
UNIT 4 ETHICAL, LEGAL AND SOCIAL ISSUES

Contents

- 4.0 Objectives
- 4.1 Introduction
- 4.2 Elsi Research Goals
- 4.3 Ethical Issues
- 4.4 Legal Issues
- 4.5 Social Issues
- 4.6 Critical Remarks
- 4.7 Some Large Philosophical Issues
- 4.8 Let us Sum Up
- 4.9 Key Words
- 4.10 Further Readings and References

4.0 OBJECTIVES

- To give the students the general overview of ELSI programs and its significance to genetic engineering.
- To see the significance of ELSI, particularly in genetic research.
- To have a comprehensive notion of both the positive and negative side effects and consequences of HGP.
- To give an overview of the ethical, legal and social issues related to genetic research.
- To see some of the dangers posed and possibilities offered by HGP and such such cutting-edge technologies

4.1 INTRODUCTION

Rapid advances in the science of genetics and its applications have presented new and complex ethical and policy issues for individuals and society. Ethical, Legal and Social Issues (ELSI) programs that identify and address these implications have been an integral part of the U.S. Human Genome Project (HGP) since its inception. These programs have resulted in a body of work that promotes education and helps guide the conduct of genetic research and the development of related medical and public policies.

A continuing challenge is to safe guard the privacy of individuals and groups who contribute DNA samples for large-scale sequence-variation studies. Other concerns have been to anticipate how the resulting data may affect concepts of race and ethnicity; identify potential uses (or misuses) of genetic data in workplaces, schools, and courts; identify commercial uses; and foresee impacts of genetic advances on the concepts of humanity and personal responsibility. The

project’s goals included not only identifying all of the approximately 24,000 genes in the human genome, but also to address the ethical, legal, and social issues (ELSI) that might arise from the availability of genetic information. Five percent of the annual budget was allocated to address the ELSI arising from the project.

The main criticism of ELSI is the failure to address the conditions raised by population-based research, especially with regard to unique processes for group decision-making and cultural worldviews. Genetic variation research such as HGP is group population research, but most ethical guidelines, according to Harry, focus on individual rights instead of group rights. She says the research represents a clash of culture: indigenous people’s life revolves around collectively and group decision making whereas the Western culture promotes individuality. Harry suggests that one of the challenges of ethical research is to include respect for collective review and decision making, while also upholding the Western model of individual rights.

4.2 ELSI RESEARCH GOALS

The HGP is probably one of the most profound research efforts in human history, which will certainly impact all of us because of the many implications for medicine and human health. The Genetic advancements and Human Genome Project has the potential to heal and restore the brokenness of creation. However it has serious ethical, social, philosophical and religious implications. Ethical, legal and social implications of the Human Genome Project are privacy and confidentiality, psychological impact and stigmatization, genetic testing, reproductive issues, education, standards, and quality control, commercialization, conceptual and philosophical implications.

- 1) **Fairness and Privacy:** fairness in the use of genetic information. Who should have access to your genetic information? (Chan and Chia 2003)
- 2) **Psychological Stigmatization:** how does knowing your predisposition to disease affect an individual?
- 3) **Genetic Testing:** should screening be done when there is no treatment available?
- 4) **Reproductive Issues:** Reproductive issues including adequate informed consent for complex and potentially controversial procedures, use of genetic information in reproductive decision making, and reproductive rights.
- 5) **Clinical Issues:** implementation of standards and quality control measures in testing procedures.
- 6) **Commercialization:** commercialization of products includes property rights (patents, copyrights, and trade secrets) and accessibility of data and materials.

Some of the Other Related Issues that are Related to ELSI are:

- Examine issues surrounding the completion of the human DNA sequence and the study of human genetic variation.

- Examine issues raised by the integration of genetic technologies and information into health care and public health activities.
- Examine issues raised by the integration of knowledge about genomics and gene-environment interactions in non-clinical settings.
- Explore how new genetic knowledge may interact with a variety of philosophical, theological, and ethical perspectives.
- Explore how racial, ethnic, and socioeconomic factors affect the use, understanding, and interpretation of genetic information; the use of genetic services; and the development of policy.

Check Your Progress I

Note: Use the space provided for your answers.s.

1) What is ELSI and give its significance?

2) What are some of the research goals of ELSI?

