

International Bioethics and Human Genetics. The Activities of UNESCO

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Abstract

The ethics program of UNESCO has started in the early 1990s with the request of the Member States to develop global ethical standards in regard to the Human Genome Project. The International Bioethics Committee (IBC) composed of 36 independent experts from all regions has been established in 1993 in order to advise the Director-General in ethical matters. The IBC drafted the Universal Declaration on the Human Genome and Human Rights that was adopted by the Member States of UNESCO in 1997 and by the United Nations in 1998. This Declaration was followed by a more specific request relating to the collection, processing, use and storage of human genetic data. The International Declaration on Human Genetic Data has been adopted in 2003. Subsequently, a much broader mandate was given in order to identify universal bioethics principles in general. This resulted in the Universal Declaration on Bioethics and Human Rights, unanimously adopted in 2005. This last Declaration is the first global statement in the area of bioethics to which governments have committed themselves. The challenge now is to translate it into practical activities in the Member States, such as ethics committees, ethics education, public debate and legislation.



الهدىء الأطلاقية الدولية وعلوم الوراثة من خلال نشاط منظمة اليونسكو

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ملخص

تأسس البرنامج الأخلاقي التابع لمنظمة اليونسكو في مطلع التسعينيات بناءً على طلب من أعضاء هيئة اليونسكو وذلك من أجل وضع معايير أخلاقية عالمية لمشروع الجينوم البشري. ومن أجل تحقيق ذلك تم تأسيس اللجنة الدولية لأخلاقيات العلوم الحيوية في عام ١٩٩٢. وتتكون هذه اللجنة من ثلاث وستون خبيراً من شتى أنحاء العالم ويكمن دورهم في تقديم النصيحة للمدير العام المسؤول عن القضايا الأخلاقية. وصاغت هذه اللجنة المسودة الأولية للبيان الرسمي الدولي فيما يتعلق بالجينوم البشري وحقوق الانسان وقد تبني هذا البيان من قبل أعضاء هيئة اليونسكو في عام ١٩٩٧ ومن قبل منظمة الأمم المتحدة في عام ١٩٩٨. واتباع الاعلان عن هذا البيان مطالب أكثر تحديداً فيما يخص عملية جمع ومعالجة واستخدام وتخزين المعلومات الجينية البشرية وتم الاعلان عنها في عام ٢٠٠٢. وفيما بعد، تم توسيع نطاق العمل ليشمل وضع معايير أخلاقية عالمية لشتى العلوم الحيوية بوجه عام. ونتج عن ذلك بيان دولي يتعلق بأخلاقيات العلوم الحيوية وحقوق الانسان وتمت الموافقة على هذا البيان وتبنيه في عام ٢٠٠٥. ويعتبر هذا البيان الأول في مجال أخلاقيات العلوم الحيوية الذي تم الاعتراف فيه عالمياً والتزمت الحكومات به. ويبقى التحدي القائم بترجمة هذا البيان إلى واقع عملي ملموس من خلال تشكيل لجان في منظمة اليونسكو لمناقشة القضايا الأخلاقية وسن القوانين وتثقيف العامة.



Introduction

Due to globalization, not only scientific and technological advances spread around the globe, but also bioethical issues. As the example of human cloning demonstrates, when a new technology has been developed in one country, it can be applied elsewhere, even if some countries want to ban its use. Medical research is increasingly multi-central and international, with more and more research subject recruited in developing countries. Also healthcare practices are global but guidelines and legal contexts differ and are sometimes absent. Rules for transplantation and procedures for organ donation, for example, are varying among countries and these different approaches have led to abuses such as organ trafficking and commercialization of transplantation practices.

Standard Setting in Bioethics

Many countries, however, only have a limited infrastructure in bioethics, lacking expertise, educational programs, bioethics committees, and legal frameworks. The global nature of science and technology implies the need for a global approach to bioethics. Member States have mandated UNESCO to set universal ethical benchmarks covering issues raised within the field of bioethics. They want to work together towards identifying basic principles and shared values regarding science, technology and health care. Standard-setting action in the field of bioethics has become a necessity that is felt throughout the world, often expressed by scientists and practitioners themselves, as well as by legislators, policy-makers, and citizens.

It was in this context that in October 2003, based on preliminary feasibility studies, UNESCO was mandated by its Member States to draw up a declaration setting out fundamental principles in the field of bioethics. After two years of intense work, these same Member States adopted, unanimously and by acclamation on 19 October 2005, the *Universal Declaration on Bioethics and Human Rights*, thus solemnly affirming the commitment of the international community to respect a certain number of universal principles for humanity in the development and application of science and technology. With this new Declaration, UNESCO strives to respond in particular to the needs of developing countries, indigenous communities and vulnerable groups or persons, all of whom are the object of special mention throughout the text.

Standard Setting and Genetics

When UNESCO was considered by States to be the most appropriate forum for the elaboration of such a text, it is without doubt because the Organization has been able to confirm its standard-setting role in the field of bioethics. UNESCO, the only specialized instance within the United Nations system that combines education, culture, science and social sciences in its field of competence, has developed a bioethics program over the past ten years that reflects the multidisciplinary and trans-cultural dimension of this debate. UNESCO is engaged in carrying out actions that involve all countries in this international discussion in order to bring out fundamental principles common to all, with respect for the cultural diversity of our societies. The success of the *Universal Declaration on the Human Genome and Human Rights* adopted in 1997 and the *International Declaration on Human Genetic Data* adopted in 2003 has reinforced UNESCO in its standard-setting action in the field of bioethics and has allowed States to place confidence in the Organization to finalize the Universal Declaration.

