chapter 4

Social and Ethical Considerations

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"Science is a match that man has just gotta light. He thought he was in a room—in moments of devotion, a temple—and that his light would be reflected from and display walls inscribed with wonderful secrets and pillars carved with philosophical systems wrought into harmony. It is a curious sensation, now that the preliminary sputter is over and the flame burns up clear, to see his hands lit and just a glimpse of himself and the patch he stands on visible, and around him, in place of all that human comfort and beauty he anticipated—darkness still. "

H.G. Wells, 1891

"The moral significance of humankind is no more threatened by peeking at the underlying musical notation, the base sequences, than is reading the score of Beethoven's last symphony diminishing to that piece of work."

Thomas H. Murray,
Case Western Reserve University, 1987

INTRODUCTION

As projects to map and sequence the human ge - nome are undertaken, their long-range social and ethical implications need to be considered as part of policy analysis, yet further knowledge is needed before many of these implications emerge. Some will arise in the course of deciding what priority to give genome projects and what level of resolution (coarse genetic linkage map, complete DNA sequence) is most appropriate. More profound ethical questions are posed by possible applications of genetic data for altering the basis of human disease, human talents, and social behavior. Questions about personal freedom, privacy, and societal versus individual rights of access to genetic information are among the most important. A full picture of the human genome will of necessity raise questions about the desirability of using genetic information to control and shape the future of human society. The complexity and urgency of these issues will increase in proportion to advances in mapping and sequencing.

Part of the reason for studying genomes is to see how variations in genes account for differences among people. Some of the issues raised in this chapter relate specifically to these variations: What will be the impact of discovering that, in their genetic endowment, human beings are either more equal or more unequal than we now suppose? other problems do not concern genetic differences, but rather the impact of discovering the extent to which genes do or do not limit the options of human beings in general. One commentator has argued that scientists bear a responsibility for using "moral imagination" to anticipate the full range of uses and consequences of their work, especially when that work is in the basic sciences (2).

The social considerations raised by genome projects include ethical issues. Ethical issues often arise in the context of debates about values, principles, or human actions that have had particular merit in the past. Such debates about what *ought* to be done often cannot be resolved by empirical inquiry. Specific genetic information such as the location of a gene along a chromosome or the sequence of nucleotide bases composing a specific gene is value-neutral and as such is not ethically troublesome. However, questions about private investment versus the allocation of Federal resources or about the proper use and availability of genetic information are ethical questions because they involve choices among actions based upon competing notions about what is good, right, or desirable.

Competing ideas about the desirable course of human action are developed from considerations about the greater good, personal freedom, benefiting others, avoiding harm, and fairness and equality. It is important to note that the ethical issues surrounding the use of and access to genetic information are not unique to the enterprise of mapping and sequencing the human genome (10) (see box 4-A). The existing uses of genetic screening, which in most cases are based on incomplete information about the location of a specific gene, already raise ethical questions. In addition, some general ethical questions are moot because of contemporary realities, for example, the question of whether there should be any human genome mapping and sequencing activities at all. This question is moot because mapping and sequencing projects have been underway for over a decade and

Box 4-A.—DNA Fingerprints

DNA fingerprints are derived from traces of human biological material such as blood, semen, hair, or other tissue. Recombinant DNA technology is applied to these samples to identify patterns of genetic sequence that are unique to each human being. Matched DNA fingerprints can establish the identity of a given individual with near certainty. DNA fingerprints, therefore, have great practical use in establishing the identity of criminals, family members, or bodily remains.

Genetic fingerprinting raises ethical issues such as the maintenance of personal autonomy when tissue samples are requested for identification purposes and the maintenance of confidentiality of individual genetic profiles. Even after tissue specimens have been discarded, there is considerable fear that genetic records will be retained in spite of the wishes of the human source of the tissue. California requires convicted sex offenders to give blood and saliva samples before their release from prison. The provision of such samples also makes it possible to discover information that may be incidental to past criminal records (e.g., XYY chromosome, drug use) but that could be used against the present or former inmates.

