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The Universal Declaration on the Human Genome and Human Rights

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Abstract

Since 1985, UNESCO studies ethical questions arising in genetics. In 1992, I established the International Bioethics Committee at UNESCO with the mission to draft the Universal Declaration on the Human Genome and Human Rights, which was adopted by UNESCO in 1997 and the United Nations in 1998. The Declaration relates the human genome with human dignity, deals with the rights of the persons concerned by human genome research and provides a reference legal framework for both stimulating the ethical debate and the harmonization of the law worldwide, favouring useful developments that respect human dignity. **To cite this article:** *F. Mayor, C. R. Biologies 326 (2003).*

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Résumé

La Déclaration Universelle sur le Génome Humain et les Droits de l'Homme. Depuis 1985, l'Unesco étudie les questions éthiques émergeant dans le domaine de la génétique. En 1992, j'ai fondé à l'Unesco le Comité international de bioéthique, avec pour mission de rédiger la Déclaration Universelle sur le Génome Humain et les Droits de l'Homme, qui a été adoptée par l'Unesco en 1997 et les Nations unies en 1998. La Déclaration met en relation le génome humain et la dignité humaine en fournissant un cadre juridique de référence pour stimuler le débat éthique et l'harmonisation des lois dans le monde, de manière à favoriser des développements utiles qui respectent la dignité humaine. **Pour citer cet article :** *F. Mayor, C. R. Biologies 326 (2003).*

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1. Introduction

Knowledge is always positive. What can be negative are the applications. They can be negative or even

perverse and we know how abominable some time has been the utilization of knowledge. This is not only in the case of genetics, even if many people think of bioethics as the only example. From the very beginning of humans on earth there have been correct and wrong utilizations of all the tools and of all the knowl-

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edge. Take for example the hammer: we can utilize the hammer properly or we can utilize the hammer as an arm to attack. This is the same at all the levels through the entire history of knowledge: there is the possibility of utilizing the knowledge in the correct way or, on the contrary, misusing it. Unfortunately, we had in the 20th century some very impressive examples of wrong utilizations of knowledge. We must repeat and repeat: what really matters is basic research, basic science. I remember that when I had the honour of being minister of Education and Science in my country, Spain, there were some ministers, the minister of Industry, the minister of Finance... – who were always telling us: “What really matters is applied science”. And I reminded them what Professor Bernardo Houssay, the Nobel prize from Argentina, said many years ago: “There is no applied science and there is no science to apply”. Therefore, what really matters is basic science and, if you have basic science you can develop applications; otherwise, you cannot. The problem arises when what is feasible is not ethically admissible, when knowledge can be utilized not in the benefit of mankind but against it.

2. The uniqueness of the human genome

In 1985 there was already a seminar in Barcelona – my birthplace –, on this issue. I was at this moment in the Centre of Molecular Biology in Madrid where was held, organized by UNESCO, a meeting on “genetic manipulations and on human rights”. Then, the problem of bioethics in genetics was related mainly with fertility, focusing on the mechanisms by which the obstacles for infertility could be overcome. Manipulations with the genes, not within the genes, should be allowed. I consider that this is a very important difference. Two years later, that means in 1987, there was a meeting in Valencia on progress in genetics and medicine. This was a very important occasion in this field to better understand and define the ethics of genetics or if you prefer “gene ethics”. The crucial difference between manipulations with the genes, in which their original sequence is not altered, whereas with those made within the genes the natural sequence is changed, was clearly established. The essential mutability and uniqueness of the genome were considered as characteristics leading to the right

of non violation of the genome. I consider that uniqueness is particularly relevant not only as a scientific concept, but as a social concept because each human being is unique, not only biologically, in permanent evolution, but also from a social and cultural point of view. And these are the capacities that underlie a unique capacity of creativity, of thinking, of designing. All those capacities are distinctive of the human race and therefore must be protected against uniformization. We must act not only as spectators receiving information but not having the possibility, the capacity or the time of reflection but as actors and authors. We must take into account our own questions and anxieties and not only those that we receive from outside.

Therefore, uniqueness is one of the most important aspects related with the genome in order to address the different ethical dimensions of this extremely important matter. In 1986, the Parliament Assembly of the Council of Europe declared in one of its recommendations the right of each unique person to its own genome, this kind of ownership that cannot be altered from outside without – in some pathological occasion – the consent of each unique human being.

