a few geneticists have succeeded in bringing the anti-racist argument before the public. Second, even if widely broadcast, the argument may not have been sufficiently persuasive to overcome deeply ingrained racism. There are indeed genetic differences among groups and, no matter how insignificant these might be, racists can always justify their hierarchical ranking of the races on the basis of these genetic differences.

We suggest that the primary obstacle in confronting the racist use of genetic information is the lack of a history of social activism among geneticists. As a result, geneticists have failed to speak out in sufficient numbers and with sufficient force to counter racist claims. In several other scientific fields, scientists have, to different degrees, recognized the potential impact of their work and attempted, often successfully, to mitigate any harmful consequences. These changes in attitudes toward "ethical" issues have occurred mainly in the last half of the twentieth century. For example, anthropologists have become extremely sensitive to the harm that they can cause the societies they study. In the aftermath of World War II, physicists became concerned about the destructive power of nuclear weapons. This heightened social conscience in both disciplines arose out of an awareness of the societal problems caused by the activities of researchers themselves.

Unlike the situation in anthropology and physics, there has been a noticeable lack of concern among geneticists about the social consequences of their work. In explaining this lack of concern, we note that up until 25 years ago genetics had been primarily an ivory tower discipline. Genetics only began to move into the public realm with the advent of biotechnology in the mid-1970s. Furthermore, since the end of the Nazi era, there have been no dramatic cases of harmful effects attributable to genetics analogous to nuclear weapons in physics or the negative impact on indigenous peoples in anthropology. One might have thought that the uses of genetic arguments and genetic studies by the eugenics movement of the early twentieth century and later by the Nazis would have caused geneticists to be more aware of the potential destructive uses of genetics (Kevles, 1985; Müller-Hill, 1988). Unfortunately, geneticists rarely discussed this history with their students, perhaps believing it to be irrelevant to late-twentieth-century genetics with its focus on the molecular basis of heredity. This absence of an historical consciousness has made it difficult for contemporary geneticists to integrate ethical concerns into their everyday work.

An intensive effort will be required to educate both those working on the HGDP and the genetics community in general. Such education would include a far broader range of issues than we have discussed here. But at a minimum, it certainly should include a study of the history of the use of genetics in racist arguments and the social impact of these arguments. An important component of these studies would be an analysis of the role played by geneticists in either making these arguments themselves, countering them, or failing to respond to them. The activities of other scientific disciplines, especially anthropology, in confronting the social impact of their research could provide models for study. Organizations such as the Human Genome Project and the various genetics professional societies should provide financial support in order to encourage the genetics community to embark on these educational efforts. These efforts would help to insure that projects such as the HGDP will enrich rather then diminish our humanity.

References

Allen, G. (1975). "Genetics, Eugenics and Class Struggle." *Genetics* 79:29-45.

Alper, J.S. and J. Beckwith (1993). "Genetic Fatalism and Social Policy: The Implications of Behavior Genetics Research." *Yale Journal of Biology and Medicine* 66:511-24.

Beckwith, J. (1993). "A Historical View of Social Responsibility in Genetics." *BioScience* 43:327-33.

Beckwith, J. (1997). "The Responsibilities of Scientists in the Genetics and Race Controversies." In E. Smith and W. Sapp (eds.), *Plain Talk about the Human Genome Project*. Tuskegee, AL: Tuskegee University Press.

Beckwith, J. (1999). "Simplicity and Complexity: Is IQ Ready for Genetics?" *Cahiers de Psychologie Cognitive* 18:161-69.

Beckwith, J. and J.S. Alper (1998). "Reconsidering Genetic Antidiscrimination Legislation." *Journal of Law, Medicine and Ethics* 26:205-10.

Billings, P.R., J. Beckwith, and J.S. Alper (1992). "The Genetic Analysis of Human Behavior: A New Era?" *Social Science and Medicine* 35:227-38.

Cavalli-Sforza, L.L. (1997). "Race Differences: Genetic Evidence." In E. Smith and W. Sapp (eds.), *Plain Talk about the Human Genome Project*. Tuskegee, AL: Tuskegee University.

Cavalli-Sforza, L.L., P. Menozzi, and A. Piazza (1994). *The History and Geography of Human Genes*. Princeton, NJ: Princeton University Press.

Kevles, D. (1985). *In the Name of Eugenics: Genetics and the Uses of Human Heredity*. Berkeley, CA: University of California Press.

Kolata, G. (1997). "Advent of Testing for Breast Cancer Leads to Fears of Disclosure and Discrimination." *The New York Times* (February 4):C1-C3.

Lewontin, R.C. (1976). "The Fallacy of Biological Determinism." *The Sciences* 16 (2):6-10.

Ludmerer, K. (1972). *Genetics and American Society*. Baltimore, MD: Johns Hopkins University Press.

Müller-Hill, B. (1988). *Murderous Science: Elimination by Scientific Selection of Jews, Gypsies and Others, Germany 1933-1945*. Oxford: Oxford University Press.

Nelkin, D. and M.S. Lindee (1995). *The DNA Mystique: The Gene as a Cultural Icon*. New York: W.H. Freeman.

Resnik, D.B. (1999). "The Human Genome Diversity Project: Ethical Problems and Solutions." *Politics and the Life Sciences* 18:15-23.