



# Human Genome Project (HGP) with an Approach to the Ethical Perspective and Human Freedom

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## Abstract

In this research, the results of the Human Genome Project (HGP) and the possible ethical problems it may cause were evaluated through concrete examples. In the study, it has been tried to reveal in detail how the social rights and freedoms, ethics, social norms and values of the individual will be affected and where the borders will begin and end in the event of the potential risks that HGP carries. Discussions have been made on the problem that the individual can be instrumentalized and turned into a commodity as a result of genetic interventions, and unfortunately, it has been determined that genetic interventions are in a structure that can lead to an intervention in the fundamental rights and freedoms of the individual. The aim of this study is to show the usage areas of the human genome project and to examine the results of this project in terms of the ethical consequences of the techniques and applications used.

**Key words:** Ethic, Genome, Project, Genetic Intervention, Freedom, Rights.

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## 1. Introduction

Genetic engineering, which started with J. Watson and F. Crick's explanation of the double helix structure of DNA (Deoxyribonucleic Acid) in 1953, and opened a new era in 1973 when S. Kochan and H. Boyer carried out the transfer of DNA to bacteria with genetic engineering. Proceedings are shaping our lives very effectively and quickly in the 21st century. One of the most important studies in this process is the Human Genome Project (HGP), which is a genetic revolution for human beings and its implementation causes ethical debates.

The Human Genome Project was officially started on October 1, 1990, with the joint efforts of the American Energy Agency and the National Institutes of Health (NIH), and was officially terminated in May 2006. (Collins and Galas, 1993, Volkan, 2006). The main purpose of the human genome project, which is one of the most important pillars of genetics, deciphering the codes that determine the genetic structure. According to the results announced in 2006, the reading of genes has been completed. However, the functions of human genes are not yet fully understood.

Although the applications of the genome project seem to have not reached the desired point yet, it is an undeniable fact that a new era has been opened, especially in the field of medicine, with the reading of genetic structure. In this field, subjects such as hereditary diseases, isolation of genetic engineering and gene manipulations continue to develop rapidly. With the discovery of restriction enzymes that accelerate DNA studies, DNA sequence analyses, polymerase chain reactions (Knoppers and Chadwick, 2005, Lorraine and Collins, 2007), and the introduction of more techniques into the field of application, the human genome project has begun to sit on more solid legs.

It is now an accepted fact that the human genome project will help to identify genes that directly or indirectly cause disease in humans, to determine their characteristics and to distinguish them from a healthy structure.

However, genetic manipulations, which have the potential to be used in a wide range of diseases from diagnosis to treatment, have also brought

with them some concerns in terms of revealing the possibility of "intervention with genes" in applications. At this point, human beings have the potential to make a copy of them and change their environment with gene technology. In this context, this potential power of gene technologies has led to the emergence of several ethical questions and problems regarding genetic manipulations today.

These ethical issues are the disruption of the natural balance of the human body, gene pollution, the risk of using genetic information as a biological weapon, efforts to create superior human beings or hard labor, gender discrimination, failure to establish standard health quality, and insurance companies' increasing insurance rates. Ethics, which originates from the Greek word "ethos", emerges as a discipline of philosophy that investigates the values, norms and rules that form the basis of individual and social relations established by people from a moral perspective, such as good and bad. When the results of human genome studies are handled within the framework of this discipline, it will be clearly seen that this project directly affects social norms and values. Because the main point that is the problem here, with the implementation of this project, human nature and its own social and ethical values have changed or will have to change.

It is an important and problematic debate in terms of ethical values that in genetic manipulations, "not an intervention in the material world of things", but an intervention in one's own "biological and natural life" (Habermas, 2003). When the human genome project is fully implemented, ethical issues and debates will come to the fore more. Possible change will progress rapidly, and will gradually take the form of intervention in human nature and life, and fundamental rights and freedoms. As a result of this, humans will appear in a structure that has become instrumentalized and turned into a commodity.

In this context, what price will be paid as a result of the possibilities offered by the genetic revolution? Will people have to pay this price by giving up their fundamental rights and freedoms? How clear are the limits of manipulating the human genome? Where and when to stop



playing with genes? Within the framework of this research, answers to all these questions have been sought. In the discussion, ethical problems that cause concern in terms of individual rights and freedoms were tried to be discussed in all their aspects by acting on concrete examples.

