

Exploring Genetics Issues Relevant to Minority Communities

www.ornl.gov/hgmis/elsi/minorities.html

During the term of the Human Genome Project (HGP), the Human Genome Program of the U.S. Department of Energy (DOE) Office of Science devoted 3% of its annual budget toward studying the ethical, legal, and social issues (ELSI) surrounding the availability and uses of personal genetic information.

Some projects examined potential ELSI concerns, and others sought to educate professionals and the public through literature, conferences, workshops, and multimedia. Educational materials and programs were developed for physicians and other medical workers, educators, students, clergy, and judges and related legal personnel.

Programs aimed specifically at minority communities were designed to inform them of the HGP's ELSI implications and to explore the project's possible impacts on community members. Following are some ways in which the DOE Human Genome Program responded to this issue.

DOE Minority Projects

- A comprehensive and well-organized network of Native-American tribal professionals focused on the HGP in a program led by Mervyn Tano of the Institute for Indigenous Resource Management in Denver, Colorado. The project was designed to introduce Native-American tribes to the basics of genetics, genetics research, and the HGP and, in turn, to inform DOE managers about tribal perspectives.
- At California State University in Los Angeles, Margaret Jefferson's project translated into Spanish the teaching module produced by the Biological Sciences Curriculum Study, *Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy*. The module was used by Spanish-speaking students and parents in selected high schools.
- To inform the Spanish-speaking public about genetics and the Human Genome Project, the DOE ELSI program supported the broadcast of about 100 Spanish-language radio episodes within a nationally syndicated science and technology series. Molly Multedo and Clay Dillingham of the Self Reliance Foundation led this project.
- The National Educational Foundation of the African-American organization, Zeta Phi Beta Sorority, Inc., planned and conducted a number of major informational workshops to introduce the fundamentals of the Human Genome Project and some of its potential implications for people of color. The conferences covered a



variety of topics from basic genetics and HGP history to gene testing and careers in genetics. Held in Chicago in 2003; Washington, D.C., and Atlanta in 2001; Philadelphia in 2000, and New Orleans in 1999, the conferences sparked many follow-up workshops all over the country. In October 2001 the Foundation collaborated with the Pennsylvania Black Caucus in planning and implementing a 2-day program on the HGP for legislators and community representatives.

- In May 1997, DOE and the NIH National Human Genome Research Institute (NHGRI) supported a meeting organized by Carmen Nieves and Ray Zilinskas of the University of Maryland to inform minority communities about the HGP. The meeting also was designed to acquaint genome project scientists and policymakers with the aspirations and interests of these communities. A book edited by Zilinskas and Peter Balint (*The Human Genome Project and Minority Communities: Ethical, Social, and Political Dilemmas*, November 2000) was built on insights gained at the conference.
- In September 1996, DOE and NIH jointly sponsored a major conference at Tuskegee University on "Plain Talk About the Human Genome Project," which addressed some of the HGP's implications for African Americans. A book of the same name, an updated compilation of all the conference talks, was published in 1997.

Whose Genome is It?

In the HGP, researchers collected blood (female) or sperm (male) samples from a large number of donors. Only a few samples were processed, with the source names protected so neither donors nor scientists knew whose DNA was being sequenced. Because the DNA sequences of any two people are 99.9% identical, the reference sequence is applicable to everyone. All humans share the same basic set of genes and genomic regulatory regions that control the development and maintenance of their biological structures and processes. In studies of individual DNA variations, which constitute only 0.1% of the human genome, researchers in both public and private sectors developed DNA resources from many representative population groups.

Studies of human variations have determined that there is no scientific basis for race and that "races" cannot be distinguished genetically.



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Minority Issues and Benefits Surrounding the HGP

Some concerns have arisen because minority communities frequently have been victims of questionable science based on poor or even misapplied genetics used to confirm preexisting social biases. Specific issues include the following:



- ✓ Need for research into diseases and their complications that disproportionately affect minority groups. Some of these are diabetes; hypertension; obesity; asthma; hereditary prostate, breast, and lung cancer; and alcoholism.
- ✓ Need to develop and make available to researchers a database of genetic variations or mutations (SNPs) linked to diseases common in minority populations. Under-representation in existing databases might lead to inadequate participation in pharmaceutical and disease research and in the therapies that could result. To meet this need, Howard University started such a database. Also, NIH NHGRI is developing a haplotype map (HapMap) of the human genome to find variations related to specific diseases and conditions, including those linked to minorities.
- ✓ Privacy and confidentiality of individual health records.
- ✓ Personal control over the use of an individual's tissue samples or other genetic material.
- ✓ Screening or other means of identification that could lead to genetic stigmatization or discrimination against minorities, particularly in regard to employment and health and life insurance.

✓ Potential for use and misuse of genetic data in the criminal justice system.

✓ Just distribution of and minority access to healthcare, public health services, and community healthcare systems.

✓ Differences in drug metabolism linked to race, ethnicity, and gender that could make race-based treatments plausible. Such selective treatments might be met with suspicion and resistance.

✓ Minority participation in clinical trials.

✓ Role of minorities in informing policies related to human genome research.

✓ Minority representation on institutional review boards that oversee research and clinical trials.

✓ Concern that some groups might be stigmatized by labeling with pseudo-scientific genetic jargon and misunderstandings.

✓ Benefits of using genetic data to trace family trees and confirm genealogical connections.



More Information on the Web

Genetics 101

www.ornl.gov/hgmis/project/info.html

Journal for Minority Medical Students, HGP Black Bag Insert

www.ornl.gov/hgmis/publicat/jmmbbag.pdf

Human Genome Project Information

www.ornl.gov/hgmis

NIH National Human Genome Research Institute

www.nhgri.nih.gov

Ethical, Legal, and Social Issues Associated with Genomic Data and Tools

www.ornl.gov/hgmis/elsi/elsi.html

Minorities and Genomics

www.ornl.gov/hgmis/elsi/minorities.html

Human Genome Diversity Project

www.stanford.edu/group/morrinst/hgdp.html

Institute on Race, Healthcare, and the Law

<http://academic.udayton.edu/health>

Zeta Phi Beta Sorority, Inc.

www.zphib1920.org/signature_programs/model.html

Communities of Color and Genetics Policy Project

www.sph.umich.edu/genpolicy

Genetics Education for Native Americans (GENA) Project

<http://members.aol.com/natamcan>