The *Universal Declaration on the Human Genome and Human Rights* formulates important principles to guide the development of genetic knowledge and the application of genetic technologies. A basic concept is that 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”; it therefore should be regarded, in a symbolic sense, as the “heritage of humanity” (Article 1). For this reason, the human genome in its natural state “shall not give rise to financial gains” (Article 4); it is also stated that benefits from advances in biology, genetics and medicine “shall be made available to all” (Article 12a).

The Declaration also emphasizes the fundamental role of human dignity and human rights. This is a basic principle: “Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics” (Article 2a). This principle implies that genetic reductionism must be rejected; individuals cannot be reduced to their genetic characteristics. It furthermore implies non-discrimination; no one shall be subjected to discrimination based on such characteristics (Article 6). An important implication also is that practices which are contrary to human dignity shall not be permitted; the text of this Article 11 explicitly refers reproductive cloning of human beings, as an example of such infringement of human dignity.



The Universal Declaration on Bioethics and Human Rights

Under the aegis of respect for human dignity, human rights and fundamental freedoms, the *Universal Declaration on Bioethics and Human Rights* has a much wider scope as the previous Declarations that have been focused on genetics. It deals with ethical issues raised by medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions. The Universal Declaration aims to define the universally acceptable norms, principles and procedures in the field of bioethics, in conformity with human rights as ensured by international law. It is thus conceived as a group of general provisions and principles that allow for a better evaluation of the implication of ethical issues at stake and to provide assistance in decision-making in this field. It does not pretend to resolve all the bioethical issues presently raised and that evolve each day. Its aim is rather to constitute a basis for States wishing to endow themselves with legislation or policies in the field of bioethics. It also aims, as far as possible, to inscribe scientific decisions and practices within the framework and respect of a certain number of general principles common to all. And it aims to foster dialogue within societies on the implications of bioethics and the sharing of knowledge in the field of science and technology.

In order to achieve these goals, the Universal Declaration presents a vested right which is reflected in its title: it anchors the principles it endorses in the rules that govern respect for human dignity, human rights and fundamental freedoms. By drawing on the 1948 *Universal Declaration of Human Rights*, it clearly enshrines bioethics in international human rights law in order to apply human rights to the specific domain of bioethics.

Apart from the already well-established principles in the scientific community such as informed consent, the principle of autonomy and individual responsibility, respect for privacy and confidentiality (also articulated in the two previous Declarations adopted by UNESCO), the *Universal Declaration on Bioethics and Human Rights* raises the issues of access to quality health care and essential medicines, nutrition and provision of clean water, to the improvement of living conditions and the environment and the reduction of poverty. The Universal Declaration thus opens perspectives for action that reach further than just medical ethics and reiterates the need to place bioethics within the context of reflection open to the political and social world. Today, bioethics goes far beyond the code of ethics of the various professional practices concerned. It implicates reflection on the evolution of society, indeed world stability, induced by scientific and technological developments. The Universal Declaration paves the way for a new agenda of bioethics at the international level.

Towards International Bioethics

Although the Universal Declaration constitutes a non-binding instrument in the eyes of international law, its value and its strength are in no way diminished. For the first time in the history of bioethics, all States of the international community are solemnly committed to respect and implement the basic principles of bioethics, set forth within a single text. Also through the Universal Declaration, bioethics finds its place on the agenda of States. Furthermore, characterized by the transparency and active participation of all the actors concerned, the elaboration process of the Universal Declaration, involving extensive consultations, has already largely contributed to the renown of the text and its general acceptance. The innovative dimension of the Declaration is that it constitutes for the first time a commitment of governments to a set of bioethical principles. Previous international declarations, although sometimes very influential, such as the *Declaration of Helsinki*, have been adopted by professional organization (such as the World Medical Association).

The timetable set out for the elaboration of the Declaration planned a first year devoted to the drafting work of the International Bioethics Committee of UNESCO (IBC) – a UNESCO advisory committee composed of independent experts – and a second year devoted to intergovernmental negotiations on the basis of the text drawn up by IBC. Nevertheless, broad consultations, hearings and conferences were carried out world-wide throughout the process of elaboration in order to associate States, other specialized agencies of the United Nations system and other intergovernmental organizations, non-governmental organizations voicing in particular vulnerable persons and groups, relevant national bodies, and specialists. By means of the Internet site that permitted the results of each meeting or consultation held to be made public and regularly posted on-line, all were free to present their views, remarks and comments to IBC on the different versions of the text. Thus, from the very beginning of the elaboration process, the Universal Declaration has promoted general recognition of bioethical concerns and has stimulated the bioethics debate in the four corners of the world, involving and nourishing intercultural dialogue on these issues.



Conclusion

The Universal Declaration on Bioethics and Human Rights should be seen therefore not as the fruit of the reflection of just a few but as the result of a long and sustained common effort in which all relevant actors have been involved. It is also the first normative instrument that has been adopted by Member States and therefore expresses a commitment of governments in the area of international bioethics. The principles articulated in the Universal Declaration are in some cases already expressed in previous Declarations adopted by UNESCO but the scope of these principles have now been widened in order to cover medicine and life sciences as a whole. Other principles articulated in the Universal Declaration are relatively new. They cover a broader area of interest, not only of more developed countries but also particularly of less developed countries, taken into account diverse cultures, religions, and schools of thought.

Notes

Further information on the Universal Declaration and the process of its elaboration, can be found on Internet at the following address: www.unesco.org/bioethics.