## 2. Human Genome Project (HGP)

The Human Genome Project is a project initiated to understand the structures, locations, and functions of human genes, which are estimated to be around 100,000 and to determine the sequence of 3 billion bases that make up the human genome. (Collins and Galas, 1993, Lowrance and Collins, 2007). In this project, it was aimed first to make a detailed map of human genes and then of all DNA sequences, in short, to analyze the gene cassette. With the analysis of the gene cassette, it is expected that there will be revolutionary changes in the understanding of human development and the expression of “normality” and “abnormality”.

Many countries such as Brazil, Canada, France, Germany, and England, etc., and many companies such as Celera IBM, etc. support this project, which was initiated in 1990 by American institutions such as the American Energy Agency and the National Health Institute. (Bökesoy and Arda, 1993, Knoppers and Chadwick, 2005, Volkan, 2006). The center, which was established in Montreux, Switzerland in 1987 to carry out the reading of the human genome, which is carried out separately in many countries, from a center and thus to save time, labor, and finances, also forms the core of HGP. A period of 15 years is foreseen for the genetic map of the human being to be produced. This project, supported by an average annual budget of 200 million dollars, (Collins and Galas, 1993, 44, Knoppers and Chadwick, 2005) was completed in May 2006. (Lowrance and Collins, 2007, Volkan, 2006). At the point reached in the project, the reading of the gene sequences is finished, but what the gene sequences mean has not yet been resolved. Studies on this subject are still ongoing.

Especially in the field of medicine, the expectations for the results of this project on behalf of science are quite large and varied. The first aim of the project is to determine the susceptibility to

more than 3000 genetic diseases for which there is no cure today, (Lowrance and Collins, 2007) to make diagnosis and treatment possible by illuminating the locations and structures of the relevant genes, and to make the necessary genetic corrections. With the project, it will be possible to diagnose and treat many diseases such as certain types of cancer, hemophilia, multiple sclerosis, and cystic fibrosis, and to develop drugs. (Lowrance and Collins, 2007, Mattick, 2003). As microorganisms will be better known with the opportunities provided by HGP, it will be easier to determine their disease-causing properties in humans, and this information will be used in energy production, reduction of toxic wastes, and development of renewable resources in the industry. (Knoppers and Chadwick, 2005, McGuire, 2008). In addition, by using DNA microchips, it will be possible to determine the individual gene profiles of individuals and thus to determine which diseases they are prone to or what appropriate treatment methods may be. Identification of all regions on DNA that differs from person to person can be used in forensic identification and paternity cases. (Mattick, 2003, McGuire, 2008). The information to be obtained will provide new opportunities in the determination of anthropology and human migrations, besides human health, will provide the opportunity to observe the genetic change experienced over generations, will provide an idea of the migration of different human groups based on the genetic structures of women and men, and will allow us to compare historical events and the development process of human populations.

Another important pillar of the project is cloning and stems cell applications. (Çoban, 2008, Çoban, 2009, McGuire, 2008). Many people will benefit from this if cloning and stem cell studies are successful. In particular, therapeutic embryo applications can be used in the treatment of many diseased organs. Experimental and clinical studies are still ongoing on diseases such as Parkinson's and Alzheimer's, which lead to various nerve cell destruction, retinal diseases of the eye, and some types of cancer. In recent years, stem cell applications have been made on retinitis pigmentosa, (night blindness) a retinal



disease, but unfortunately, cases resulting in cancer were found in a few of the mice in which this application was made. (Wang et al., 2010). As can be seen, these studies come up with expectations and results that may be beneficial for humanity.

While the human genome project is trying to respond to these expectations, on the other hand, the idea that its potential power can “lead to abuses” makes it feel intense, and this causes some concerns. From an ethical point of view, one of these concerns is the manipulation of genomes in a way that disrupts the nature of the human structure, thus allowing people to change their nature permanently. In addition to this, the following questions are also faced: How will the pre-diagnosis of genetic diseases affect the person, his view of the future, and the relationship of that person with the environment? How accurate and ethical is it in terms of the right to life to be notified in advance that an individual has a disease that will result in death? On the other hand, treatment methods such as gene therapy and cloning may allow only a group of people to benefit from these treatments, instead of increasing the standard health quality of the whole society. In this context, what should be the limits of the use of stem cells and especially cloning? Should it be limited to therapeutic use only or should it be used for reproductive purposes as well?

