

[Citation: Zilinskas, R.A. and P.J. Balint. 2001. "The Human Genome Project and Minority Communities: The Importance of Dialogue and Access to Information." In R.A. Zilinskas and P.J. Balint, editors. *The Human Genome Project and Minority Communities: Ethical, Social, and Political Dilemmas*. Westport, CT: Praeger, pp. 125-134.]

## **The HGP and Minority Communities: The Importance of Dialogue and Access to Information**

Raymond A. Zilinskas and Peter J. Balint

### **INTRODUCTION**

The degree of apprehension and suspicion with which scientific activities involving genetics, biotechnology, and genetic engineering are viewed differs depending on who is doing the viewing. To scientists performing basic research, genetics is a scientific field of inquiry that broadens our understanding of life processes and the mechanisms of heredity. Biotechnology provides specialized tools, including the exquisite techniques of genetic engineering, that allow investigators to perform their research with great precision. To researchers working in the private sector, genetics provides information on the physiological properties of life forms that may be useful in the development of commercial products. Biotechnology provides scientists in business and industry with techniques to modify organisms to produce such substances as medicines and specialty chemicals that may be difficult if not impossible to obtain by conventional means. Both basic and applied scientists are familiar with these methods and processes. Since they are convinced that benefits far outweigh risks, they rarely harbor serious misgivings about genetics or about the tools of biotechnology that they and their colleagues use to uncover the secrets of life and develop useful new products and applications.

Members of the general public on the other hand are often apprehensive about bioscientific advances. When most people think of genetics, they think only of heredity, and most non-scientists have little understanding of genetic engineering. Given this lack of knowledge, it is not surprising that fears arise. Concern about the potential risks and benefits of biotechnology research surfaced initially after genetic engineering techniques were first successfully demonstrated in the early 1970s. By 1975 the mass media had begun to pay considerable attention to biotechnology, reporting that some scientists and other experts were apprehensive about the genetic engineering of microorganisms. During the early years of such research, some commentators worried that these activities might by accident create monstrous new forms of

bacteria capable of producing awful diseases or causing irreparable harm to the environment. Some hypothesized that military scientists might design lethal new pathogens for use in biological warfare.

Responding to these concerns, bioscientists and administrators at the National Institutes of Health (NIH) worked together to formulate guidelines governing research involving genetic engineering. What became known as the NIH guidelines governed the conditions under which genetic research could be performed; the higher the risk posed to workers and society by a proposed research project, the more confining the conditions under which research could be carried out. Some research activities, perceived as being particularly risky, were banned entirely. The NIH guidelines served as a model for similar protocols promulgated by governments of other countries.

As these guidelines were being drafted and applied, other research was undertaken in various academic laboratories to assess the level of risk in genetic engineering experiments involving microorganisms. The findings were reassuring; the probability that this type of activity would by accident create new pathogens was found to be vanishingly low. The reason is that infectivity and pathogenicity are complex traits, governed by many genes located precisely in three-dimensional space within the genome of a pathogenic microorganism. It became clear that in view of this complexity the transfer of one or two targeted genes from one microorganism to another was highly unlikely to imbue a benign recipient organism with pathogenic properties.

These early predictions of minimal risk have been borne out by experience. No negative effects have been observed from approximately 30 years of genetic engineering of microorganisms in academic and industrial laboratories. Perhaps the NIH guidelines succeeded in protecting society from potentially dangerous lines of research, or perhaps the genetic engineering of microorganisms is inherently innocuous. In any event, as research continued without adverse effects, public concern about this type of scientific activity had largely subsided by the early 1980s.

## **THE CONTROVERSY OVER AGRICULTURAL BIOTECHNOLOGY**

Around this time, however, a new turning point was reached in applied biotechnology; namely, the use of genetically engineered organisms in the open environment. When the developer of a newly engineered plant species—the so-called ice-free strawberry plant—first requested permission from the U.S.

