

Ethical issues in the human genome project



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The Human Genome Project was the largest international scientific research conducted in the field of Biology. This research project began in 1990 with a mission of discovering all the genes in human DNA and determining the sequences of chemical base pairs which make up the DNA of human. The Human Genome Project was coordinated by the Department of Energy and National Institute of Health, in the USA. The research involved thousands of scientists, biologists, chemists, engineers, computer scientists, mathematicians and human participants from around the world. The researchers plotted several types of biological maps that enabled many other researchers to improve their knowledge and to use them in proceeding with their researches.

According to web definitions, a genome is “ The set of genes that are carried by an individual”. A chromosome is a genetic structure that contains cells that contain thousands of genes. The human genome is stored in 23 chromosome pairs. Gene sequencing is a process that determines the sequence of DNA of an organism’s genome. The genome that was sequenced for the first time was a virus and was done in 1977. Scientists have discovered that there are over 3 billion DNA base pairs in a haploid human genome. One of the aims of the human genome project was to plot maps that are capable of providing a way for the researchers to locate specific genes in a chromosome.

The primary aim of the Human Genome Project was to identify and map all the DNA pairs. There are many applications of Genome research, namely, Bio Technology, Bio Medical Research, Molecular Medicine, DNA Forensics, Agriculture, Livestock Breeding and bio-processing. The outcome of the

Human Genome Project enables improved diagnosis of disease, Rational Drug design, creation of customized drugs and Gene therapy. These are several benefits of the HGP in the context of Molecular Medicine and Bio Medical Research. The maps created by the HGP have enabled researchers to unveil many genetic conditions such as inherited colon cancer, Breast cancer and Alzheimer's disease. The HGP (in the filed of DNA forensic) will enable to identify suspects by identifying DNA found in crime scenes, identify parents, and other relationships, and to identify DNA precisely in any context. Furthermore, it enables creation of nutritious products and Biopesticides as benefits to the field of Agriculture and Bioprocessing. Plants and animals that are more immune to diseases could be created by understanding plant and animal genomes. Moreover, it will enable to reduce cost of agriculture and to provide customers with more nutritious and quality products.

The benefits for Bioarchaelogy, Human Evolution and Anthropology are the ability to study the evolution of humans by understanding the genomics, ability to study migration of different populations and to discover the relationships between the archaebacteria, eukaryotes and prokaryotes.

On the contrary to the above mentioned benefits, the Human Genome project and its applications have encountered significant social, ethical and legal issues. The main issue is allowing access to gathered genetic information. If the information is accessible by anyone, it could be misused. For example an employer can access this information, and use it in making decisions when they hire people. There may be people who are having genetic disorders, yet physically fit and capable of working. Nevertheless,
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the employers can decide not to hire them considering the possibility of developing a medical disorder. Decisions are made based on the employee's personal genetic information. This could be unfair to a certain group of people with genetic disorders. Making decision based on the genetic information of the employees is unlawful under section 202 of the Genetic Information Non Discrimination Act of 2008. According to Section 202, Employer Practices, it is unlawful for an employer not to hire or to discharge or to discriminate any employee based on their genetic information.

If the data is accessed by Insurance companies, they could use it to earn profits. The person who is willing to insure himself will have to pay a premium depending on the severity of the disease he has. For example, a cancer patient's premium will be higher than the premium of a normal person. The ethical issue is discrimination based on the genetic information. It is a known fact that discrimination is used to discourage people in many places such as schools, workplaces, universities, and even in public. There are many instances in which people had to leave workplaces, and children faced many problems in schools due to embarrassment which was a consequence of discrimination. Race and ethnicity discrimination was the most prominent form of discrimination. It has deviated into genetic discrimination since the genetic information is now available. This may cause embarrassment to people with certain genetic disorders, discourage them and even lose their confidence which could let them down. To regulate this situation, many governments have set laws and legislations that describe the penalties of discrimination. One such legislation is the Employee Retirement Income Security Act of 1974. Section 702 of the act States " (A) In General -

For purposes of this section, a group health plan, and a health insurance issuer offering group health insurance coverage in connection with a group health plan, may not adjust premium or contribution amounts for the group covered under such plan on the basis of genetic discrimination.” It further discusses the penalties for the insurers and employers who use discrimination as a form of gaining profit.