3. Building the Declaration on the Human Genome and Human Rights

In 1991, Prof. François Gros brought to my attention the initiative of genome scientists led by Charles Auffray to support free dissemination worldwide of the already identified sequences of the human genome, in order to facilitate the development of medically useful applications. He was the pioneer of a movement that had of course the immediate support of many people including myself as the Director General of UNESCO. In October 1992, I organized with Prof. François Gros a session at UNESCO to discuss publicly this initiative. At this moment this was crucial because there were already some very clear intentions related with international industries to have patents on sequences used to develop procedures that can lead to different products, which would be equivalent to a copyright but on the human genome itself. And I remember the enthusiasm and I think the lucidity with which we pioneered this movement which had immediately a lot of support in France and in many other

countries in order to clearly show that the genome belongs to all human beings. Soon after, guided by the principal of this genome ownership and therefore the inadmissibility of anybody predetermining the characteristics of a distinct human being, I started to set up at UNESCO, after very positive contacts with the Human Genome Organization, an International Bioethics Committee in order to prepare a draft of a Declaration on the Human Genome. I want to emphasize the role played by Mme Noëlle Lenoir from the French Constitutional Court. She really played a fantastic role because as you can imagine this was not only a matter of scientific input but of international legal input. She played at UNESCO and subsequently in the European Union a very crucial role in this respect. After 5 years of difficult work and being always in close contact with those that were leading the human genome decoding, as well as the International Commission on the Human Genome, with many and frequent meetings of experts on one side and legal advisors on the other, and the representations of the governments, the Universal Declaration on the Human Genome and Human Rights was drafted and approved unanimously in the General Conference of UNESCO in November of 1997 [1]. One year later, on the initiative of France, the 186 countries adopted the Declaration unanimously at the General Assembly of the United Nations.

4. The Declaration on the human genome and human rights [1]

4.1. Preamble of the Declaration

In the preamble of the Declaration, the general Conference started “*Recalling that the Preamble of UNESCO’s Constitution refers to “the democratic principles of the dignity, equality and mutual respect of men”, rejects any “doctrine of the inequality of men and races”, stipulates “that the wide diffusion of culture, and the education of humanity for justice and liberty and peace are indispensable to the dignity of men and constitute a sacred duty which all the nations must fulfil in a spirit of mutual assistance and concern”.*

Then it continued: “...*Bearing in mind... the international instruments on the applications of genetics in the field of intellectual property...*”, including “the

Paris Convention for the Protection of Industrial Property of 20 March 1883, as last revised at Stockholm on 14 July 1967”, and “the Trade Related Aspects of Intellectual Property Rights Agreement (TRIPs) annexed to the Agreement establishing the World Trade Organization, which entered into force on first January 1995”.

I consider that this mention, related with the issues of copyright or patentability of the human genome, in the year 1997, was important in reference to the agreement establishing the World Trade Organisation in January 1995. It was important because at the beginning there were different positions related with procedures but also the intellectual property and the copyright of not only the procedures but also many other dimensions that can come into play in the field of patents.

Finally it stated: “*Bearing in mind also the United Nations Convention on Biological Diversity of 5 June 1992 and emphasizing in that connection that the recognition of the genetic diversity of humanity, must not give rise to any interpretation of a social or political nature which could call into question “the inherent dignity and (...) the equal and inalienable rights of all members of the human family”, in accordance with the Preamble to the Universal Declaration of Human Rights.*” and “*Recognizing that research on the human genome and the resulting applications open up vast prospects for progress in improving the health of individuals and of humankind as a whole, but emphasizing that such research should fully respect human dignity, freedom and human rights, as well as the prohibition of all forms of discrimination based on genetic characteristics”.*

4.2. Relating the human genome and human dignity

The first part is the core of the Declaration and is therefore worth mentioning entirely:

“The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity” (Article 1).

“Everyone has a right to respect for their dignity and for their rights regardless of their genetic char-

acteristics” and “That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity” (Article 2).

“The human genome, which by its nature evolves, is subject to mutations. It contains potentialities that are expressed differently according to each individual’s natural and social environment including the individual’s state of health, living conditions, nutrition and education” (Article 3).

“The human genome in its natural state shall not give rise to financial gains” (Article 4).

This last statement is very short as I like, very short but very clear cut statement, supporting the rights of people, of the concerned people, to give their consent and keep the right to privacy and confidentiality, so that no discrimination can be established with this new, very important knowledge, if it is applied in the right way.