4.3 ETHICAL ISSUES

It is often asked whether it is right for human beings to manipulate human genes at all, as if this in some sense “playing God” by altering fundamental aspects of human makeup which are God’s prerogative only, or simply that it is a dangerous “tampering with nature” in a way which we have neither the right nor the skill to do. We need to worry about whether genetic technology generated from the HGP will make us less accepting of people who are different. For example, if it is possible to predict and prevent the birth of a child with a gene-related disorder, how will we react to children who have that disorder? At the same time the non reproductive cloning requires abortion (Kilner, Pentz and Young 1997). Here life is created specifically for the purpose of destroying it and then cannibalizing it essentially for spare parts. Human life is intrinsically sacred even at this early stage of development.

Genetic modification of trees to reduce Co2 levels is a new attempt in genetic world. It aims to bring a benefit to all people which would be treating them as an

end in themselves. A comparison with the duty based ethics of Kant would show more light into this. Immanuel Kant says that we should treat each person as an end in themselves and not merely as a means to an end. Kant see it as a duty to implement this technology, provides we look as much care as possible to ensure that it was for the welfare (Lewis 2007). Thus the humanity will benefit from a stabilization of the climate by genetically modified trees. It is Kantian duty to act in the interests of future generations to treat them all as ends in themselves. However if something goes wrong, then humanity would suffer from changes to their eco-system.

What are some of the Ethical considerations for using gene therapy?

Some questions to consider are:

- What is normal and what is a disability or disorder, and who decides?
- Are disabilities diseases? Do they need to be cured or prevented?
- Does searching for a cure demean the lives of individuals presently affected by disabilities?
- Is somatic gene therapy (which is done in the adult cells of persons known to have the disease) more or less ethical than germline gene therapy (which is done in egg and sperm cells and prevents the trait from being passed on to further generations)? In cases of somatic gene therapy, the procedure may have to be repeated in future generations.
- Preliminary attempts at gene therapy are exorbitantly expensive. Who will have access to these therapies? Who will pay for their use?

What are the ethical issues surrounding gene?

Because gene therapy involves making changes to the body's set of basic instructions, it raises many unique ethical concerns. The ethical questions surrounding gene therapy include:

- How can "good" and "bad" uses of gene therapy be distinguished?
- Who decides which traits are normal and which constitute a disability or disorder?
- Will the high costs of gene therapy make it available only to the wealthy?
- Could the widespread use of gene therapy make society less accepting of people who are different?
- Should people be allowed to use gene therapy to enhance basic human traits such as height, intelligence, or athletic ability?
- Short-lived nature of gene therapy – Before gene therapy can become a permanent cure for any condition, the therapeutic DNA introduced into target cells must remain functional and the cells containing the therapeutic DNA must be long-lived and stable. Problems with integrating therapeutic DNA into the genome and the rapidly dividing nature of many cells prevent gene therapy from achieving any long-term benefits. Patients will have to undergo multiple rounds of gene therapy.

- Immune response – Anytime a foreign object is introduced into human tissues, the immune system has evolved to attack the invader. The risk of stimulating the immune system in a way that reduces gene therapy effectiveness is always a possibility. Furthermore, the immune-system's enhanced response to invaders that it has seen before makes it difficult for gene therapy to be repeated in patients.
- Problems with viral vectors – Viruses, the carrier of choice in most gene therapy studies, present a variety of potential problems to the patient — toxicity, immune and inflammatory responses, and gene control and targeting issues. In addition, there is always the fear that the viral vector, once inside the patient, may recover its ability to cause disease.
- Multi-gene disorders – Conditions or disorders that arise from mutations in a single gene are the best candidates for gene therapy. Unfortunately, some of the most commonly occurring disorders, such as heart disease, high blood pressure, Alzheimer's disease, arthritis, and diabetes, are caused by the combined effects of variations in many genes. Multi-gene or multi-factorial disorders such as these would be especially difficult to treat effectively using gene therapy.

Current gene therapy research has focused on treating individuals by targeting the therapy to body cells such as bone marrow or blood cells. This type of gene therapy cannot be passed on to a person's children. Gene therapy could be targeted to egg and sperm cells (germ cells), however, which would allow the inserted gene to be passed, on to future generations. This approach is known as germ-line gene therapy (Harwood 1994).

