

International Bioethics Committee

ULUSLARARASI BİYOETİK KOMİTESİ

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Summary

International Bioethics Committee of UNESCO (IBC) was founded to debate the ethical, social and human problems of the rapid development of life sciences. The IBC has investigated two subjects. The first subject is to study the issues of bioethics with which we are confronted today because of the rapid progress made in science and technology. The second subject is to draw up an international instrument for the protection of the human genome.

The universal Declaration on the Human Genome and Human Rights was accepted on II November 1997. This declaration has a dual framework based on the protection of every individual human being in his/her dignity and his/her human rights in the field of the human genome research and its application. The Declaration prohibits any form of discrimination based on genetic characteristics. Today, this committee has 36 members.

In this article, the characteristics and principles of this committee have been pointed out and some scientific results have been obtained.

Key Words: Bioethics, Human Genome, Universal Declaration

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Özet

Uluslararası Unesco Biyoetik komitesi, yaşam bilimlerinin hızlı gelişmeleri ile ilgili etik, sosyal problemleri tartışmak için kuruldu. Birinci konu, günümüzde, bilim ve teknolojiadaki hızlı gelişme nedeniyle karşılaşılan biyoetik konuları incelemekle ilgilidir. İkinci konu, insan genomunu korumak için bazı uluslararası yolları kullanmaktır.

Uluslararası İnsan Genomu ve İnsan Hakları Deklarasyonu, II Kasım 1997'de kabul edildi. Bu deklarasyon, insan genomu araştırması ve uygulaması alanında her insanı ve onun haklarını korumaya dayalı çift bir çerçeve taşır. Deklarasyon, genetik özelliklere dayanan herhangi bir ayırımı yasaklar. Bu komitenin bugün 36 üyesi vardır.

Bu makalede, bu komitenin özellikleri ve prensipleri incelenmekte ve bazı bilimsel sonuçlar elde edilmektedir.

Anahtar Kelimeler: Biyoetik, İnsan Genomu, Uluslararası Deklarasyon

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1. In 1993, the International Bioethics Committee of UNESCO (IBC) was created to encourage the debate, at a world-wide level, on the ethical, social and human consequences of the rapid development of life sciences. The IBC, the only international consultative body in the field of bioethics, had a transdisciplinary composition of

approximately 50 eminent people from all over the world acting in their personal capacity.

2. The IBC has pursued two objectives:

-To allow exchange of views on the issues of bioethics with which we are confronted today because of the very rapid progress made in science and technology.

-To draw up an international instrument for the protection of the human genome

3. The last objective was achieved on 11 November 1997 by the adoption of the Universal

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Declaration on the Human Genome and Human Rights by the General Conference of UNESCO.

I. Universal Declaration on the Human Genome and Human Rights

4. The Universal Declaration on the Human Genome and Human Rights has a dual framework based on the protection of every individual human being in his/her dignity and his/her human rights in the field of the human genome research and its application. In one word, the ideology of Humanity is set out in this Declaration.

5. The first framework is the dialectic of freedom of research and the rights of the persons concerned. The Declaration affirms the need to guarantee the freedom of research in the framework of the respect for human dignity and the protection of human rights. Practices contrary to human dignity are not allowed. The respect of the rights of the persons concerned is dealt with through free and informed consent, special consideration with regard to vulnerable persons and groups and the confidentiality of genetic data.

6. The second framework concerns the protection of human rights from the aspect of the genetic characteristics of each human being. The Declaration prohibits any form of discrimination based on genetic characteristics. In this respect, the confidentiality of genetic data associated with an identifiable person is the central factor. However, this raises a difficult question: to whom does genetic belong?

7. The Declaration underlines the role of States both in considering the relevant ethical, legal and social implications and in promoting genetic research. Solidarity and international cooperation is also a key principle for equitable development in the field of genetics.

8. This Declaration is a declaration of principles and thus an ethical instrument which is not legally binding. It is a starting point and not an end itself. The fact of the adoption of this Declaration by UNESCO and of its endorsement by the United Nations General Assembly is a land mark in the history of Humanity. The implementation of the Declaration is the key factor for protecting human dignity and human rights in the field of genetics.

9. As a global forum of bioethics discussion, the IBC has discussed various questions of bioethics in its annual sessions:

Subjects Discussed in the Plenary Sessions:

2nd Session (1994): Genetic Screening and Testing, Therapeutic Applications Stemming from Genetic Engineering;

3rd Session (1995): Genetic Counselling, Ethics and Neurosciences, Bioethics and Human Population Genetics Research;

4th Session (1996): Access to Experimental Treatment and Experimentation on Human Subjects, Food, Plant Biotechnology and Ethics;

5th Session (1998): Bioethics and Women, Ethics and Preventive Medicine, Ethics and Uses of Genetic Engineering in Industry, Follow-up of the Universal Declaration on the Human Genome and Human Rights;

6th Session (1999): Bioethics and Public Debate, Confidentiality and Genetic Data, State of Art in Bio-Science.

II. New International Bioethics Committee

10. The IBC has been reconstituted in accordance with the Resolution 29 C/17 concerning the implementation of the Universal Declaration on the Human Genome and Human Rights. The new Committee is composed of 36 members, always in an individual capacity. The current IBC has a dual role of innovation and continuation. The Committee is an innovation, since it is operating henceforth on the basis of Statutes and a new composition. Also, the creation of the Intergovernmental Bioethics Committee (IGBC) in parallel serves to guarantee dialogue with the IBC. And the Committee represents continuity, since one of its main tasks is the implementation of the Declaration.