In the United States to date, practical applications of DNA fingerprinting have involved tests of specific suspects or known criminals. There are plans in California to store this information in the world's first computerized data bank of DNA fingerprints. In Great Britain, however, a DNA analysis of blood samples from all men and boys between the ages of 13 and 30 in Leicester County was conducted in an attempt to identify the person who raped and murdered two teenage girls. A 17-year-oId boy originally charged with the crimes was released when his genetic profile did not match that derived from the semen left in the victims. More conventional investigative methods were later used to catch a suspect, a local baker who had avoided the test. The mass screening effort left investigators with a genetic profileon every young man in the county, information they later destroyed.

DNA fingerprinting has also been used as proof of paternity for immigration purposes. In 1986, Britain's Home Office received 12,000 immigration applications from the wives and children of Bangladeshi and Pakistani men residing in the United Kingdom. The burden of proof is on the applicant, but establishing the family identity can be difficult because of sketchy documentary evidence. Blood tests can also be inconclusive, but DNA fingerprinting results are accepted as proof of paternity by the Home Office.

Testing of extended families has been used in Argentina to identify the children of at least 9,000 Argentineans who disappeared between 1975 and 1983, abducted by special units of the ruling military and police. Many of the children born to the disappeared adults were kidnapped and adopted by military "parents, " who claimed to be their biological parents. Once genetic testing of the extended family revealed the true identity of the child in question, the child was placed back in the home of its biological relatives. It was initially feared that transferring a child from its military "parents" who were kidnappers but who had nevertheless reared the child for years would be agonizing. In practice, the transferred children became integrated into their biological families with minimal trauma,

SOURCES:
Office of Technology Assessment, based on Herman, R , "British Police Embrace 'DNA Fingerprints" *The Washington Post*, Nov 24, 1987
A J Jeffreys, J F Y Brookfield, and R. Semeonoff, "Positive Identification of an Immigration Test-Case Using *Human* DNA Fingerprints," *Nature* 317818.819, 1985.
J M Diamond, "Abducted Orphans Identified by Grandpaternity Testing," *Nature* 327552.553 1987

there has been no concerted effort to prohibit them. The more immediate questions, therefore, are how these projects should best proceed from now on and what use should be made of new genetic information.

Each of the following sections begins with a list of important social and ethical questions, followed by a short general discussion establishing the context of these issues and, in some cases, outlining opposing arguments. Decisions about mapping and sequencing rest in part on arguments about appropriate allocation of resources, Arguments about access to versus control of knowledge turn on debates about the relative importance of ethical principles such as autonomy (that is, self-determination or personal freedom of action) and beneficence (the duty to act in ways that benefit and do not inflict harm on others). There is general concern about the ways in which personal freedom of action might be either enhanced or diminished by increased knowledge about human genetics. Finally, there is significant concern about the possibility of eugenics, that is, that new and existing information will be used in attempts to improve hereditary qualities. The social and ethical arguments relevant to mapping and sequencing the human genome reveal the tension between an attempt to arrive at some clear insight about duties and obligations and an attempt to weigh benefits versus harms. The purpose of this chapter is to describe and clarify important points of social and ethical controversy, not to resolve them.

BASIC RESEARCH

- How should the conduct of research in the basic sciences, such as genome mapping and sequencing, be influenced by a concern for the social good?
- What are the considerations when basic research in the biological sciences seems to take resources away from areas of research that might have more immediate social benefit?

A genetic linkage map of the human genome already exists and progress has been made in the development of a physical map. Practical debate, therefore, centers on questions about the most efficient and effective way to develop the complete physical map, that is, whether the whole human genome should be sequenced in a systematic way and how new genetic information should be applied.