The idea of germ-line gene therapy is controversial. While it could spare future generations in a family from having a particular genetic disorder, it might affect the development of a fetus in unexpected ways or have long-term side effects that are not yet known. Because people who would be affected by germ-line gene therapy are not yet born, they can't choose whether to have the treatment (Harwood 1994). Because of these ethical concerns, the U.S. Government does not allow federal funds to be used for research on germ-line gene therapy in people.

- At the ethical level we also need to ask the following questions:
- What is normal and what is a disability or disorder, and who decides? Are disabilities diseases?
- Do they need to be always cured or prevented?
- Does searching for a cure demean the lives of individuals presently affected by disabilities?
- Is somatic gene therapy (which is done in the adult cells of persons known to have the disease) more or less ethical than germ line gene therapy (which is done in egg and sperm cells and prevents the trait from being passed on to further generations)?
- In cases of somatic gene therapy, the procedure may have to be repeated in future generations. Can we give this burden to the future generation?

Preliminary attempts at gene therapy are exorbitantly expensive. Who will have access to these therapies? Who will pay for their use? The eradication of disease through germ-line therapy might not seem, by itself, to raise many ethical questions. After all, humans have eradicated the smallpox virus from the world, why not diseases with genetic components? Do doctors not have the moral obligation to provide the very best treatment to their patients and would not the eradication of the disease be more cost effective in the long run than continually treating adults with somatic gene therapy? The main ethical problem arises in defining a “treatable” disease. Some might say that eradication of a genetic disease for which there no treatment is and which is always fatal, should be pursued with all means possible. Others say that this would be the start of a slippery slope moving on toward the treatment of less obvious diseases and then to genetic enhancement.

Some argue that if the technology is advanced in order to eradicate some diseases, it will inevitably be used by parents wishing to “enhance” their children, giving them the genes for raven black hair and blue eyes or athletic prowess. It was serious ethical concerns about genetic enhancement that prompted the Council of Europe to adopt the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. Article 13 of the Convention states that “an intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.

“Article 11 of the UNESCO (Universal Declaration on the Human Genome and Human Rights) states that “practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted.” It is left to individual states; however, to define exactly what they believe these practices to be. Thus, while some countries, such as the signatories to the European Convention, may prohibit germ-line therapy, others may not. It is the existence of national differences in regulation of research on human embryos that has allowed controversial research to be performed, for example, in Singapore. Regulation has thus slowed down the progress of research but not prevented it.

Another ethical consideration with respect to germ-line therapy is defining what is normal, what a disability is, and what a disease is. Which of the genetic variations within a population ought to be eradicated, if any? In trying to eradicate a certain variation, are we demeaning those in the population who currently carry the gene? Somatic gene therapy has its own, less controversial, set of ELS implications. These may be less ominous than eugenics but are of perhaps more immediate concern, given the more advanced state of the technology. Effectively, gene therapy involves the introduction of a properly functioning gene into target tissues in the hopes that it will be translated into a properly functioning protein, which will mask the malfunctioning protein. Often the new gene is placed into a modified virus, which is then introduced into a patient in the hope that the gene will be introduced into a tissue and properly expressed.

Such types of therapy, after much research on laboratory in animals, have now reached the clinical trial stage. Unfortunately, what works for a mouse does not always work for a human being. In one highly publicized case, a patient, Jesse Gelsinger, was given an injection of a virus in the hope of introducing a protein

into the liver. Mouse studies showed good absorption of the gene into the liver; however, the mouse has a much higher concentration of viral receptors on its liver cells than do humans. The virus did not absorb well into the human patient and, for still unknown reasons, created a massive immune response, causing the patient to die. The original plan for the trials had been to use the virus only on children in a coma caused by the lack of the particular liver enzyme; however, ethical and safety reviews caused the researchers to change the trial direction and use adults only.

Many questions are now being asked regarding the ethics and scientific judgment of those performing such clinical trials. How well are “volunteer” patients informed of the possible risks and benefits? How objective are investigators who have equity in the companies that are funding the trials? One of the risks at this stage of gene therapy is the excessive public anticipation, created in part by some researchers, with respect to future benefits. This anticipation may turn to public distrust of science, if the benefits fail to be realized and problems such as that in the Gel-singer case continue to occur. Some clinical trials have shown positive results, and so there is still hope that somatic gene therapy will become a powerful medical tool (Green 2007).

