ARCHIVED: WMA DECLARATION ON THE HUMAN GENOME PROJECT

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and rescinded at the WMA General Assembly, Santiago 2005

PREAMBLE

The Human Genome Project is based on the assumption that the information contained in the gene will enable us to diagnose a large number of genetic diseases in utero or even before that; it will enable us to make decisions before procreation.

The key to the understanding of genetic diseases is in the identification and characterization of the genes after mutation. Henceforth, one can state that the understanding of all the human biology is enclosed in the identification of 50,000 to 100,000 genes in the human body's chromosomes.

The Human Genome Project can enable us to identify and characterize the genes involved in the main genetic diseases; later on, it would be possible to identify and characterize the genes involved in diseases with a genetic component together with other factors such as Diabetis, Schizophrenia and Alzheimer. In these diseases the gene creates a predisposition to the disease rather than being the cause itself. These diseases cause severe social problems and if it is possible to diagnose the predisposition before the appearance of the disease, it might be possible to prevent it by changes in life-style, by diet modification and periodic check-ups.

In the second half of the 20th century a conceptional revolution has occurred when one started thinking of diseases in terms of biochemistry. A new revolution is happening now which locates in the gene the instructions for all the biochemical processes in the body's cells.

Policy Problems

There are many important ethical reasons to get the genetic information as quickly as possible so that we may better understand many diseases. However, this information may be frustrating unless we develop at the same time therapeutic means and unless we will inform the public of the various genetic options so that the individual may select the best ones.

Another question is whether the invested efforts are justified compared with other ways to reach those objectives with lesser cost. Should the project aspire to a comprehensive inventory or is it preferable to start step by step with less pretentiousness, and progress modularly ?

Funding the Project

The Human Genome Project is considered a formidable project, similar to the space program, therefore one may claim that there is no proportion between the investment and its return. The estimated cost of the project is $3 billion during 15 years, i.e. $200 million a year. This cost may not seem extraordinary when we know that the Cystic Fibrosis Foundation, in the USA, only, has spent $120 million in the last four years, for this disease alone. Thus, the financial scarecrow should not prevent the development of the project.

Another disturbing factor stems from the interdiction – in some countries – to allocate funds for clinical research in human embryos. After having spent money on mapping the genes there could be no money allocated for clinical research based on the outcomes.

Conflict between the protection of privacy and the need for scientific collaboration

The mapping of the human genes has to be anonymous, but the information acquired will apply to every human being regardless of individual differences, colour or race. The information should be general property and should not be used for business aims. Therefore no patents should be given for the human genome or parts of it.

Genetic discrimination in private insurance and employment

here is a conflict between the increasing potential of new technologies to reveal genetic heterogeneity and the criterion for private insurance and employment. It may be desirable, regarding genetic factors, to adopt the same tacit consensus which prohibits the use of race discrimination in employment or insurance.

Genetic mapping may become a source of stigmatization and social discrimination, and the “risky population” may turn into a “defective population”.

The danger of Eugenics and the use of genes for non-medical aims

Eugenics is based on the assumption that the genes have a decisive importance, and the way to change their distribution in the population is to change reproductive behaviour. According to this concept the general good justifies the limitations on the individual’s liberty. The power of information raises concern about how it will be used. There is still fear of government eugenics programs for “the improvement of the race”, and the use of medical technology not for medical purposes.

RECOMMENDATIONS

The ethical issues raised by the Human Genome Project are not linked with the technology itself but with its proper use. Due to the power of this new tool, its ethical, legal and social issues should be examined whilst the program is still at its start.

Some of the opposition stems from the fear that the researcher may tend “to play God” or to interfere with the laws of nature. If we free ourselves from an uncompromising opposition to the Human Genome Project, we can assess the ethical outcomes with the same parameters that guide us whenever we examine a new diagnostic or therapeutic method. The main criteria remain the evaluation of risk versus advantage, the respect of a person as a human being and the respect of autonomy and privacy.

There is a need to state general ethical and legal guidelines to prevent discrimination and the genetic stigma of the population at risk.

The basic guidelines are:

- The genetic service should be easily accessible to everyone in order to prevent its exploitation by only those who have resources which will increase social inequality.
- There is a need for international information and transfer of technology and knowledge between all countries.
- One should respect the will of persons screened and their right to decide about their participation and about the use of the information obtained.
- Full information should be given to the patient or his legal agent. Medical secrecy should be kept and information should not be passed on to a third party without consent. Even if family members of the patient may be at risk, medical secrecy has to be kept unless there is a serious harm and this harm could be avoided by disclosing the information; the confidentiality can be breached only as a last resort when all trials to convince the patient to pass on the information by himself, have failed; even in this case, the relevant genetic information only should be disclosed.
- The disclosure of information to a third party or the accessibility to personal genetic data should be allowed only with the patient’s informed consent.