Another way of misusing the gathered information is using it to discriminate minority ethnic groups or communities. The Universal Declaration of Human Rights and the Human Genome states, “ No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedom and human dignity”. Therefore even though a person’s genetic information is revealed, he has the right to live without being a victim of discrimination.

Nevertheless, the existence of the genetic information may lead to several social issues such as racial discrimination. Currently, most people in European countries are victims of racial criticism. The human genome project requires quite a large number of genes to be gathered and stored and then to be tested. The genetic differences between groups of people can be emphasized. This may have a psychological impact due to the differences between genetics.

One of the greatest achievements of the Human Genome Project was the genetic map which is capable of facilitating researchers to pinpoint specific genes in a chromosome. This enables to discover a significant amount of disorders in the human body and doctors to quickly identify the disorders within their patients. Several decades ago, people were not allowed to be

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aware of the diseases and only the scientists were allowed to discover them and find treatments. The society has revolutionized, and people live more sophisticated lives, therefore, awareness of such diseases is at a higher level. Many people argue that patients have a right to be aware of their illnesses; on the other hand, this has a negative impact on the patients' mentality. Even if a genetic disorder is discovered, it takes some time to discover the treatments. For instance, cancer was discovered, several decades ago, however proper treatments with no side effects have not been found yet. Similarly, when a genetic disorder is diagnosed, it can create frustration and anxiety. This frustration and anxiety will remain within the patient's mind until the treatments are discovered and the patient is treated. This may take a short time period or may take a couple of years. It is a well known fact that a person can live longer and happier as long as he is not aware of his illnesses. Another drawback is that people might be discouraged and refuse to live their normal lives due to frustration. Awareness of the genetic disorders can ultimately result in a group of people who are mentally ill which would become a severe social issue.

Applying new genetics to unborn children is another area which may cause ethical and social implications. The discoveries of the Human Genome Project have enabled the scientists and doctors to replace cells in unborn children. This implies that parents can have custom-made babies, with the desired features. A possible dilemma is issues related to In-Vitro-Fertilization. In Vitro Fertilization is the process of fertilizing egg cells by male cells (spermatocyte) outside the womb. Since genetic information is available, genes with all good features could be selected and "high grade" embryos

could be created. The concept of “ Designer Baby” is introduced with this technology. These embryos could be sold at different prices which may cause in every human having a price and it will depend on the race, intelligence level, eye, or hair color and immunity to diseases. Prices of these designer babies will depend on the quality of the baby. Social issues may arise among people who are able to afford for a high quality designer baby and people who are not capable of owning one. Another possible social issue is the competition among the designer babies when they grow older. Every parent would want their baby to be a high quality designer baby. The rate of child kidnaps and murders could rise as a result of the designer baby concept.

As stated in the previous paragraphs, one of the main objectives of the Human Genome project was to map the DNA sequence. This enables the doctors to modify the embryos and create humans who can live longer, more intelligent and more immune to various diseases. In addition to the issues raised by having designer babies, creation of “ super human” with fewer defects have raised religious issues. It contradicts with the religious beliefs on God of many people. Creation of “ super human” has raised controversial issues among the scientists who are involved in research based on creating humans and spiritual and religious leaders. This is because many religions believe that the creator of humans is God. They believe that the superiority of human is decided by god. The argument brought by them is that only god has the power to create a living creature and humans are not creators, but only creations. They also believe that humans shall never become powerful than God. Moreover, they strongly believe that these scientific researches

and developments have disappointed God, and the harsh punishments should be given to scientists who are engaged in such research. This religious issue could grow into a serious social issue where people might start attacking the scientists. Previous researches have shown that most people are against modifying embryos to create better quality humans. Furthermore, it is evident that people who are against the creation of “super human” are mostly religious and spiritual leaders and people who strongly believe in God.