4.4 LEGAL ISSUES

Medical therapies: Scientists are now discovering the genes which “trigger” various genetic diseases which, in turn, constitute a large part of the inherited causes of the suffering of humanity. For example, the genes which express Huntington’s disease, a serious affliction, have been identified on the human genome. Their discovery permits the conduct of extremely accurate tests which can now identify those people who carry and may transmit this genetic condition. That knowledge would, theoretically, in combination with prenatal tests and abortion, permit the future elimination of carriers of Huntington’s. So we need to ask the following questions:

- Is such elimination of carriers of Huntington’s desirable? Can it be distinguished from the abortion of a foetus with Down syndrome?
- Where does this process of medical elimination of the results of “defective” genes begin and end?
- Is there a less life-destructive means of using the genetic information to delay the onset or diminish the symptoms of Huntington’s disease whilst respecting the life of a person born with those genes or others like it?

Criminal Law: For the lawyer, the discovery of genetic causes of disorders and of some antisocial conduct may have implications for the future. The criminal law is built upon a general hypothesis of free will. For the crime to be established it is normally necessary to prove both the act of the accused and the will occasioning that act. Some related issues are:

- What are the implications for the law of discovering that, in some cases at least, for some people, the act is practically nothing but the product of a genetic characteristic?
- Can we persist, in all cases, with the unquestioned hypothesis of free will in the face of scientific knowledge which casts doubt upon it?

- Privacy and Confidentiality: The basic rule of the healthcare professions has long been respect for the confidences of the patient. This rule goes back at least to the Hippocratic Oath. It existed in ancient civilisations.
- When a disorder is of a genetic characteristic, is the “patient” the individual or the entire family?
- Does a family in such circumstances have a right to override the wishes of the patient and to secure data about the patient’s genes relevant to genetic features important for them all?
- Should a patient have a right not to know the determinants of his or her future medical conditions?

Third Party Interests: This last question leads to the rights of third parties. Should an employer have a right to require an employee to submit to genetic testing to show, with greater perfection, the likely future health status of the employee? Should an insurer be entitled to secure a detailed genetic profile of the insured? Until now, insurance has generally involved the sharing, within the community, of the risks attached to medical conditions which are largely unpredictable.

If such conditions can be predicted with perfect or near perfect accuracy, would that not shift the scales unfairly to the advantage of insurers? Where insurers can require those seeking insurance to submit to old-fashioned medical tests, is it sensible to close off knowledge of the best medical information that may be made available by genetic tests?

Intellectual Property: One of the key issues of genetic research concerns the desirability of permitting the patenting of human genes or their sequences as the basis for future therapeutic applications. Of course, in every country, the patentability of such matter depends upon the terms of the local law on intellectual property protection. That law is itself normally the product of national legislation and is often influenced by international law. At conferences on the genome, strong views are commonly expressed by participants from developing countries and elsewhere about this topic. They urge that the human genome is the common heritage of humanity. That it belongs to the human species as a whole - some say to God - and not to private corporations engaged in research, however potentially beneficial such research may prove to be. They point to the fact that Watson and Crick never attempted to secure the slightest commercial advantage for themselves from their discoveries.

Human Rights: An important element in UNESCO’s Universal Declaration on Human rights and the Human Genome, to which I will now turn, is the attempt to reconcile the development of genetic technology and research on the human genome with fundamental human rights and human dignity inhering in every individual (Podimattom 2003).

4.5 SOCIAL ISSUES

The HGP is rich with promises, but also fraught with social implications. It is quite likely that the new knowledge from the HGP will be used in ways that don’t always have to do with health. Our challenge is to reduce any negative impacts, which result from the misuse of genetic information. Researchers,

scientists, business and governmental people who are involved in the HGP must avoid any activity that could cause harm while they pursue professional and personal goals.

On the other hand, individuals not directly participating in genetic research are responsible to educate themselves and seek information about potential risks and benefits of genetic research and about the interventions that it produces before they utilize new genetic technologies. Individuals with access to information about their genetic endowments will be able to predict their susceptibility to genetically related disorders in the future (Chan and Chia 2003). Threats evolve around the major question of whether or not an individual has access to genetic technologies. One type of threat occurs when individuals are denied access to technologies that would benefit them. The likelihood of genetic technologies becoming available to some peoples but not to others, and that a major determinant of access will be wealth, raises profound social issues. In view of Global collaboration the HGP should also has to deal with rules especially fair regulations that concern the access and uses of the new information.

