



Human Genome Research: Societal and Ethical Issues

Social Impact

When considering a complex and powerful technology like genetic modification in humans, extra care must be given to taking into account the social impact and ramifications. The reason for this is that the consequences of any mistakes can be very long lasting. Genetic alterations in a person will have an effect for the rest of that person's life. In the case where germ (reproductive) cells are modified, the changes are passed on to the next generation. Some problems or side effects may not show up for many years or even until the next generation.



"Genetics is still a relatively young science, and its applications in gene therapy are at an even more rudimentary stage. This calls for prudence and the operation of the "precautionary principle", until we have reasonable evidence about possible side effects and also the long-term effects on the body as a whole. For example, gene therapy seeks to recover the main function of a defective gene, such as stimulating a vital protein, by manipulating or replacing it. But either the gene, or the mechanism used to introduce it into the body, may have secondary effects which need to be assessed and monitored over a due period of time."

See "[Moral and Ethical Issues in Gene Therapy](#)"

Who are the stakeholders?

Since the impact of genetic modification (or gene therapy) has potentially far-reaching and long-lasting effects, society as a whole can be viewed as having a large stake in this type of endeavor. More specifically however, there are

type of education more specifically. However, there are some who have a more immediate interest. Specifically, people who have genetic disorders that are not curable without gene therapy will benefit.

An important consideration for society is that there is risk involved. We need to consider and weigh the likelihood of what risks that can be foreseen, and to act accordingly. In doing this, society must recognize that, especially in the early stages, we will not be in a position to know what all the risks are until something has gone wrong. The effect of CFC's on the ozone layer is a recent case. We can take reasonable precautions, but there is no such thing as risk-free technology, and more than there is risk-free life.

In weighing the risks, it is important to consider the needs of those who will most likely benefit from genetic modification. Someone who is desperately ill with a genetic disease will see the risk versus reward tradeoffs in an entirely different light than someone who is healthy. The sick person very well may be willing to risk the few years of painful life that are in store for him against the possibility that he might be cured.

The potential scope and cost of genetic therapies also brings with it a potential payoff for biotech companies that discover new and effective gene based treatments. In that light, these companies and their investors can be considered major stakeholders.

Who will benefit?

The immediate beneficiaries of human genome research are those who are afflicted with one of the relatively small number of rare diseases that result from a defect in a single gene. It is important to note however that the vast majority of both diseases and normal human characteristics - like height, physical endurance, artistic ability and intelligence - are highly complex and involve the interactions of many different genes as well as environmental influences and individual choices. Even supposedly simple things like the inheritance of hair and eye color are now known result from complex genetic interaction. Because of this, it will be a long time before there are gene therapies that can effectively address a genetic predisposition to heart disease and cancer. These diseases, like many others have some genetic components as well as environmental components.

How are the poor affected?

The poor have as much need as anyone (if not more) for medical advances. The problem is that access to advanced treatments is more difficult for the poor. Currently gene

therapy is only in experimental trials and only a few disorders are targeted for these trials. When some of these therapies become approved and available, the poor will be the last to have access to them. However, this should not be viewed as an indictment of the technology itself but rather raise questions about how medical treatment is accessed. On the one hand, it seems unfair to withhold medical treatment from someone who needs it just because he can't pay for it. On the other hand, someone must pay for the treatment and it doesn't seem fair to withhold treatment from everyone because there is no equal access. From a pragmatic standpoint, early advances in the field are financed with the view that there will be a return on the large investment that is needed to develop the treatments. With this in mind, it is inevitable that the cost of new and advanced medical treatments will be high at first even if they may be reduced in the future. The question then becomes how to pay for the treatments. Different societies have come to different conclusions on the question of paying for medical treatment. These are independent from the development of genetic therapy specifically but will have an effect on how the advances are made.

Does it bring society together?

The question of bringing society together is a difficult one. Of course, people do not want to see others suffer and in general are favorable to medical advances that cure illness and restore health and bodily function. However, there are deep questions and ethical concerns that affect society's attitude to a developing genetic manipulation technology. Differing attitudes on the subject may serve to divide society. These attitudes can be deeply held since our genetic makeup is at the core of our lives and perception about who we are.

The attitude that is held in society is influenced by many factors such as: How are the issues presented by the media? How does the government get involved and what level of trust does the public have in those who are making the decisions? What motives drive the industry? The Church of Scotland "Society, Religion and Technology Project" has the following observations on the subject of public perception.

"An example of this is the fact that ordinary people may well perceive gene therapy as different from other medical interventions, whatever the experts or ethical committees may say. The intuition that it feels more risky to be playing about with the stuff we're made of at its most fundamental biological level is a real perception. which should not be

discounted on the grounds of ignorance on the part of the lay public. If a significant slice of a society holds that perception, then that has to be taken into account in how that society assesses and regulates the technology. This is a "societal" limit to technology - what a society is prepared to accept being offered to it. It may not necessarily agree with what the experts, the Government or the industry say is "safe" or "ethical" or "acceptable". Moreover, painful experience shows that it is not just a matter of scientists "educating" the people. There is often a gulf of trust and communication as well as in understanding. Thus to talk of "improving the human race" by means of genetic engineering would seem to be as fantastic as most science fiction, quite apart from any ethical objections. Unfortunately, eugenic experimentation under the Nazi regime in Germany, has not only cast a shadow over the whole field of genetics, rather as Hiroshima has for nuclear power, but it has demonstrated what as Christians we would suspect from human sinfulness and perversity - that we could never discount the political possibility of genetic abuse if ever the technology were feasible"

See "[Moral and Ethical Issues in Gene Therapy](#)"