Forensic Investigation is another area which is benefitted by the Human Genome Project. Nevertheless, it can be the origin of many social and ethical issues. The DNA gathered by the HGP is stored in a database known as the National DNA databank: CODIS. The goal of storing this information is to use it for forensic investigation, in criminology. Investigations involving DNA is considered to be more accurate. The Combined DNA Index System has become a powerful tool to reduce violent crime as it combines DNA technologies with computers. Two indexes are used in CODIS, namely, The Convicted Offender Index and The Forensic Index. These indexes are generated using the biological evidences gathered from the crime scene. DNA profiles are then created using Short Tandem Repeat analysis. Different software is utilized in CODIS to search for the indexes for matching DNA profiles. According to the sources, the databank contains more than five million DNA profiles. DNA is tested to identify criminals, but when the tests are done, used DNA records should be destroyed. Proper Disposal of the DNA information is vital or else the person’s entire genetic information would be available. This again could be used to discriminate people or to accuse

innocent people for crimes which they have not committed. Another distressing issue is the violation of privacy of the owners of the genetic information. Genetic information is considered as private and confidential information of a person and privacy implies that a person has the right to decide the extent of disclosing his or her genetic information. Privacy is violated due to not having proper means of disposing the used samples. Accusing innocent people or arresting them is another negative aspect of storing DNA in a databank. This technology matches DNA profiles of crimes with victims and therefore, it can match a person who has been in the crime scene earlier. This way, innocent people could be accused and arrested, hence discriminated and cornered by the society.

Another alarming issue is populating criminal databases with DNA samples of people belonging to ethnic minorities. This is mainly done with an intention of discrimination and discouraging people. This is due to not gathering and storing genetic information in an unbiased manner such that it would not be unfair for a group of people. For example, a controversial problem occurred in a European country, for storing DNA samples in a biased manner such that the criminal databases were mostly populated with innocent people belonging to ethnic minorities. Consequently, innocent people were arrested and questioned.

Gene Testing is yet another area which may cause social issues. In gene testing, DNA sample are taken and stored in databases, and sometimes used to compare with other people's DNA samples. Once a DNA test is done, the company issues a copy to the owner of the DNA and results are kept in hard copy files as well as databases. These hard copy files could be accessed by <https://assignbuster.com/ethical-issues-in-the-human-genome-project/>

any one and refer to the genetic information and test results of some one. The database can also be hacked and the genetic information can be revealed. It is a known fact that no database is hundred percent secure even if it is an offline database. Therefore security is a main issue in genetic testing. Some of this DNA samples are compared with other samples during tests, and mostly done without the consent of the owner of the DNA sample. Privacy is the main issue of having a massive databank with DNA information of millions of people. DNA can provide information about people including their probability of having certain diseases, sexual orientation or certain behaviors. Gaining access to this information would violate the privacy of another. Police, forensic science service and researchers can access this information without the consent of the people. This violates the privacy of the people. One can use this information unethically, against another to discriminate or to harm someone emotionally. Celebrities would be the first to lose their privacy as many people are keen on gathering information about them. This information could be published and could be the origin of many other issues in their personal lives. The probability for genetic discrimination by the government, schools, employers and insurance companies may increase. Invading someone else's privacy is illegal according to many privacy laws and legislations set by many governments. According to the Privacy Law of the United States of America, privacy is " the expectation that confidential personal information disclosed in a private place will not be disclosed to third parties, when that disclosure would cause embarrassments or emotional distress to a person of reasonable sensitivities." Furthermore, it discusses the penalties of invading other people's privacy.

