Human Genome Mapping: a Jewish Perspective

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The Human Genome Project

Science in the twentieth century has launched three great projects: (1) the Manhattan Project for the development of nuclear weapons, which took place in the United States between 1942 and 1945 under the technical supervision of Robert Oppenheimer; (2) the American Space Project, which started in the late 1950's and led to the landing on the moon in 1968; and (3) the Human Genome Project, which is being conducted now in thousands of laboratories throughout the world.

The Human Genome Project is one of the most ambitious projects ever undertaken in the life sciences. Billions of dollars have been allocated to numerous research groups all over the world in order to produce a map of the thousands of genes which constitute the human genome. A complete genome map should fully reveal to us which nucleotide “words” control which clinical conditions in man; in other words, which genetic components imply biologic anomaly or greater sensitivity to malignant disease, and which components determine psychological or intellectual characteristics.

When the mapping is complete, it will be possible to check the hundreds of thousands of genes in any individual and to decipher the genetic information contained in them. The vast pool of raw data inherent in any genetic mapping can serve to achieve either positive or negative goals. The knowledge contained in the genes has great predictive capacity regarding the individual’s future, namely his chances of spontaneously contracting specific diseases, such as heart disease or cancer, at various ages and his chances of achieving success in sports or in intellectual endeavors. It follows that the project has far-reaching ramifications in many areas of society, e.g., work relations, insurance, the army, medicine, and family relations. Such knowledge is so powerful that it can destroy
human society. It is no wonder that the very existence of the Human Genome Project is a cause of concern for so many people.

**The Issues**

The Jewish perspective is formed by Jewish law, and when one talks about law, one has to be precise and accurate. There are three principle issues here:

1. Does Jewish law permit research on human genome mapping?
2. Having done the screening, who is the proprietor of the mapping? Who owns the data derived from public screening or from private mapping tests?
3. Under what conditions is one obligated to reveal genetic data to an insurance company, employer or spouse?

**“Happy Is the Man That Feareth Always”**

The first question introduces us to a new world. Anyone familiar with the Human Genome Project has experienced different emotions, including fear. One may feel that the easiest solution is to withdraw, to keep away from such a frightening project. These fears remind us of the words of King Solomon, “Happy is the man that feareth always” ("Ashrei adam mefached tamid," Proverbs 28:14), which can be interpreted as glorifying the person who is constantly afraid. But this is an incorrect interpretation. In fact, King Solomon meant to praise the person who is always cautious. Fear is praiseworthy when it motivates caution, when it brings one to check oneself and to make sure that one is not going to fall into a trap, step on a hidden mine, or slide down a slippery slope. King Solomon did not mean that one should avoid taking responsibility or making decisions.

Consider another maxim by King Solomon: “For in much wisdom is much grief, and he that increases knowledge increases sorrow” ("Ki berov chochma rov ka’as, veyosif da’at yosif mach’ov," Ecclesiastes 1:18).

We all recognize that knowledge can cause sorrow and grief. Does this mean that we should shun knowledge? A patient in the final stages of Alzheimer’s disease no longer comprehends his surroundings and feels no fear, pain or sorrow once his physiologic needs are satisfied. Would we wish to be in such a peaceful state?
The categorical answer is no. By no means is potential grief a reason to ban the pursuit of human knowledge.

Therefore, the answer to our first question is apparent: There is no prohibition.

**Who Is the Proprietor?**

The second question is more complex. Who is the proprietor of any specific information acquired by public screening or private tests? Let us say that I pay a laboratory to do a genome mapping on my own blood. After paying, I want the results. Who is the owner of the data? I am, of course. In general, I can do with it whatever I choose. (We shall see some exceptions in the discussion on the third question.)

On the other hand, there are cases in which such data would clearly not be mine. For example, at the Hebrew University Hadassah Medical Center I saw an announcement calling for volunteers to participate in an experimental trial. Each volunteer would be paid one hundred dollars for two hours of physical and blood tests which would take place after signing a legal document stating that the subject would have no claim to the test results. I enrolled for the trial. My blood pressure was checked and samples of my blood were taken. Within a few weeks the tests were analyzed, providing much biological data about me, including the complete mapping of my genome. Here, of course, I am not the owner of the research results.

Other cases fall between these two extremes. Let us consider a practical example. The Ministry of Health was allocated several million dollars to conduct a screening test for all the residents of Jerusalem, without discrimination. No one was obligated and no one was coerced to undergo testing, yet everyone came for the tests. Who is the owner of the data resulting from these tests? The answer depends on the terms of the contract.

**What Are the Terms of the Contract?**

What are the terms of the legal agreement between the government and the individuals who gave their blood samples? These terms could be part of a written law or a written contract between the people and their government. They could also be part of an unwritten contract. The owner of the data is the one who owns it according to the contract.
In America the government is obligated to serve its citizens. In Russia until not long ago, the rule was that the people had to serve their government. What is the situation in Israel? We believe that the American idea will prevail, namely that every person who is examined will have at least partial ownership of his medical data. The subjects must at least be informed that such data exist, and they should be able to obtain the information on request.

This approach provides a clear solution to the question of ownership of data as long as it is clear what the laws and the agreements are between us and our government. Sometimes, because of good or bad agreements the owner of the data is not the patient. In such cases, such data remains with the Ministry of Health or at Hadassah Hospital. One should still ask: is the hospital or the government obligated to inform the subjects concerning their medical data?