Department of Agriculture (USDA) to field-test this creation, the proposal rekindled public apprehension over biotechnology. Environmental non-governmental organizations in particular opposed the planned field tests. Public hearings were held during which opponents voiced concerns about the possibility that genetically engineered plants would “escape” the test site through cross-pollination with native species. When this happened, they warned, the ecological balance would be disturbed. Opponents argued that once genetically engineered traits spread beyond the limits of the field test area they could never be retrieved, and that effects would continue to ripple out indefinitely through surrounding ecosystems with unpredictable adverse consequences. Eventually, the USDA ruled that the proposed field test posed little if any risk to the environment and allowed it to proceed. This first deliberate application of genetically engineered organisms into the open environment has been followed by many more. Approximately 3,000 different modified plants and microorganisms have been released. As with the laboratory biotechnology experiments described earlier, the dire consequences feared by opponents of open environment applications of genetically engineered agricultural organisms have failed to materialize.

This time, however, despite little evidence of environmental or human health problems, public apprehension has not subsided. Concern about the widespread use of genetically engineered plants and other agricultural products continues to rise. This was particularly apparent during demonstrations at the recent World Trade Organization meeting in Seattle. Clearly, scientists and non-scientists often have very different views about the potential risks associated with modern biotechnology. Proponents see genetic engineering as the key to continuing the growth of agricultural productivity necessary to feed an expanding human population. Opponents raise the specter of dangerous unintended consequences for humans and the environment.

An example may help to illustrate the controversy. During the early 1990s scientists at Monsanto Company developed a genetically engineered soybean plant. This manmade variety, called Roundup Ready, was awarded a patent in 1996. The Roundup Ready soybean has been altered to include a gene from a bacterium that makes the plant resistant to glyphosate, the key ingredient in Monsanto’s Roundup herbicide. Farmers who plant Roundup Ready plants are able to increase harvests; they can spray the herbicide in their fields, effectively killing weeds, without damaging their soybean crop.

Two types of what may be called “scientific” concerns have been raised about the use of Roundup Ready soybeans and other genetically engineered plants. First, there is the question of gene transfer; the modified gene in Roundup Ready soybeans could pass to native weeds, making them herbicide-resistant as well. A similar unplanned transfer has already been observed in Denmark. There, rapeseed, a native European plant used to make vegetable oil, was genetically altered to resist a pesticide. In open environment applications, this new characteristic soon appeared in weeds that grew nearby.

A second concern is that food harvested from genetically modified crops may be hazardous to people who suffer from allergies. For example, Pioneer Hi-Bred International, a Des Moines-based seed company, developed a genetically modified soybean by inserting genes from Brazil nuts. The product was never marketed, however, because it was deemed potentially dangerous to people with nut allergies. Susceptible consumers may be caught unawares when characteristics from one species, to which they are allergic, are implanted in other species that they normally consume without adverse reactions.

In addition to worries about risks to human health and the environment, there are also concerns about the social and economic implications of agricultural biotechnology. With its new, more productive, and therefore more profitable varieties, Monsanto might gain a commanding position in the agricultural sector, and be able to control the market for its own benefit. If genetically engineered crops were designed not to produce usable seeds, for example, growers would then be required to purchase seeds from Monsanto each year to renew their crops. Moreover, once farmers were dependent on a product such as Roundup Ready soybeans, they would also have to purchase Roundup herbicide, thereby increasing Monsanto’s market power. As cycles developed whereby weeds became resistant to herbicides through cross-pollination, farmers would then be dependent on new soybean varieties developed by Monsanto and, of course, on new Monsanto herbicides.

Another social cost associated with agricultural biotechnology has to do with a perceived change in the “natural” purity of food staples. According to recent surveys, 85 percent of Europeans wish to avoid genetically modified foods. Up to now, Americans have generally appeared to be more tolerant of the new technology, but attitudes are changing as negative publicity continues. Both politicians and industry representatives are concerned about the public response. Scientists in academia and industry, who are convinced that these products are safe, worry that beneficial advances will be derailed by irrational fears.

On the other hand, many consumer advocates urge full disclosure and broad consumer choice. One possible solution is for legislators to adopt laws requiring producers to label foods that have been genetically engineered. Consumers could then assert their preferences in the marketplace. So far, food producers have resisted this approach.

The example of genetically engineered crops illustrates the complex public policy problems raised by advances in biotechnology. Scientific and popular attitudes often conflict. Difficult political decisions have to be made in the face of risk and uncertainty. There are opportunities for extraordinary social benefits from biotechnology, but science-based arguments cannot entirely quell public fears. Publicity about the cloning of mammals and the use of fetal tissue for biomedical research heightens public apprehension and polarizes the debate. The current situation is different from that of the 1970s and 1980s, when scientific disputes over risk predominated. Today, arguments cover a broad spectrum of ethical, legal, and social issues.