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Article four of universal Declaration of the Human Genome and Human Rights states that “ The human genome in its natural state shall not give rise to financial gains”. In most countries it is believed that DNA, when removed from a person, is not considered to be in its natural form, hence it is used to gain financial benefits. For instance, in the US, innovations are encouraged by allowing gene patenting. Though using genomes to gain profits is against the Universal declaration of Human Rights many companies tend to use this to gain profits. But many people are against gene patenting for various reasons including their strong beliefs which says that human gene sequences should never be patented. It is also believed that human genome is an inherent part of every person. Gene patenting is prohibited in some parts of the world and there has been evidence of situations in which legal bodies have denied to grant patents.

Another area of the Human Genome Project which will cause several ethical, legal and social issues is genetic Testing, Screening and Counseling. As a result of identifying new genes, tests that can determine the level of risk for a particular genetic disease are developed. This will enable people to know whether there is a potential of developing a disease or a genetic disorder which could be passed on to their children. This will have a negative impact on the society. Also it could change the whole life of a person. For example, a person could be mentally letdown if he gets to know that he has a high possibility of developing a rare disease which could not be cured. If this information is revealed, and accessed by an employer this person might not be granted a job. Similarly, if the person wants to get an insurance coverage

for himself, he might be required to pay a higher premium to the insurers depending on his disease.

Genetic engineering involves manipulation of genes. The map created as a result of the Human Genome Project provides information that will enable to diagnose and treat many diseases. The map can also help in determining the genetic foundation of physical and psychological behavior. As a result, it is possible to alter the behaviors with the involvement of genetics. Two areas of genetic engineering is somatic cell manipulation which alters body cells and germline manipulation which alters reproductive cells. The use of Somatic cell manipulation is ethically accepted as it limits the changes that can be done to an individual. Since it alters only the body cells, the risks are not inherited by the descendants. In contrast, the germline cell manipulation raises ethical issues since the manipulations of reproductive cells can extend the risks across the generations. Genetic engineering done on humans may cause health issues. For example, genes of one person could be enhanced to increase a person's height further than his natural height. But this may cause stress to other parts of the body such as the heart. As a result, the person might be left physically ill.

Another key ethical issue of the Human Genome Project is the use of genetic screening. According to web definitions genetic screening is " The process of testing individuals in a population for certain hereditary defects." Mandatory genetic screening for adults raises many ethical issues related to privacy and personal liberty. Furthermore, Genetic screening of infants, young infants and other vulnerable groups who cannot grant their consent is unethical. For example, in most cases, infants are screened without the consent of parents.

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Screening is done based on an assumption that parents are willing to know about the probable diseases that might develop in their children. There is evidence of situations where genetic screening has been used as a form of discrimination. For example, in insuring patients who are willing to obtain a health insurance, there are required to pay extra amounts.

In addition to the applications discussed earlier, Agriculture and livestock breeding are two other applications of the genome research. As opposed to the above applications, these areas do not use humans for testing. Yet it may give rise to many health issues which might convert into social issues with time. These applications entails of developing bio engineered food and animals, also known as genetic engineering. This process is similar to genetic engineering done on humans. Though many researchers explain the positive aspect of bio engineered food, many health issues and other side effects night arise by consuming modified food. Many companies tend to create genetically modified food regardless of the consumers' health. Regular consumption of genetically modified food may severely damage the health of people; as a consequence, people of a country may not be able to involve in the development process of the country. Furthermore, companies would refuse to hire people and as a result, the country can be populated with unhealthy and unemployed people.

Though the mission of The Human Genome Project was accomplished, it is evident that the potential and current applications of the Human Genome Research have caused many issues. Ethical and social issues included issues concerning the privacy of the people, discrimination, unauthorized access to the gathered information and security issues and many other related issues.

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Issues related to the informed consent and legal issues were also caused by the applications of the genome research. The concepts of “super human” and “designer baby” were two controversial concepts that caused religious and social issues. Furthermore, other applications in the field of agriculture and genetic engineered food could cause health issues in the society. In my opinion, the Human Genome project and its current and potential applications have a significant amount of social, ethical, religious and legal issues which would directly affect many people’s lives.