4.3. About the rights of the persons concerned by human genome research

The second part of the Declaration deals with the rights of the persons concerned, emphasizing, as I mentioned before that *“Research, treatment or diagnosis affecting an individual’s genome shall be undertaken only after rigorous and prior assessment of the potential risks and benefits...In all cases, the prior, free and informed consent of the person concerned shall be obtained...The right of each individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected”* (Article 5); that *“No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity”* (Article 6), and that *“In order to protect human rights and fundamental freedoms, limitations to the principles of consent and confidentiality may only be prescribed by law, for compelling reasons within the bounds of public international law and the international law of human rights”* (Article 9).

4.4. About the conditions of research on the human genome

The third part of the Declaration refers to research on the human genome. Article 11 is particularly important in emphasizing that *“practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted. States and competent international organizations are invited to co-operate in identifying such practices and in taking, at national or international level, the measures necessary to ensure that the principles set out in this Declaration are respected.”* This is another clear cut statement endorsed by all the countries, all the scientific communities, including the Human Genome Organisation, declaring that cloning is against the human dignity. We must never forget that Adolf Hitler and the Nazis were trying this special preconditioning of the characteristics of newborns, based at that time on Mendelian genetics.

In addition, the Declaration goes further in Article 12 to state that *“Benefits from advances in biology, genetics and medicine, concerning the human genome, shall be made available to all, with due regard to the dignity and human rights of each individual”* and that *“Freedom of research, which is necessary for the progress of knowledge, is part of freedom of thought. The applications of research, including applications in biology, genetics and medicine, concerning the human genome, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole.”*

It also emphasizes that optimal conditions for the exercise of scientific activity should be developed: *“The responsibilities inherent in the activities of researchers, including meticulousness, caution, intellectual honesty and integrity in carrying out their research as well as in the presentation and utilization of their findings, should be the subject of particular attention in the framework of research on the human genome, because of its ethical and social implications. Public and private science policy-makers also have particular responsibilities in this respect”* (Article 13); and *“States should recognize the value of promoting, at various levels as appropriate, the establishment of independent, multidisciplinary and pluralist ethics committees to assess the ethical, legal and so-*

cial issues raised by research on the human genome and its applications” (Article 16).

4.5. Solidarity and international co-operation for implementation of the Declaration

Solidarity and international co-operation should be supported by States which “*should make every effort, with due and appropriate regard for the principles set out in this Declaration, to continue fostering the international dissemination of scientific knowledge concerning the human genome, human diversity and genetic research and, in that regard, to foster scientific and cultural co-operation, particularly between industrialized and developing countries*” (Article 18).

Promotion of the principles set out in the Declaration should be performed “*through the promotion of education in bioethics, at all levels, in particular for those responsible for science policies*” (Article 20), and “*appropriate measures... to facilitate on this subject an open international discussion, ensuring the free expression of various socio-cultural, religious and philosophical opinions*” (Article 21).

Finally, the International Bioethics Committee of UNESCO should facilitate implementation of the Declaration by organizing “*appropriate consultations with parties concerned, such as vulnerable groups. It should make recommendations, in accordance with UNESCO’s statutory procedures, addressed to the General Conference and give advice concerning the follow-up of this Declaration, in particular regarding the identification of practices that could be contrary to human dignity, such as germ-line interventions*” (Article 24).

5. Stimulating the debate and future directions

The public debate has been growing very rapidly and they have here some quotations of the Declaration

in the developing world in Cameroun for example where a number of organisations are taking part on this debate. It is essential that such organizations are involved in the meetings of the International Bioethics Committee dealing now with many other aspects concerning, for example, the importance of energy in the oceans and the importance that this has on the environment. I would like to emphasize here that also the third world universities are active contributors of this public debate on the dissemination of knowledge. I think it is very important that although they cannot contribute to the sequencing of the human genome because they have no possibilities of doing so, they are present in the debate and sharing their views with the scientists of the other countries. This sharing is what really matters particularly when we are dealing with ethical issues.

In 1972, Paul Berg and his colleagues alerted the world at the Asilomar conference saying: “*we are now in the position to transform one normal bacterial in one pathogenic bacteria*”, underlining that the scientific community, we had in our hands the possibility of misusing or using the new technology of genetic engineering in a perverse way. He was thinking also to the possible applications in biologic war and he said very clearly: “*... this will be completely crazy...* ”. And after all these years, we can realize that the scientific community has not done what constituted, *El Grito de Asilomar*, the high voice, the cry of Asilomar. This has not taken place. Today we can be reassured. I think that the dreams of the Hitlers and Frankensteins will not take place, and that the limits between what is feasible and what is admissible for human dignity will be respected.

References

- [1] The Universal Declaration on the Human Genome and Human Rights (1997), <http://www.unesco.org/general/eng/legal/index.shtml>.