“Don’t Stand by When Your Fellow Man Is in Danger”

Let us assume that a private institution paid for the tests and owns the information. By paying, the patient can probably obtain the results. But if he does not want to pay or does not have the money, then the owner of the data can sometimes be forced to release them to the patient.

There are three cases. When human life is in danger and the relevant information could prolong or save a life, Jewish law is very simple: “Don’t stand by when your fellow man is in danger” (“Lo ta’amod al dam re’cha,” Leviticus 19:16). Anyone who is able to help has an obligation to release any information necessary to save a life.

The Law of Restoration of Lost Property

The second case simply concerns the quality of life or personal finances. When knowledge of the facts can improve the quality of someone’s life or save him financial expense, is the owner of the medical data obligated to provide them?

The Jewish law of restoration of lost property directly relates to this issue. Let us say that I find a thousand dollars. I know who lost it and there is a way to return it to him or to inform the police and thus help him to regain his loss. According to Jewish law, it is obligatory to return the money. But what if by doing so I would incur financial loss?
If I return the money or take it to the police station, I will lose several working hours. Do I have the right to be compensated for the lost time? The Talmud writes, “If a person will lose money by following the law of restoration of lost property, he can always ask for and receive compensation” (Bava Metzia 30a). He can receive compensation for the time involved in restoring lost property at the rate that an average person would be paid for doing his regular work.

The Condition for Costly Compensation

Another example involves a finder who is not a salaried worker. He is, perhaps, a lawyer who charges three hundred dollars per hour. Handling the lost property may take several hours, meaning a loss higher than one thousand dollars, which is the amount of the lost money. In this case the owner of the money would not want to cover the losses of the finder.

On the other hand, if the value of the wallet is ten thousand dollars it does pay the owner to compensate the finder. In such cases there are specific regulations in Jewish law. The finder can still require compensation, but he has to receive the approval of a court of law in advance. He has to declare that he will take care to return the lost property, but under the condition of full compensation for his lost time. If he does not do so in advance, he may be compensated only at the rate of pay of an average worker.

As formulated by Maimonides, the commandment to restore lost property includes the obligation to help a person stay healthy. Accordingly, there is no difference in principle between restoration of possessions and restoration of health. The rule governing compensation for the restoration of health is the same as the rule of compensation for restoration of lost property.

It follows that if a medical institution incurs expenses in releasing medical information, those expenses should be compensated. Therefore, releasing the requested medical data, which is a kind of restoration of property, could be conditioned by suitable compensation.

What Expenses Can Be Included in the Compensation?

As stated above, a medical institution is allowed to charge for its expenses. What expenses are included? Expenditures on medical information cover not only the printing of the report and the price
of the chemicals used for the tests; the cost of building the laboratory and buying the equipment must also be considered. Although most of these expenses were incurred long before the test was done, in many cases the institute will be allowed to take into account all these prior expenses. The society or its representatives can agree to require compensation for all the expenses necessary to allow a medical institution to invest money for the benefit of the public.

**Privacy vs. Deception**

The third issue deals with the conflict between the basic right of privacy and the prohibition of deception. Under what conditions is a person obligated to release data to an insurance company, an employer or a spouse? There is a great difference between an insurance company and an employer. An insurance company may legally declare that it has two different premiums: one for people who have undergone a screening test and provide medical information, and one for those who do not provide such information.∗

The situation is different if a person withholds medical information from the insurance company. Such behavior is clearly a deception. If he knows that he is going to die within a week and nonetheless buys a life insurance policy without giving this information to the insurance company, it is a deception. Whenever a relationship is based on the assumption that certain information is unavailable to either of them and it turns out that one of them had the information, it is a deception.

Although this is always true in the case of insurance, it is not necessarily so in employer-employee relations. In principle, one does not have any obligation to inform one’s employer about all his or her bad habits. For example, one is not obliged to volunteer that from time to time he gets very angry, nor does one have to provide the employer with a full list of bad habits. The employer can interview the employee or have his handwriting checked in order to obtain the information he needs. There are some exceptions to this rule, but this is beyond the scope of this paper.

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∗ The statistical idea is similar to a common genetics issue. It is known that the incidence of Down’s syndrome is age-dependent. There are general age-dependent rates without knowing the results of an alpha-fetoprotein (αFP) examination, and more specific rates for women who provide these results.
When the subject is the relationship between partners we can conclude that no one may withhold information whenever a relationship between partners or spouses is based on the assumption that such information is unavailable.

**Compulsory Employee Screening**

Although an employer cannot force an employee to undergo screening, he can make such screening a condition for employment. Still, one is not obliged to surrender information. When asked directly, the employee has to tell the truth. He can say that he refuses to surrender the information or that he wants to keep it private. The employer can then decide whether or not to employ him.

**Summary**

1. It is permissible to develop mapping systems for the human genome with the condition that researchers do not ignore the moral dilemmas and that the research be executed on the basis of appropriate, rigorous guidelines.
2. Ownership of the results of genome mapping depends on an explicit or tacit agreement between the subjects of the study and those conducting the study.
3. There are situations in which the commandment to save a life or to cure a sick person obligates revealing genetic data to the subject even if he is unable to pay for it.
4. Use of data acquired through genome mapping can be ethical. But in the absence of rigorous guidelines and proper controls, unethical or even criminal misuse is liable to occur.