## **THE HUMAN GENOME PROJECT**

Yet another milestone in biotechnology was passed when the Human Genome Project (HGP) commenced. Although the HGP is not biotechnology *per se*—rather it falls within the general rubric of genetics, and the work involved is almost entirely basic research—it is nevertheless supremely important because of its promise to revolutionize biotechnology applications, particularly in health care.

By 2003, scientists working on the HGP are expected to have successfully mapped the entire human DNA, believed to contain between 80,000 and 140,000 genes. Clarifying where genes are located on the 46 chromosomes that constitute the human genome will be a significant scientific achievement, but the story will not end at that point. The implications of the next step, functional genomics, which consists of identifying the functions of genes mapped by the HGP, are likely to be even more momentous.

The functions of some human genes have already been determined, and that knowledge is currently being applied by industry to develop new diagnostics and therapeutics, and by the medical community to develop new treatments and improve genetic counseling. But this is only a small beginning, so far involving fewer than 100 genes. After the HGP ends in 2003, we can expect a significant portion of the research community established to complete the project will turn its collective attention to functional

genomics. When this happens, the real revolution will begin, and the landscape of medicine, public health, and other related disciplines will change beyond recognition.

### **ETHICAL, LEGAL, AND SOCIAL IMPLICATIONS OF THE HGP**

Like other recent advances in bioscience, however, the HGP is not free of controversy. Until now, concerns related to genetic engineering and biotechnology have focused on risks to human health and the environment, but the Human Genome Project raises a new set of ethical, legal, and social questions. Primary among these is the worry that the medical establishment, government agencies, schools, the insurance industry, and other private and public sector institutions may gain access to and misuse personal genetic information. There is a fear that people will be categorized, stereotyped, and stigmatized based on their genetic makeup.

In minority communities in particular, suspicions run deep. During the conference reported on in this book, some participants recalled past government-sponsored research projects that suffered from profound ethical failures. We heard about the Tuskegee study of syphilis in black men, misguided studies of sickle cell anemia, studies to clarify the hereditary basis of American Indian tribes, and others. The eugenics movement of the 1920s was mentioned. This unfortunate tradition of unethical research with racial overtones threatens to undermine public confidence in the HGP, particularly among minorities. Some people are concerned that research with the potential to reveal genetic links to racial traits and behavioral characteristics is more likely to harm than help members of minority communities. Conversely, the fear is also expressed that where positive effects do result from the HGP, benefits will accrue disproportionately to the privileged. In other words, some believe that minorities are most likely to be harmed and least likely to be helped by advances in genetics research.

Of course, the HGP does not have any direct racial overtones. It is a search for basic knowledge that certainly will benefit everyone. Nevertheless, suspicious questions were asked at the conference about its various aspects. One that kept recurring was, whose genome is being mapped? The implication was that if the genome studied were that of a Caucasian, African Americans and other minorities might not benefit equally from its results. The explanation that the genome being mapped is a composite of several individuals satisfied some participants, but not all.

We believe the best way to dispel suspicions of this valuable scientific enterprise is to deliver trustworthy and objective information in an understandable way. The general public, which pays for the project and is likely to be its primary beneficiary, must have access to reliable information. Furthermore, an informed public will be in a much stronger position to make sure that findings generated by the HGP are not misused to the detriment of individuals or groups. Consequently, our primary motivation in organizing the conference was to promote an open exchange of information about genetic research.

## **LESSONS FROM THE CONFERENCE**

Now that some time has passed since the conference was held, we have the opportunity to evaluate its outcomes. Did the conference succeed in informing the minority communities in Maryland about scientific and social implications of the HGP? Surveys conducted by the Survey Research Center, and reported in this volume, indicate mixed results. Most respondents indicated they were favorably disposed towards science and believed it had bettered their lives. More pertinent, the large majority of respondents agreed that they had learned a great deal about the HGP and its social, legal, and ethical aspects from conference activities. Yet some respondents appeared to be more concerned about the HGP after the conference than before. This may be a reflection of their almost complete lack of knowledge about the HGP prior to attending the conference. As a result of both formal conference presentations and more informal discussions, many participants became aware for the first time of the possibility that information from the HGP might be misused, and this frightened them. Moreover, it appeared to some participants that governments at both the federal and state levels were either not aware of potential problems or, if aware, doing little to address them. Unfortunately, therefore, some participants left the conference with more apprehensions than when they came. This emphasizes the importance of providing further access to balanced and authoritative information to support reasoned debate on human genetics research and on appropriate regulatory safeguards.