11. At the Fifth Session of the IBC, which was in fact the first meeting of the new Committee, a round-table and three working sessions were held. The Session on "Bioethics and Women's Rights" revealed how necessary it is to improve and standardize the situation of women in each society. The report, which will be published before the end of this year, will contain a through comparative study

of the various issues concerned. The Session on "Ethics and Preventive Medicine" revealed the areas of light and the shadow-land of preventive medicine. It is essential that we investigate the usefulness and effectiveness of biotechnology and of advanced genetic engineering. It is also important for us to devote thought to the physician-patient relationship. The follow-up of the Declaration was also discussed in a working session, and was put to the further consideration of a working group. The Round Table debate on ethics with regard to the uses of genetic engineering in industry revealed how difficult it is to resolve the confrontation between, on the one hand, bioethics as well as human rights, and, on the other, the logic of the market economy.

12. The Committee, at the end of the session, decided to reform the methodology of its work. It was decided to hold regularly two working groups in order to discuss more thoroughly various bioethical issues. It was also decided to divide the session into two parts, that is, public working sessions and closed working sessions reserved to the members of the IBC. The purpose of such a reform is to assume the responsibility of the Committee through in-depth discussions between the members of the IBC.

III. Sixth Session of the IBC

13. The sixth session was composed of a round table and four working sessions, two of which were devoted to the examination of the subjects assigned to the working groups. The round table on "Bioethics and Public Debate: Information, Education, Participation" highlighted the difficulty and the meaning of promoting public debate in the field of bioethics. Bioethics is not only an area of reflection for decision-makers or scientists, or even individuals. It is also, and above all, a subject for the public at large. The importance of education at various levels was underlined, not only in medical schools and other scientific faculties but also at secondary school level.

14. The Working Group on the Follow-Up of the Declaration, the most urgent task of our Committee, presented proposals in view of the application of Article 24 of the Declaration concerning its implementation. These proposals concern

various crucial factors, namely the means of disseminating the principles set out in the Declaration, consultation with parties concerned, the recommendations and opinions of the IBC, the identification of practices contrary to human dignity and proposals on the subjects to be dealt with in the near future. The Committee approved the Draft Guidelines for the Implementation of the Declaration, which was later adopted by the General Conference.

15. The last working session was devoted to "Ethics and the Confidentiality of Genetic Data", which had been studied by another Working Group. The report established after this working session is of high quality with thorough investigation of various elements relevant to the subject, and deals with: identification of various types of genetic data, criteria for the application of the principle of confidentiality, limitations to the principle of confidentiality, and bioethics awareness-building and education. Thus it clearly shows that the confidentiality problem arises where various ethical issues overlap.

IV. Guidelines for the Implementation of the Declaration

16. Particular emphasis should be placed on the Guidelines for the Implementation of the Universal Declaration on Human Genome and the Human Rights. Under the Headings of "Why guidelines?", "What to do?", "How?", "For whom are these guidelines intended?" and "Evaluation", these Guidelines set out a whole range of measures for implementing the Declaration.

a. Why Guidelines?

Because the implementation of the Declaration is most urgent, since scientific progress in genetics and biology is accelerating and, at one and the same time, giving humanity both hope and ethical dilemmas.

b. What to Do?

Object of the Guidelines

Dissemination of principles, education, exchange of studies and analysis, respect for the freedom of research, North-South co-operation, etc.

c. How?

Various Modes of Action

Translation, publication, public debates, education and training audiovisual materials, creation of independent, pluralist and multidisciplinary ethics bodies.

d. For Whom Are These Guidelines Intended?

States, International Organizations, NGOs, Decision-Makers, Lawmakers, Ethics Committees, Scientists, Individuals/Families.

e. Evaluation

Evaluation of the results obtained through the Guidelines and the impact of the Declaration.

V. Intergovernmental Bioethics Committee (IGBC)

17. The Intergovernmental Bioethics Committee was established pursuant to the Statutes of the new IBC. The IGBC is composed of 36 representatives of the Member States elected by the General Conference. The purpose of this new body is to foster dialogue between the IBC, whose members act in an individual capacity, and the IGBC, whose members are the States which are the ultimate agency of the implementation of the Declaration.

18. The IGBC held its first session immediately following the sixth session of the IBC, and the two Committees held their first joint session. The IGBC's discussions were characterized by constructive collaboration and mutual support with the IBC. The IGBC noted with satisfaction the Draft Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights, and raised some important points regarding these guidelines, namely, relations with vulnerable

groups and budgetary implications. It expressed the hope concerning the criteria for programme of work of the IBC, such as: identification of practices contrary to human dignity, specialized fields of UNESCO, relevance of the subjects to the Declaration and inter-organizational co-operation.

19. The IGBC expressed its hope to cooperate closer with the IBC, on ameliorating its working methods, in particular the holding of the sessions alternately with the session of the IBC so as to amply examine the IBC's conclusions.

VI. Conclusion: Prospects

20. At the kind invitation of the Ecuadorian Government, the IBC will hold its Seventh Session in Quito from 7 to 9 November 2000. The subjects to be discussed in Quito are: Education in Bioethics, Economic Aspects of the Human Genome Research, The Ethical Aspects of Embryonic Stem Cell Research, Solidarity and International Co-operation between Developed and Developing Countries concerning the Human Genome, Consultation with Patients' Associations, State-of-the-Art on Neuroscience, on ageing, and on the post-genome-sequence phase. The IBC will also dwell on its future programme of work, including for example, intellectual property issues, and insurance and the genetic data.

21. The IBC is continuing its efforts to disseminate "the Ideology of Humanity" based on human dignity. We do hope to fully cooperate with and give assistance to the national bioethics committees as well as relevant organizations, international or non-governmental, and individuals. Our ultimate goal is to contribute to the welfare and the happiness of humanity by constructing ethical fortification in the heart of humanity.