As it can be understood, the things that can be done with HGP seem dazzling. While he promises “sunny days and eternity” to humanity on one side, he also gives the power to create a commoditized slave type based on discrimination by destroying fundamental rights and freedoms on the other hand. From this point of view, it can be seen that the ethical problems it carries are worth discussing.

Then, in light of our explanations above, what needs to be done is, is a comprehensive evaluation and discussion of this new technology, its implications, and application areas. In this context, it would be appropriate to present and discuss in detail how the social rights and freedoms, ethics, social norms, and values of the individual will be affected and where the borders will begin and end in case of the realization of potential risks.

### 3. Ethical Evaluation of the Result of the Human Genome Project

The composition of very different genes in our cells determines the boundaries of each of us and what we are as members of the “Homo sapiens” species. In this context, the genome project is capable of revealing what makes us human. (Bökesoy and Arda, 1993). It even makes it possible for people to re-evaluate “one”, “what is not,” and to “reorganize” one with genetic manipulations. At this point, genetic engineering is confronted with “ethical” questioning, which consists of a bundle of social norms and values. One of the functions of ethical inquiry is to help us understand the “moral possibilities” in each situation and to develop our individual moral sensibility. (McGuire, 2008). In this case, in ethical inquiry, it would be appropriate to discuss “in which framework we can put the will to know” that motivates people, which genetic applications will offer us. What will be the cost of gene technology’s contributions to humanity? How clear are the limits of manipulating the human genome? Will a person know where and when to stop? Does man have the right to implement everything that can be done using the possibilities of technology? Or should there be a “reasonable” limit to what can be done? In determining this “acceptable” line, our “own” ethical values, norms, and ethical problem-solving ability will of course guide us.

Accordingly, let’s try to convey through a case study how the subjective position of the individual can affect his own moral attitude regarding HGP. According to Shepherd (2004), Jamie, who is seen as the “first designed baby” of England, was born because of prenatal interventions with the intention of protecting the life of his four-year-old brother Charlie and curing his illness. Charlie, who has a hereditary blood disease, leads a ‘normal’ life like everyone else, depending on the stem cells taken from the umbilical cord of his brother, who has tissue compatibility.

However, genetic imaging of embryos is subject to the permission of the British government, and the British government, as an authority, rejected this application with the thought that “Jamie would not benefit from genetic imaging”.



Accordingly, the family had this practice done in a clinic in Chicago. Here, Jamie's embryo with the highest tissue compatibility because of imaging and genetic testing of the embryo was selected from among nine other embryos and placed in the mother. After Jamie's birth, the umbilical cord was removed for later use in Charlie's treatment. Looking at the available data, it is not yet known whether Jamie will develop the same inherited disease or whether Charlie will respond positively to treatment and recovery.

When we look at this situation from an ethical point of view, this situation seems to contradict the idea that "man is not a means, but an end", especially in Kant's theory of ethics. Because Charlie's recovery depends on Jamie's existence. So Jamie was born into the world as a tool for Charlie's survival. Man should not be used as a "tool" for any purpose, regardless of the reason. In this case, using Jamie as a tool for his older brother poses an ethical problem. In addition, Jamie's consent, which is a prerequisite for clinical treatment, was not obtained in this instrumentalization process. It is not even possible to predict how Jamie, who has become instrumental with the consent of the family, will react to this in the future, how he will make sense of his existence in a moral context and what kind of problems it will cause in his personality. The individual's thinking that he came into existence only for someone else, and that his right to life is tied to a certain purpose, will cause the individual to lose his self-respect and value. The instrumentalization of humans in genetic practice processes has the potential to deeply affect the ethical understanding of the species itself. (Habermas, 2003).

Based on this personal situation, can a generalizable ethical attitude be reached for the HGP results? Is research on the embryo a violation of the principle of preserving life? If the embryo is accepted as a member of the human species, it appears as a "right" subject in the context of human rights, and at this point, the status of the embryo is between "having a human life" and "being a human with rights". (Çoban 2004, Çoban 2009). In this case, respect for human dignity entails respect for the embryo, as Jamie is a potential

individual.