How these questions are answered depends upon the values attached to scientific progress and the relationship between scientific progress and human good, There is a strong argument that basic scientific research is valuable in and of itself and should be pursued for its own sake. Coordinated, systematic mapping of the human genome is consistent with this view, and proponents argue for resources and against constraints in the name of conducting *good science*. Others argue that scientists need to be responsive to and sometimes even constrained by the public interest (7).

LEVELS OF RESOLUTION

- What level of resolution of the physical map is really needed, and for what purposes?

while even a rough genetic map, permitting the identification of markers linked with major diseases, might prove useful to insurers or others bent on identifying high-risk individuals, it would have less value for basic researchers than a more precise map. From an ethical standpoint, the key arguments about levels of resolution, or molecular detail, are based on the distribution of costs and benefits involved. If the public is asked to pay an appreciable portion of the cost, then it deserves to participate in the political debate about embarking on an expensive, full-scale project. Scientific and technical factors being equal, chromosomal regions in which greater clarity would benefit many people (e.g., those associated with prevalent genetic diseases) might be addressed first. If the largest share of the costs is borne by the private sector, then few, if any, questions of priority will be posed, other than those chosen by the persons investing in the projects.

ACCESS AND OWNERSHIP

- What are the ethical considerations pertaining to control of knowledge and access to information generated by mapping and sequencing efforts?
- Who should have access to map and sequence information in data banks?
- Do scientists have a duty to share information; what are the practical extent and limits of such an obligation?
- Who owns genetic information?
- Do property rights to individuals' genetic identities adhere to them or to the human species (14)?
- Is genetic information merely a more detailed account of an individual's vital statistics, or should this information be treated as intrinsically private, not to be sought or disclosed without the individual's express consent (10)?

There is a method in scientific research that allows investigators to pursue their hunches, test their hypotheses, replicate their results, and publish their findings in roughly that order. Careful adherence to this process ensures accuracy and the orderly development of knowledge. The time lag between discovery of new information and communication of it, however, has caused some commentators to question whether scientists have the right to withhold information about genetic markers that might be of great interest to the public at large.

From an ethical perspective, it may be argued that genetic information is by definition in the public domain: The human genome is a collective property that should be held in common among all persons of human heritage (8). An opposing argument is that, since gene sequences are not commonly knowable and understanding them requires the use of expensive and often patentable machinery, discovery of sequences and the fruits that derive from them belong to the person who uncovered them. By this reasoning, it does not matter whether the sequences are unique or how they might be used, it is the labor and inventiveness associated with the discovery of them that makes them valid intellectual property. Current patent law takes the latter tack but limits patentability by preventing the patenting of a person or an idea.

One prominent scientist has acknowledged the public's special claim to the genome but argues that a public enterprise may not be the best way to satisfy this claim and that delay on so urgent a project serves no one (5). A significant portion of the value of the genetic information gathered through human genome projects will not be fully realized until some decades after the projects are completed, but there is little doubt that it will help elucidate the function and physical location of genes that cause or predispose to illness and disease. For this reason alone, the sequences will have substantial commercial value.

COMMERCIALIZATION

- What facets, if any, of human genome mapping and sequencing activities should be commercialized?

The commercial value of genome sequences has already been recognized by companies that have applied for patents on a number of specific materials and techniques. At least one company has argued that it has the right to copyright and control the materials and maps that it develops (5).

The selective forces of the marketplace have generated a database network, some portions of which are in the public domain and others of which are held by individual companies. The ethical issues of privatization of this knowledge turn on the importance of sequences lost to others by academic communities or corporations which have restricted the use of them. On one level, the problem is largely academic, since the data needed for a complete map and sequence could be assembled by the public sector, with duplication or purchase of the data held by private parties. On another level, however, the Potential loss of critical data, the duplication of effort, and the control of knowledge raise serious questions about a combined scheme of public versus proprietary hold-

ing of fundamental knowledge. There is a strong argument that parts of research that are funded publicly should yield public information, while allowing scientists and others to retain the benefits of commercial exploitation of inventions.

