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RESEARCH ETHICS

Human Genome Project

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Human Genome Project (HGP) is the international scientific government funded project, which formally began in 1990 in United States. It was planned initially for 15 years, however due to enhanced scientific technology it got completed in 13 years (two years ahead of time). This project was coordinated by US Department of Energy and National Institutes of Health. Its primary objective was to address the ethical, legal, and social issues (ELSI) that may arise from the project.¹

The main focus of the project was to study and identify human genetic make up and its sequencing. The secondary aim was to record this data for analysis and utilize it for improvement of future generations. The sequence of last chromosome was published in journal Nature in May 2006. It is tricky to say what complete sequencing of gene is, but the scientists involved in this project did so according to the definition employed by international human genome project.¹

This project is a giant leap in scientific progress in terms of diagnosis and perhaps treatment of diseases. There is a large group of diseases which are genetic in origin. Diseases like sickle cell

anemia are caused by a single genetic error while in conditions like hypertension and diabetes mellitus multiple genes are involved. If research can locate the responsible genes, this could revolutionize biomedicine in the 21st century.²

The research and its advantages are undeniable but there are certain ethical and moral issues associated with it that cannot be ignored. HGP will have strong impact on society. It is an established fact that there can never be one definitive human sequence and every human being has different and individual genetic make up. To define what is "normal" is going to be a tough task. Existing social and political mechanisms do not seem adequate to regulate the outcomes. Questions like "who will have access to how much of any individual's information?" will arise about controlling the manipulations of human genetic materials.³

An important issue related to this research is the application and use of this information. Knowledge about genes causing diseases without having the ability to treat them can only create frustration and seems to provide no practical benefit. The other aspect is use of this research to prevent diseases through reproductive regulation and intervention. If it is discovered that a person will develop a disease in his/her later life for example Parkinson's disease, will that information be of any significance to that patient?²

It is human nature to aspire for perfection and when it comes to their future generations, their demands can reach the limits of obsession. It will be a general demand to have perfect children and

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"perfection" will be a term difficult to define. Parents would like to choose things like color of skin, height and weight of their children. A propensity for obesity might be considered reason to limit reproduction. We may see parents wanting to abort the fetus they consider sick or abnormal, with desires to produce only healthy offspring. Society needs to think on these lines.²

We are not even prepared to face workplace dilemmas. If employers gain access to anyone's genetic code, they would naturally want to hire people with greatest potential for productivity. We don't even know if the employees will have the right to refuse genetic testing and what would the law (if we are able to formulate one) say about the rights of employers to hire or fire employees on basis of their genetic make up!⁴

Should mandatory genetic screening for adults be allowed? The problem gets more complicated when we think about infants and children who cannot give proper consent. The role of parental consent in this regard is also questionable.⁵

The collection and usage of genetic information also raises several questions. The human genome project was international scientific government funded project. In 1998 another privately funded research was started by American researcher Craig Venter by his firm Celera Genomics. The firm wanted to patent many genome sequences. According to the UNESCO declaration on the human genome and human rights, 1997 the human genome information should be freely available.⁶ In March 2000 President Clinton announced that patenting of genome sequences is not permissible. So in 2003 and 2005 both HGP and Celera genomics announced their drafts with the information their research came up with.¹

With new changes in patent law many human gene sequences are being patented. This means the access to such information is being restricted and a market is being created with competitive prices for genetic information. At present there is confusion about the extent of freely available versus "patented" genetic information and new laws have to be made to clarify the issues.⁶

The genetic research is being conducted in developed countries due to obvious economic

reasons but its implications will affect the whole human population in general. Muslim world seems to be unaware of the significance of this project. There are only four Muslim countries in Human Genome Organization (HUGO) that proves this point further.⁴ Islam believes in alleviation of pain and working against diseases so until now there is no debate about therapeutic strategies used to improve genetically determined diseases.⁷ Whereas Islamic world partly allows somatic gene therapy and replacement of defective genes there is still debate about eugenics and dysgenics.⁸

To conclude, we can say that like all other advanced scientific research projects, this is something which will contribute to the betterment of humanity and greater good. However, there are certain crucial concerns associated with it. More discussions and research is needed about different aspects of the project

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