The regulation of access of technologies and information obtained from the HGP should be handled very carefully and is probably one of the most difficult tasks for the future. This is especially true since the project has international dimensions and opinions on this issue differ among participating countries. That leads into another question, whether countries that do not directly contribute to the success of the HGP should be treated differently in terms of access to information and technologies being generated from the HGP.

Humans are the moral agents in this world with a capacity to think, evaluate, choose, communicate and articulate. It has been argued that the most significant issue genetic science forces on society concerns the understanding of human nature. Objectification also represents a fundamental breach of human dignity. To treat persons who are the sources of genetic material for cloning or persons who are created through cloning as mere objects, means or instruments violates the religious principle of human dignity as well as the secular principle of respect for persons.

Genetic Discrimination

One of the problems some fear might result from knowledge of the human genome is the emergence of a whole population of socially marginalized individuals, unable to obtain a job, a family, insurance, or health care and stigmatized by the rest of society. Insurance companies already insist that those identified at risk of Huntington's disease must take a genetic test. If the results are positive, insurance is frequently refused. Insurance companies are on record as saying that if genetic information was available, they would use it in their risk assessment.

In Canada, the refusal to insure a Huntington's patient does not have dire consequences; in general, public insurance covers many aspects of care, though the level of care varies across the country and the coverage for pharmaceuticals is less clear. In countries without a public health insurance system, however, the plight of such a non-insured person can be a nightmare. Care may be available but finding it is very difficult. As more genetic tests become available, insurance is likely to be more and more expensive for those carrying what the insurance companies deem to be risky genes.

The public insurance schemes may also start to feel the pressure for such genetic testing, and be forced to make policy decisions based on the funding available and the knowledge of genetic predisposition to disease within populations. Gene therapy is at the experimental stage at this point but will certainly be very expensive when it first comes into regular use. Who will pay for it? If not public insurance, will the therapy be available only to rich people, thus creating an ever widening gap between groups in society, based on both money and genetic inheritance? Employers may also want access to genetic information. Some genes might reveal a susceptibility to environmental damage that was incompatible with a certain workplace environment. Employers might choose to screen out workers carrying that gene rather than trying to improve the environment. Individuals with genes associated with certain behavioural traits might also be excluded from the workplace (Olyshevsky 2002).

Racial Discrimination

Although no genetic-employment discrimination case has been brought before U.S. federal or state courts, in 2001 the Equal Employment Opportunity Commission (EEOC) settled the first lawsuit alleging this type of discrimination. EEOC filed a suit against the Burlington Northern Santa Fe (BNSF) Railroad for secretly testing its employees for a rare genetic condition that causes carpal tunnel syndrome as one of its many symptoms. BNSF claimed that the testing was a way of determining whether the high incidence of repetitive-stress injuries among its employees was work-related. Besides testing for this rare problem, company-paid doctors also were instructed to screen for several other medical conditions such as diabetes and alcoholism. BNSF employees examined by company doctors were not told that they were being genetically tested. One employee who refused testing was threatened with possible termination.

On behalf of BNSF employees, EEOC argued that the tests were unlawful under the Americans with Disabilities Act because they were not job-related, and any condition of employment based on such tests would be cause for illegal discrimination based on disability. The lawsuit was settled quickly with BNSF agreeing to everything sought by EEOC. Besides the BNSF case, the Council for Responsible Genetics claims that hundreds of genetic-discrimination cases have been documented. In one case, genetic testing indicated that a young boy had Fragile X Syndrome, an inherited form of mental retardation. The insurance company for the boy's family dropped his health coverage, claiming the syndrome was a pre-existing condition. In another case, a social worker lost her job within a week of mentioning that her mother had died of Huntington's disease and that she had a 50% chance of developing it.

Despite claims of hundreds of genetic-discrimination incidents, an article from the January 2003 issue of the *European Journal of Human Genetics* reports a real need for a comprehensive investigation of these claims. The article warns that many studies rely on unverified, subjective accounts from individuals who believe they have been unfairly subjected to genetic discrimination by employers or insurance companies. Rarely are these subjective accounts assessed objectively to determine whether actions taken by employers and insurers were truly based on genetic factors or other legitimate concerns.