DIAGNOSTIC/THERAPEUTIC GAP

- What are the ethical implications of the growing gap between diagnostic and therapeutic capabilities?
- Should diagnostic information about genetic disorders for which there is no therapeutic remedy be handled differently from that about disorders for which there are therapeutic interventions?

There is no doubt that continuing scientific advances in mapping and sequencing the human genome accelerate diagnostic applications. One philosopher has noted that the ability to map the human genome yields information about susceptibility that is more precise, more certain, and potentially more threatening to individual freedom and privacy than earlier methods of presymptomatic diagnosis and vague hypotheses about familial traits (10). A related issue is the need to protect information that may be available to or sought by third parties such as insurance companies or employers. Progress to date indicates that the ability to diagnose a genetic abnormality precedes the development of therapeutic interventions and that this gap may be growing. This is true for many genetic diseases, an important example being Huntington's disease (see box 7-A in ch. 7).

PHYSICIAN PRACTICE

- Do physicians and other health care providers face a conflict between an increasingly reductive approach to medical science and a focus on holistic patient care (17)?

Increased information about human genetics changes attitudes and alters the knowledge that serves as a basis for health care interventions. Physicians and other health care providers must constantly alter their views and understanding of human behavior, health, and disease. There are many examples of diseases that were once thought to be amenable to preventive health care that are now known to have a genetic component or cause. On a practical level this presents obvious difficulties, as health care providers are increasingly uncertain whether they are dealing with patterns of health and illness in individuals that can be ameliorated by changes in life style and medical treatment or if such patterns are in large part a matter of genetic destiny. In addition, the ethical principle of respect for persons indicates that individuals must be treated with care, compassion, and hope because they are persons and not merely the embodiments of a genetic formula or code,

REPRODUCTIVE CHOICES

- What ethical considerations arise from the increased ability of parents to determine the genetic endowment of their children (through such practices as selective termination of pregnancy, selective discarding of human embryos created in vitro, or selection of X- or Y-bearing sperm to determine the sex of the child)?

The ethical question of one generation's duties and obligations to another becomes more evident as genome mapping generates data pointing to the serious consequences of certain cultural practices or mating patterns. For example, it has been demonstrated that, if it were possible to choose the sex of their children, many individuals and couples would prefer that their firstborn be male

(18). It has also been demonstrated that firstborn children benefit from their early period of exclusive parental attention. If firstborn boys became the norm, it might further compromise equality of opportunity between men and women (16). In such circumstances, the conflicts among values and ethical principles such as autonomy, justice, and beneficence will be strong. Human mating that proceeds without the use of genetic data about the risks of transmitting diseases will produce greater mortality and medical costs than if carriers of potentially deleterious genes are alerted to their status and encouraged to mate with noncarriers or to use artificial insemination or other reproductive strategies (3).

On a practical level, the availability of information that couples might use to select embryos created in vitro has been hampered by an absence of federally funded research concerning many aspects of human fertilization. There has been a de facto moratorium on such research since 1980 (13).

EUGENIC IMPLICATIONS

- What ethical concerns arise from possible eugenic applications of mapping and sequencing data?

The possibility of mastery and control over human DNA once again raises the highly charged issue of genetic selection. One major difference between current and previous attempts at eugenic manipulation is that any potential eugenicist will have substantially more powerful techniques to effect desired ends and more data with which to muster support. With even the modest knowledge achieved in their first century, genetic techniques have become sophisticated enough to permit the use of selective breeding to produce animals with desired qualities.