The history of opinions and researches aimed at eliminating diseased and defective genes is quite old. The idea of "better, smarter, healthier, taller..." people as a result of reproduction goes back to Plato. But the "modern version" of this approach, which emerged under the name "eugenics," belongs to Francis Galton. (Bökesoy ve Arda, Kevles, 1992). The word eugenics has a meaning like "innate well-being" or "hereditary nobility." (Bökesoy ve Arda, 1993, Kevles, 1992).

In this context, if we look at Jamie's situation here, Has Jamie's family jumped into the enriching field of "eugenics", (Shepherd, 2004) or can it be said that the family approaches the unborn child as a second person? How will the right of families to make eugenic decisions affect the future of their genetically programmed children? Is the person whose genes are programmed the author of his own life history? Does the ethical responsibility for his own life rest with him or the gene designer? Can we be sure that unlimited intelligence and an unforgettable memory always or unpredictably produce positive results for the person with these characteristics? Apart from that, what will be the future of the others after one of the selected embryos is placed in the mother? Unfortunately, such ethical questions involving the human element and human nature do not seem easy to answer. Habermas (2003) states that the arguments against genetic determination are "built around the fact that the gene designer assumes the role of determining the identity and personal life history of the person he/she designs". (Çoban, 2004). This genetic determination completely eliminates the ability of the individual to determine his own future, and it directly interferes with the fundamental rights and freedoms of the individual. This causes damage to the dignity of the individual. However, the purpose and quality of the gene designer gains importance. Kant's understanding of ethics is everywhere and always "not what we should do, but what we should want". In contrast to an unconscious "doing", "wanting" is a work of consciousness and will. (Öktem, 2007). In this case, the desire to use "what" the gene designer wants,



“whether genetic intervention for therapeutic or eugenic purposes” is ethically important. In other words, what makes the action meaningful is that the “willing” underlying it is determined not by any content, but by the moral law. In Kant’s words, the value of an action depends on the essentially good intention. Although genetic power is inherently “good”, there will always be a possibility that it will turn into an action that can be “willed” to be considered bad in terms of its consequences.

In addition, the fact that the information obtained by the decoding of the genetic code becomes a tool that serves political and ethnic purposes will mean a departure from common sense. (Bökesoy and Arda, 1993, Lowrance and Collins, 2007). Gene technology, which will help to develop knowledge about evolution, will lead us to reinterpret “ourselves”, “what we are or not”. (Bökesoy and Arda, 1993). It is also possible to determine some privileges through social analysis. If these privileges explain interpersonal differences such as intelligence, can social responsibility be expected to disappear altogether? How will the discussion of the biological origin of determinism explain the “human responsibility and obligation”?

In this context, another issue that needs to be discussed from an ethical point of view is to what extent, for what purposes and by whom the “knowledge” for the solution of the genetic code will be used. The “patent right” is also highly controversial in the use of the obtained information in “production”. Detection of diagnosis areas or carriers for some diseases that are currently incurable by deciphering the genetic code, and being aware of these conditions, may cause problems both in themselves and in their relationships with their environment. For example, it can now be detected with gene therapies that leukemia cells are formed 5-10 years before the disease occurs in leukemia patients. (Aydın 2005). What will the individual gain from being aware of this situation and knowing that the individual will catch this disease after 5 or 10 years? This situation may cause a negative change in the quality of life and standard of living of the individual rather than gain. It will be inevitable for the individu-

al to experience some social and psychological problems. These problems limit the fundamental rights and freedoms of the individual and may cause a problem that may extend to the individual giving up his right to life. In addition, knowing that the individual carries a defective gene will always bring the risk of conflict between the individual and society. In fact, the possession of this information by spouse, sibling, employer, etc. will eliminate the personal nature of the information. Thus, the rights and freedoms of the person will be interfered with ethically, and the dignity of the individual will be damaged.