The cultural implications of the concept of gentrification come into full view when they search for genes that may for example explain alcoholism,

homosexuality, aggressive behaviour, or difficulties in learning are the cases in point. While in the past certain types of individual behaviour were interpreted as representations of individual life choices within the parameters of a given society, Genetification of Life interprets these same choices as ultimately constituted at the genetic level and expression at the biological level “beyond freedom and dignity” (Nelson 1994).

Check Your Progress II

Note: Use the space provided for your answers.

1) How do you relate the need for privacy and genetic determination?

2) Briefly describe some of the social issues connected with Human Genome Project?

4.6 CRITICAL REMARKS

The Human Genome Project also include work on identifying and addressing the ethical, legal, and social issues that are and will be created by this new knowledge. The societal concerns identified include:

- Fairness in the use of genetic information by insurers, employers, courts, schools, adoption agencies, and the military, among others.
- Privacy and confidentiality of genetic information.
- Psychological impact and stigmatization due to an individual’s genetic differences.
- Reproductive issues, including adequate informed consent for complex and potentially controversial procedures, use of genetic information in reproductive decision making, and reproductive rights.
- Clinical issues, including the education of doctors and other health service providers, patients, and the general public in genetic capabilities, scientific limitations, and social risks; and implementation of standards and quality-control measures in testing procedures.
- Uncertainties associated with gene tests for susceptibilities and complex conditions(e.g., heart disease) linked to multiple genes and gene-environment interactions.

- Conceptual and philosophical implications regarding human responsibility, free will vs genetic determinism, aim concepts of health and disease.
- Health and environmental issues concerning genetically modified foods (GMFs) and microbes.
- Commercialization of products, including property rights (patents, copyrights, and trade secrets) and accessibility of data and materials. Commodification of Human beings will become a major concern as human beings would turn out to be marketing products.

4.7 SOME LARGE PHILOSOPHICAL ISSUES

The new breakthroughs in genetics will question the traditional/religious understanding of the concept of God, creation and death. Are we at the beginning of a New World, where we can attain immortality? We are at the stage of Playing God for the whole Universe? Here the famous Nietzsche words would be applicable. “Is man one of God’s Blunders? Or is God one of man’s blunders “. Science allows us to either transcend or arrest our own aging process. “Given all the responsibility to God and to our fellow human beings, do we have a right to let experimentations and ownership of new life move ahead without public regulation?” (Evans 2002)

One of the most interesting and profound changes is not with the biotech firms or venture capitalists but with the way we see ourselves. We live in a culture that links genes or DNA sequences to complex predispositions and patterns of behavior, usually without even bothering to think about what a gene actually is. Thus when we talk about a gene for crime and gene for love as if the gene determines the behavior by rigid mechanical chain of deterministic slavery (Chan and Chia 2003). It calls us to critically analyze the human responsibility, free will vs. genetic determinism. Designer drugs like Prozac and Ritalin have the effect of modifying and muting human diversity. It has a serious impact on human diversity, dignity and human rights based on our sense of innate human nature since it is the human nature that gives us moral sense and provides us with social skills to live in a society and serves as a ground for philosophical discussions of rights, justice and morality.

Genetics advancement must not act as a barrier in our life especially in taking responsibility for our lives and the choices we make. In Germany, there is a widespread opposition to learning a lot about human genetics The Hitler Nazi regime in Germany between 1933 and 1945 killed millions of Jews, Gypsies, mental patients, and disabled people in concentration camps in the name of the pseudoscience eugenics. Any suggestion that eugenic improvements may be feasible, as a result of gained knowledge from the HGP, are alarming signs and create strong objections to the sequencing of human genome. That eugenics philosophy which lead to the horrors of National Socialism in Germany have made many people appropriately sensitive to the potential abuses of genetic science.