When Francis Galton defined eugenics in 1883 as the science of improving the "stock)" he intended the concept to extend to any techniques that might serve to increase the representation of those with "good genes." Thus, he indicated that eugenics was "by no means confined to questions of judicious mating, but takes cognizance of all the influences that tend, in however remote a degree, to give the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had" (4). Prior to the development of recombinant DNA technology, eugenic aims were primarily achieved by attempting to control social practices such as marriage. New technologies for identifying traits and altering genes make it possible for eugenic goals to be achieved through technological as opposed to social control.

Knowledge of human genetics will amplify the power to intervene in the diagnosis and treatment of disease. Each time a person who would otherwise have died of a disease caused or influenced by a gene is treated successfully by genetic or nongenetic means, the frequency of that gene in the population increases [Lappe, see app. A]. Human genome projects will intensify and accelerate the already difficult debates about who should have access to one's genetic information by providing faster and cheaper methods of testing for genetic variations, by making much more information available, and by increasing the specificity of genetic information (15). The ethical debate about eugenic applications more properly focuses on how to use new information rather than on whether *to discover* it. Eugenic programs are offensive because they single out particular people and therefore can be socially coercive and threatening to the ideas that human beings have dignity and are free agents.

Positive Eugenics

Beginning with Plato, philosophers have recognized that eugenic ends could be achieved through subtle or direct incentives to bring together presumptively fit human beings. Positive eugenics is defined here as the achievement of systematic or planned genetic changes in individuals or their offspring that improve overall human life and health and that can be achieved by programs that

do not require direct manipulation of genetic material.

Most commentators have rejected or cast doubt on any uses of genetic engineering to enhance or directly improve the human condition. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research declared that efforts to improve or enhance normal people, as opposed to ameliorating the deleterious effects of genes, is at best problematic (11).

It may well be that the problem with positive eugenics has more to do with the means than with the ends. The basic objective of improving the human condition is generally supported, although debates about just what constitutes such improvement continue. Many concerns about eugenic policies in the past focused on the methods used to attain them, such as sterilization, rather than on the ends themselves.

Negative Eugenics

Negative eugenics refers to policies and programs that are intended to reduce the occurrence of genetically determined disease. It implies the selective elimination of gametes (ova or sperm) and fetuses that carry deleterious genes, as well as the discouraging of carriers of markers for genetic disease from procreation. There are few technical obstacles to karyotyping human beings for eugenic reasons. Verbal genetic histories of sperm donors, for example, are designed to exclude donors carrying some genetic diseases. Such a screening process, accompanied by a physical examination and laboratory tests, has already been recommended by the Ethics Committee of the American Fertility Society (l). The development of specific genetic tests could make gamete screening easier and more specific and will also expand existing capabilities to conduct prenatal tests.

Eugenics of Normalcy

The third eugenic use of genetic information would be to ensure not merely that a person lacks severe incapacitating genetic conditions, but that each individual has at least a modicum of normal genes. One commentator has argued that individuals have a paramount right to be born with a normal, adequate hereditary endowment (6). This argument is based on the idea that there can be some consensus about the nature of a normal genetic endowment for different groups of the human species. The idea of genetic normalcy, once far-fetched, is drawing closer with the development of a full genetic map and sequence; however, concepts of what is normal will always be influenced by cultural variations and subject to considerable debate.

ATTITUDES

- How will a complete map and sequence of the human genome transform attitudes and perceptions of ourselves and others?

One of the strongest arguments for supporting human genome projects is that they will provide knowledge about the determinants of the human condition. One group of scientists has urged support of human genome projects because sequencing the human genome will provide one of the most powerful tools humankind has ever had for deciphering the mysteries of its own existence (12).

The relevance of this proposition will depend on the degree to which complex human behaviors are determined by understandable genetic factors. It will also depend on how important human genome projects are to understanding genetic factors for complex traits. Whether higher human attributes are reducible to molecular constructs is a topic of considerable debate in the philosophy of biology, and human genome projects would doubtless enlarge and intensify this debate. A reasonable hypothesis is that, while little information of director immediate value regarding complex behaviors is likely to result from human genome projects, insights into the possible construction of control regions for the development of the human embryo, the genetic basis for organizing neuronal pathways, and the genetic control of sexual differentiation will all be significantly

enhanced. In the long run, knowledge of human genetics will make scientific understanding of human life more sophisticated.