It is also a controversial issue that which type of genetic information will be sufficient to gather people under the same heading, whether they have the right to hide this information from others (employers, official institutions...), and whether the right to refuse genetic information requests can be mentioned. (Bökesoy and Arda, 1993). The fact that gene analyses are requested from individuals when applying for a job or for insurance transactions and these are criteria in the selection of candidates will overshadow the effort spent in this field and the scientificity of the subject. This will lead to the emergence of genetic discrimination. Heidi Williams experienced this type of genetic discrimination in the United States in 2004. (Özalp, 2007). “Humana Insurance” did not accept the health insurance that Heidi Williams wanted to make for her twin children. Accordingly, twins have two copies of genes, one normal and the other abnormal. However, they do not show any symptoms resulting from this abnormality that will seriously affect their lives. Humana Company changed the decision after the event was heard and reflected in the media, and had to agree to take out the twins’ health insurance. The twins’ mother, Heidi Williams, reacted after what had happened, “Humana Company made me feel guilty and stated that “it embarrassed me because of the need to learn the genetic status of my children”. (Özalp, 2007). Here, it is clearly seen that the mother’s “will to know” and the insurance company’s “use of information” demand do not coincide ethically, and this justifies the concerns. It is a mystery how the feeling of guilt and shame inflicted on the mother



will affect the relationship between the mother and the child carrying the defective gene in the future. As in this case, although gene technologies are “good” in their essence, they can turn into an action that can be characterized as bad in terms of its results, depending on “voluntary”.

Another striking example of genetic discrimination is the use of genome analysis as a criterion for recruiting black workers in the United States. It has been determined by genome analyzes that the black race overreacts to some chemicals and suffers from respiratory problems at low pressures. For this reason, between 1970 and 1980, some black people in the American army were not allowed to enter the Air Defense Academy. (Jürgen, 2006, Özalp, 2007).

According to a study conducted in 1996 on 917 people with various genetic diseases, 200 cases of genetic discrimination were encountered. (Jürgen, 2006). As in the examples, those who made genetic discrimination were insurance companies, business owners and other organizations using genetic information. As a result, many Americans are reluctant to take advantage of advances in genetic testing, fearing that genetic testing may face discrimination in “hiring and insurance relationships” rather than improving their health.

As seen in these cases, the moral attitude of individuals is surrounded by interpersonal relations. The individual’s own story, as justified by his own ethical values, enters into dialogue and interacts with other stories. This mutual interaction brings along culturally and socially differentiated moral ratings of individual experiences. These moral differences can lead to, or even trigger, normative conflicts. In such a conflict environment, it becomes difficult to determine ethical principles and put them into practice. At the point reached in gene technologies, there is an increasing concern that conflict environments based on discrimination will increase.

## Results

There are very broad horizons in front of genetic applications and it is clearly seen that giant steps have been taken in this field as well. Especially with the complete decoding of the codes of the genes and the gene cassette, great

steps are taken in genetic diagnosis and treatment with steps such as cloning, stem cell and embryo studies. Especially the next generation has the potential to benefit the most from these steps. For example, with the widespread use of genetic manipulations and the wide use of gene therapies, it will be possible to treat many diseases for middle-aged and elderly people. Perhaps none of these diseases will be seen in the next generation. Because the increase in genetic manipulations that make prenatal intervention possible, the use of these technologies by future generations and the development of prevention methods will reduce or completely eliminate the risk of catching current diseases. This is an indication of how important HGP’s results are. In particular, the positive evaluation of the results of HGP and its positive use increases the hope that radical solutions will be found against diseases. However, along with these positive developments, the ethical problems discussed above should not be ignored.

## Discussion

The instrumentalization of man, his transformation into a commodity, and even his becoming a slave human seems possible with the misuse of this technology. Genetic manipulations have the feature of pushing the individual into a normative conflict, such as choosing between fundamental rights and freedoms and individual dignity. This situation may leave the individual to choose between his own ethical values and norms, individual and society, individual and social norms. It should not be forgotten that in these studies, the human being is not as a tool, but always as a goal and to act accordingly. Ethical principles created by considering the benefit of humanity in the development process of gene technologies and appropriate behaviors will serve a higher purpose, such as social benefit. Despite the ethical problems discussed the fact that genetic engineering will be a great source of light and hope for humanity in the future should not be ignored when used for the right purposes. In this case, as the last word to be said, is Winston Churchill’s World War II, about the state of the human genome project today. After World War II he said, “This is not the end, nor is it the beginning of the



end. At most, this is the end of the beginning” would be quite appropriate.

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