The goal of the conference was to reduce suspicions among minority communities about the HGP's ethical, legal, and social implications by increasing their knowledge. We had also hoped that the conference would be the first step of a long-term multifaceted program to involve minority communities in state-level efforts to ensure that benefits from the HGP were shared equitably and that wise legislation was

adopted to prevent misuse of personal genetic information. Our hopes for this extended project were given a substantial boost during the waning hours of the conference when approximately 30 participants indicated their strong desire to contribute to the success of proposed follow-up activities. In the end, however, we could not interest any government agency or private foundation in sponsoring the effort, so it faded.

We also failed in efforts to promote interactions between scientists who perform HGP research and leaders of minority communities. The Washington-Baltimore corridor is home to many academic institutions, biotechnology industries, and other public and private laboratories where research that directly or indirectly relates to the HGP is conducted. Before the conference, we contacted the managers and administrators of these facilities and asked them to help publicize the conference. We also asked them to encourage bench scientists working at their institutions to participate in the conference as resource persons. In the event, not one did. In contrast, we had no problem finding scientists willing to make formal presentations. Perhaps an invitation to address a conference is seen as an opportunity for public service and as a favorable reflection on the individual and his or her employer. On the other hand, a request to attend as a participant and mingle with community members is seen as less beneficial and not accepted.

Despite our lack of success in involving minority communities with HGP-related activities over the long-term and in stimulating interactions between scientists and the public, we argue forcefully that such efforts are vital and should be promoted. We believe the Department of Energy, the National Institute of Human Genome Research, and other public and private institutions could serve the public good by sponsoring programs to reduce public apprehension about genetic research. When minority communities become less fearful of such government activities, science and society both benefit.

## **CONCLUSION**

There are several promising developments in regard to safeguarding information generated by the HGP. On February 8, 2000, President Clinton signed an executive order limiting the use of genetic information by federal agencies. The order has two parts. First, it prohibits the collection of genetic information by agencies. Second, it prohibits the use of genetic information in decisions relating to hiring and promotion. The order affects 2.8 million civilian government workers. The order does not cover the approximately 14 million military personnel, but the Department of Defense already follows similar rules.

There are also two bills before Congress that, if passed, would provide comprehensive protection to all U.S. residents. The first, offered by Tom Daschle (D-SD) and Edward Kennedy (D-MA) in the Senate and Louise McIntosh Slaughter (D-NY) in the House of Representatives, aims to protect people from employment discrimination based on the use of genetic information. The second, currently in a House-Senate Conference Committee, strengthens patients' rights when dealing with health maintenance organizations. Included in the bill is a provision, drafted by Senator Olympia Snowe (R-ME), that forbids health insurers from using genetic information to raise rates or drop coverage.

The public needs protection from potential misuses of genetic information. The track record of past medical and genetic research suggests that abuses are possible. On the other hand, the public is likely to see enormous benefits as genetic mechanisms that underlie many human diseases are better understood and new therapies become possible. An educated citizenry is essential both to demand enlightened legislation that protects against the abuse of genetic information and to support continuing scientific research in the field of genetics so that the full social benefits can be realized.

#### **SUGGESTED FURTHER READINGS**

Blakeslee, S. 1997. Some biologists ask, "Are genes everything?" *New York Times*, 2 September, pp. C1,C8.

Carson, R.A. and M.A. Rothstein (eds). 1999. *Behavioral Genetics: The Clash of Culture and Biology*. Baltimore: Johns Hopkins University Press.

Haseltine, W.A. 1997. Discovering genes for new medicines. *Scientific American* 276(3):92-97.

Lehmann, V. and A. Lorch. 1999. The race for the human genome. *Biotechnology and Development Monitor* 40:6-9.

Rubin, A.J. 2000. Clinton curbs the use of genetic data. *Los Angeles Times*, 9 February, p. A12.

Schoofs, M. 1997. The myth of race: What DNA says about human ancestry—and bigotry. *Village Voice*, 28 October, pp. 34-35.

Smith, E. and W. Sapp (eds). 1997. *Plain Talk about the Human Genome Project*. Tuskegee, AL: Tuskegee University.