Genetics shortens the gap between us and other species. However it widens the view of human variation (DeGrazia 2005). There are differences among us that go to the heart of our self and our personhood. What is then considered acceptable diversity? Where is the line between medical treatment and enhancement? These

are the some of the important and significant questions for the philosophers to ponder. Genetic manipulation becomes arbitrary and unjust when it reduces life to an object, when it forgets that it is dealing with a human subject. Life is the supreme good of man. First of all, anything that is harmful to it must be opposed. Only then what is good must be sought out and pursued. The question before human beings is whether they are capable of seizing the moment of creative opportunity and deciding how to make this new technology serve the well- being of human kind. If they succeed in doing so, this will go down in history as crowning of life. On the other hand, if the human beings deal with it irresponsibly without giving their critical and reflective ability a chance, they might end up in clowning life which in no way is the choice of humanity.

4.8 LET US SUM UP

Many of the ethical, legal and social issues that are being discussed with respect to the Human Genome Project are not new. Genetic tests for a variety of diseases are currently available and some people are already struggling with the ethical and practical implications. What will change over the next few years, as a result of the Human Genome Project, is the scale of the issues and how society will have to cope with the greyer areas of genetic disease and disability. Dealing with a single gene that causes death or chronic disability is one issue; dealing with whole sets of genes whose impacts vary depending on environmental interactions is another.

The rate of scientific advancement has tended to outstrip the legislative capacity of governing bodies and there has been some media “overhype” with respect to genetic research and its potential for treatment of disease. It will be years before many of the genetic tests are available and before genetic diseases can be treated. Society as a whole must use this time to discuss and decide on how genetic information ought to be used, before the choices are made for them. It is a discussion that those with genetic dispositions to diseases such as Huntington’s have long wanted to make more public.

The Human Genome Project is a remarkable breakthrough in medical science and biological study and while there are ethical questions about the use of the information, overall, knowing the map of the human genome has allowed incredible medical breakthroughs in recent years. Processes such as genetic testing and gene therapy have created more awareness about certain inherited diseases such as cystic fibrosis and sickle cell anaemia and have helped countless people alter their lifestyles so they do fall prey to diseases such as Alzheimer’s or breast cancer, which are both inherited susceptibilities. While there are still moral questions to be answered, such as those addressing the issue of altering the genome of unborn children, the Human Genome Project can certainly be identified as a benefit to the world when the data is handled by the right people? So in this unit we have taken up some of the basic ethical, legal, social and philosophical issues related to Genetic Engineering. Larger discussion and debate on these issues are really needed.

Check Your Progress III

Note: Use the space provided for your answers.s.

- 1) What is commodification of human beings?
.....
.....
.....
.....
.....
- 2) Describe some of the larger philosophical issues dealing with genetic engineering?
.....
.....
.....
.....
.....

4.9 KEY WORDS

- Commodification : The tendency to treat humans beings as commodities or objects for use.
- GM : Genetically modified (GM) foods are foods derived from genetically modified organisms. Genetically modified organisms have had specific changes introduced into their DNA by genetic engineering techniques.
- GMO : A genetically modified organism (GMO) or genetically engineered organism (GEO) is an organism whose genetic material has been altered using genetic engineering techniques

4.10 FURTHER READINGS AND REFERENCES

Chan, Mark Ly and Roland Chia. Eds. *Beyond Determinism and Reductionism*. Hindmarsh: ATF Press Publications, 2003.

DeGrazia, David. *Human Identity and Bio Ethics*. New York: CambridgeUniversity Press, 2005.

Evans, John H. *Playing God*.London: The University of Chicago Press Ltd, 2002.

Green, Ronald M. *Babies by Design The Ethics of Genetic Choice*. London: Yale University Press,2007.

Harwood, Adrian J. *Protocols for Gene Analysis*.Totowa, New Jersey: Humana Press, 1994.

Kilner, John F Rebecca D Pentz and Frank E Young. Eds. *Genetic Ethics*. Cumbria: William B Eerdmans Publishing Company, 1997.

Lewis, Rick. "Human Futures." in *Philosophy Now*. Issue 61. London: Anja Publications Ltd, May- June 2007.

Nelson, J Robert. *On the New Frontiers of Genetics and Religion*. Michigan: William B, Eerdmans Publishing Company, Grand Rapids, 1994.

Olyshevsky, George. *Understanding the Genome*. New York: Warner Books, Byron Preiss Visual Publications, 2002.

Pandikattu, Kuruvilla. "Crucial Challenges and Creative Possibilities of Genetic Biology." *SatyaNilayam: Chennai Journal of Intercultural Philosophy* (January 2005): 42-59.