A greatly increased understanding of how genes shape characteristics could influence human beings' attitudes toward themselves and others [Glover, see app. A]. Such increased understanding might highlight the degree to which genetic factors are equal or unequal for traits that confer social advantage. This information might reveal that human beings have fewer options than they suppose and could thereby encourage a determinist view of human choices (see box 4-B), or it could reveal just the opposite. A general increase in genetic information might also alter social customs based on erroneous scientific assumptions.

Many individuals have general beliefs about their genetic potential for achievement in certain spheres of activity, about the limits of possible improvement through effort or environmental change. These intuitive beliefs are often vague and inaccurate. often, it is only in regard to a few skills or characteristics that individuals have pushed against the limits of their potential. When science makes it possible to trace the actual limits of individuals, intuitive perceptions may turn out to be wrong. This has the potential of both enhancing and limiting personal liberty.

Box 4-B.—Determinism and the Human Genome

Determinism in biology is the general thesis that, for every action taken, there are causal mechanisms that preclude any other action. Mapping and sequencing the human genome will not alone impose a determinist view of human nature. Seeing where genes are located, or knowing the order of bases in the DNA, will not alone make behavior predictable.

But mapping and sequencing *together with* tracing the pathways between genes and behavior will start to paint a determinist picture. Scientists are now starting to work out these pathways. Take, for example, the pattern of behavior classified by psychiatrists as sensation seeking, which involves a disposition toward gambling and alcoholism. This behavior is correlated with low levels of activity of the platelet monoamine oxidase. These levels of activity have been shown by studies of twins to be largely under genetic control.

In a determinist model, human actions can be explained in terms of causal mechanisms, even though those mechanisms may be very complex. If this model is right, it seems that what human beings do, just as much as what billiard balls do, is the product of a set of laws operating in particular circumstances.

This view of human nature is disturbing. It suggests that a Godlike scientist, with complete knowledge of all the relevant causal laws and of the circumstances in which they operate, could successfully predict human action. In two different ways, determinism is at least an apparent threat to our attitudes. First, the elimination of genuine choice would leave no room for the belief that we can partly create, actualize, or modify ourselves. Second, undermining choice may also undermine many emotional reactions to others. The determinist picture may not leave room for justifiable resentment of what people do or for justifiable feelings of blame or guilt.

There are alternative views within determinism. *Hard determinism* is the view that individual choice is entirely ruled out, along with the emotional responses linked to holding people responsible for what they do. *Soft determinism* asserts that free choice and responsibility are compatible with determinism.

The issue is whether the soft determinist can resist the hard determinist's argument against freedom and the reactive attitudes. There are two strategies for resisting: 1) to point out that determinism is not the same as fatalism, that even in a deterministic world what human beings do influences the future; and 2) to disagree that determinism eliminates genuine choice, attempting to work out a model of free action that is compatible with determinism.

SOURCES
Office of Technology Assessment, 1988
Clover, see app A.

ROLE OF GOVERNMENT

- what is the proper role of government in mapping and sequencing the human genome?
- Specifically, does the government have a role in deciding what data should be collected in gene mapping and sequencing? How should this information be disseminated and guarded from abuse?

The lines of power, coercion, and authority in the public and private scientific sectors are blurred because the first genetic maps are being made in corporations (e.g., Collaborative Research, Inc.) and in private philanthropies based in universities (e.g., the Howard Hughes Medical Institute at the University of Utah).

The ethical arguments for involving the Federal Government in the process of genome mapping, whether by shaping, constraining, blocking, or doing nothing, center on the public interest in making resources available in ways that are consistent with the considerations of beneficence, justice, and autonomy. These issues encompass academic freedom or freedom of scientific inquiry because the projects have universal and lasting implications. Once the human genome is mapped and sequenced, the resulting data will have widespread implications for generations to come [Lappe, see app. A].

