



*Presidenza del Consiglio dei Ministri*

## **NATIONAL BIOETHICS COMMITTEE**

### **HUMAN GENOME PROJECT**

(18th March 1994)

#### *abstract*

The opinion provides an ethical evaluation on the "Human Genome Project", which represents a major effort on behalf of the International scientific community to improve knowledge of the genetic mechanisms that regulate vital activities. The Committee emphasizes the benefits that may derive from the Project in terms of fundamental knowledge and the diagnostic and therapeutic possibilities; however, it does not neglect the significant ethical, anthropological and social implications which may arise.

The first part of the document illustrates the technical and scientific aspects of the Project and the contribution that Italian participation provides. It concludes with a historical reconstruction of genetic research activities.

The second part deals with the ethical and social implications of the Human Genome Project, and raises in advance the issue of allocation of financial resources, pointing out the need not to neglect other equally important medical and scientific research projects. Furthermore, it advocates the use of special caution against the privatisation and patenting of acquired knowledge on the human genome, in order to guarantee free access to the most important information.

This analysis is not limited merely to the implications arising from technical applications, but, it involves the whole scientific enterprise; this is also due to the fact that it is increasingly difficult to distinguish the more strictly scientific aspects from the technological ones. Contemporary genetics is a particularly problematic issue as regards the religious and philosophical concepts sustaining the irreducibility of the human person to mere biological material. Therefore, the Human Genome Project requires comprehensive evaluation of its anthropological and cultural effects, in order to avoid discrimination based on knowledge of a person's genetic heritage.

With regard to the applications of genetics, the Committee draws attention to the currently existing gap between the diagnostic capacities and the therapeutic possibilities, particularly in the field of prenatal diagnostics. On account of this, it is recommended that the acknowledgement of the right not to know should be primary, and due caution should be used in the processing of genetic data in order to protect the privacy of those involved. More generally, research and genetic diagnosis should never serve as a pretext on which to base discrimination between people.

Lastly, it raises the issue of genetic manipulation, on which the Committee recommends careful appraisal of the interaction between genetic patrimony and the environment, in order to reconsider the deterministic approach that sees in eugenics the solution to many problems concerning the human condition.