

## **Observations on the Universal Declaration on the Human Genome and Human Rights**

(Paris, 11 November 1997) \*

The Holy See is convinced of the importance of this international document on the human genome and the rights of the human person. Faced with rapid developments in science and technology, with all their promises and risks, UNESCO has sought to affirm the need for controls in the area. For the first time, it proclaimed in a solemn Declaration the need to protect the human genome for the good of future generations, together with the rights and dignity of human beings, freedom of research and the demands of solidarity.

The Declaration contains many commendable elements: these include the rejection of all genetic reductionism (Articles 2b and 3), the affirmation of the primacy of respect for the human person over research (Article 10), the rejection of discrimination of various kinds (Article 6), the confidentiality of data (Article 7), the promotion of independent ethics committees (Article 16), the commitment of States to foster education in bioethics and debate open to religious concerns (Articles 20 and 21). Finally, it is interesting that a procedure for monitoring the application of the Declaration is envisaged (Article 24).

Because of the document's importance, the Holy See considers it necessary to offer some observations relating to fundamental elements of the Declaration, which asks States to apply the principles which it enunciates (Article 22).

### **The relationship between human dignity and the human genome**

Article 1 affirms that "the human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their dignity and diversity": as formulated, the text would seem to mean that the genome is the foundation of the human being's dignity. In reality, it is human dignity and the unity of the human family which confer value upon the human genome and require that it be protected in a special way.

### **Application of the notion of "heritage of humanity" to the human genome**

The second part of Article 1 declares: "In a symbolic sense, it is the heritage of humanity". According to the Explanatory Note (No. 20), this formulation implies the responsibility of all humanity, excluding however an unacceptable collective appropriation. Yet the phrase

remains vague and unclear; it would be better to avoid notions such as “heritage of humanity” and to affirm instead that “all humanity has a special responsibility to protect the human genome”.

Moreover, the genome has two dimensions: a general dimension inasmuch as it is a characteristic of all those who belong to the human species, and an individual dimension inasmuch as it is different for each human being, who receives it from his or her parents at the moment of conception: this is what it normally means to speak of the “genetic heritage” of a human being. It seems clear that this “heritage” should be given fundamental juridical protection, since this “heritage” belongs concretely and individually to each human being.

### **Free and informed consent**

Article 5a covers the rights of those who undergo “research, treatment or diagnosis” on their own genome. In elaborating specific norms, it would be best to distinguish between research, treatment and diagnosis, since they require interventions of different kinds.

Article 5e provides guidelines for research on the genome of a person unable to give consent. When this research is carried out not for the sake of any direct health benefit for the person, but in the interests of a third party, it is envisaged that such research will be carried out only “by way of exception, with utmost restraint”. Given that it is a question of research, and therefore a very restricted intervention on the patient, it can be acceptable, provided that “it is not otherwise possible” and, if the subject is unable to give consent, that further conditions are met: minimal risk, consent by those whose legal right it is to give it, undoubted advantage for the health of persons in the same category, lack of other resources and possibilities for research.

### **Information on the results of a genetic examination**

Article 5c affirms respect for the right of each person to decide whether or not to be informed of the results of a genetic examination. Yet the right of the individual concerned cannot be absolute in this regard: there is a need to consider cases where this information has consequences for the health of other persons (e.g. family members).

Moreover, it would be appropriate to state the requirement that information on the results of the test be accompanied by a professional “genetic consultation”.

## **Conscientious objection on the part of researchers and health workers**

Article 10 - "No research concerning the human genome or its applications [...] should prevail over the respect for human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people" - is very timely. It would be good to add respect for conscientious objection on the part of researchers and health workers, so that recognition is given to the right of persons working in these areas to refuse, for reasons of conscience, to carry out interventions on the human genome.

## **Rejection of human cloning**

Article 11 declares that cloning with a view to the reproduction of human beings is a practice contrary to human dignity and should not be allowed. Regrettably, this formulation does not exclude human cloning, equally unacceptable, for other purposes, e.g. research or therapy.

## **Freedom of research**

Article 12b rightly recognizes that "freedom of research [...] is part of freedom of thought". This is a necessary but not sufficient condition, in the sense that to conduct research with true freedom there is a need likewise to guarantee freedom of conscience and religion. The Universal Declaration of Human Rights (Article 18) and the International Covenant on Civil and Political Rights (Article 18) put freedom of conscience and religion on the same level as freedom of thought. Therefore, the words "freedom of conscience and religion" should be added wherever mention is made of freedom of thought in connection with freedom of research.

## **Research aimed at preventing genetic disease**

Article 17 encourages States to develop research designed to include the "prevention" of genetic disease. It should be kept in mind that "prevention" can be understood in different ways. The Holy See is opposed to strategies of interference with fetal anomalies with a view to deciding who should and should not be born on the basis of genetic criteria.

## **Lack of reference to the embryo and fetus**

The Declaration limits itself intentionally to the human genome. Thus it does not define the bearers of the rights which it proclaims; it does not affirm that these rights belong to every human being from the moment when he or she emerges as an individual from his or her

genetic heritage. Nor is there any reference to the embryo and the fetus. The question is delicate, especially as regards the embryo in the first 6-7 days of life. The fact that unborn human beings and human embryos are not explicitly protected opens the door, particularly in the field of genetic intervention, to the very forms of discrimination and the violations of human dignity which the Declaration seeks to ban.

\* Document edited by the "Informal Working Party of Bioethics" (of whom Bishop Mons. Elio Sgreccia is also a member), Section for "Relations with States", Secretariat of State (Vatican City).