The precise boundary between basic and applied science is hard to draw, but there is enough understanding of where it lies to be able to use it as a basis for policy. A case might very well be made for a government policy that would leave basic research unrestricted but that would place some stringent controls on applied research and technological applications, for example, by ensuring that genetic testing is voluntary and access to data is controlled.

All research carries with it the likelihood of changing one's conception of the world and so of changing one's attitudes. For these reasons, there is a strong case against government intervention to stop research. There are four main arguments:

1. Stopping research might be opting for comfortable ignorance or illusion rather than uncomfortable truth. The growth of science has rested on the preference for uncomfortable truth. Those who view science as one of mankind's finest creations will be dismayed at any wholesale repudiation of this preference.
2. It is unlikely that existing world views, beliefs, and attitudes can be protected by shutting down basic research. The knowledge that such protection was needed might itself start to undermine existing views.
3. As a practical matter, it maybe that government cannot stop basic research, It is not easy to monitor what goes on in laboratories, and what is stopped in one country may take place in another [Glover, see app. A].
4. Stopping research blocks both possible benefits and risks. The belief that research can be performed to permit benefits while coping with and occasionally avoiding risks is a matter of historical precedent.

DUTIES BEYOND BORDERS

- What, if any, ethical issues are raised when considerations of international competitiveness influence basic scientific research?
- What, if any, are the duties and obligations of the United States to disseminate mapping and sequencing information abroad?
- What are the implications of shared information for international competitiveness?
- What are the international implications of sharing technological applications of mapping and sequencing information?
- what issues are involved when applications of genetic information or biotechnology that are of great use to Third World countries are not developed or fully exploited because they are less profitable for industrialized countries?

The United States has recently proposed an international framework of rules for science. The

purpose of this framework is to see that all nations do their fair share of basic research and that all the results of such research be made public, except for those with strategic implications (9). The increased protection of intellectual property and patent rights for technological innovations formed the basis of this proposal; these rights were also central to recent international trade talks. There is some sentiment that barriers to the transfer of technology would continue even if there were no reward for intellectual property. one commentator has noted that, unless products are protected by a set of principles now, basic scientific results could become increasingly restricted; some nations might do less basic research and instead emphasize applying other nations' results (9).

The most common single-gene defects, disorders of the hemoglobin molecules that carry oxygen in red blood cells, are highly prevalent in many nations in Southern Europe, Africa, the Middle East, and Asia. Such nations would benefit most if research tools became widely available as they were developed and if priorities for which chromosomal regions are mapped first took world prevalence of disorders into account. Use of map and sequence information by developing nations may also require special attention to devising screening tests that are cheap and simple, and might entail access to services (e.g., sequencing or mapping) located in developed nations [Weatherall, see app. A].

CONCLUSION

All human beings have a vital interest in the social and ethical implications of mapping and sequencing the human genome. It is not surprising, therefore, that there are debates about how genome projects should proceed. These extend beyond considerations of scientific efficacy and involve the interests of patients, research subjects, physicians, academicians, lawyers, entrepreneurs, and politicians. Mapping the human genome accelerates our rate of understanding—and the distance between increased understanding and direct intervention to alter the human genome is shrinking. Add to this the development of scientific tools such as gene probes, and immediate practical questions are posed: How should basic research be conducted? What level of resolution in mapping is necessary? Who should have access to and ownership of data banks and clone repositories? How should thorny questions surrounding commercialization be handled? Long-range questions about eugenics, reproductive choices, the role of government, and possible duties and obligations beyond national borders also arise. These questions are complex and are not likely to be resolved in the near future. It will therefore be necessary to ensure that some means for explicitly addressing ethicaI issues attends scientific work.

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