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*International Bioethics
Committee (IBC)*

*Comité international
de bioéthique (CIB)*

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Elaboration of the Declaration on Universal Norms on Bioethics : First Outline of a Text

This first outline of a text for a declaration on universal norms on bioethics has been elaborated by the IBC Drafting Group at its first and second meetings (Paris, 30 April 2004 et 2-3 June 2004), taking into consideration the results of the written consultation with Member States and the IBC Extraordinary session (Paris, 27-29 April 2004) on the scope and structure of the future declaration.

This outline is not complete. It is not to be considered definite but as a step in the drafting process of the Drafting Group and the IBC in its entirety.

Universal Declaration on Bioethics [and Humanity / Humankind / Human Beings]*

The General Conference,

Recalling the Universal Declaration on the Human Genome and Human Rights adopted by the General Conference of UNESCO on 11 November 1997 and the International Declaration on Human Genetic Data adopted by the General Conference of UNESCO on 16 October 2003,

Also recalling the Universal Declaration of Human Rights of 10 December 1948, the two United Nations International Covenants on Economic, Social and Cultural Rights and on Civil and Political Rights of 16 December 1966, the United Nations International Convention on the Elimination of All Forms of Racial Discrimination of 21 December 1965, the United Nations Convention on the Elimination of All Forms of Discrimination against Women of 18 December 1979, the United Nations Convention on the Rights of the Child of 20 November 1989, the United Nations Convention on Biological Diversity of 5 June 1992, the Recommendation of UNESCO on the Status of Scientific Researchers of 20 November 1974, the UNESCO Declaration on Race and Racial Prejudice of 27 November 1978, the UNESCO Declaration on the Responsibilities of the Present Generations Towards Future Generations of 12 November 1997, the UNESCO Universal Declaration on Cultural Diversity of 2 November 2001, the Trade Related Aspects of Intellectual Property Rights Agreements (TRIPs) annexed to the Agreement establishing the World Trade Organization, which entered into force on 1 January 1995, the Doha Declaration on the TRIPs Agreement and Public Health of 14 November 2001 and the other international human rights instruments adopted by the United Nations and the specialized agencies of the United Nations system,

Bearing in mind the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine of the Council of Europe, adopted in 1996 and entered into force in 1997, as well as the other international and regional instruments, national legislation and regulations in the field of bioethics,

Also bearing in mind the international and regional codes of conduct and guidelines and other ethical texts in the field of science and technology, such as the Declaration of Helsinki of the World Medical Association on Ethical Principles for Medical Research Involving Human Subjects, adopted in 1964 and amended in 1975, 1989, 1993, 1996, 2000 and 2002, the Declaration of Lisbon of the World Medical Association on the Rights of the Patient adopted in 1981 and amended in 1995, and the International Ethical Guidelines for Biomedical Research Involving Human Subjects of the Council for International Organizations of Medical Sciences adopted in 1982 and amended in 1993 and 2002,

* The words in [square brackets] offer variants of the wording concerned.

Considering that, by virtue of its Constitution, it is incumbent upon UNESCO to act towards “the democratic principles of the dignity, equality and mutual respect of men” and to reject any “doctrine of the inequality of men and races”, and that all nations have a sacred duty to fulfil in a spirit of mutual assistance,

Considering also that it is the mission of UNESCO to develop universal principles and norms based on shared values in order to meet emerging challenges in science, to guide scientific and technological development and social transformation, taking into account the responsibility of the present towards future generations,

Bearing in mind UNESCO’s activities and programmes in the field of natural, social and human sciences, aiming at placing scientific and technological development in a context of ethical reflection, and at promoting the sustainable use and conservation of the biological diversity and the improvement of the relationship between human beings and their environment,

Aware that human beings are an integral part of the biosphere and that, as such, they have responsibilities and duties towards all other forms of life that the present Declaration has the purpose of upholding,

Recognizing that scientific and technological development have been of great benefit to humankind [in increasing inter alia life expectancy and improving quality of life] and emphasizing that such development should always seek the welfare of individuals and humankind as a whole in the respect for human dignity, rights and freedoms,

Bearing in mind that cultural diversity, as a source of exchange, innovation and creativity, is necessary for humankind and, in this sense, it is the common heritage of humanity,

Convinced that ethical reflection is an integral part of scientific and technological development and that bioethics plays today a predominant role in the social choices that need to be made,

Stressing the need to reinforce international cooperation in the field of bioethics, taking into account in particular the special needs of developing countries,

Considering that questions of bioethics raised by advances in science and technology, which have been addressed in part by the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data, should be treated as a whole, drawing on the principles already affirmed in these two international instruments and taking account not only of the current scientific context but also of future developments,

Proclaims the principles that follow and adopts the present Declaration.

[Use of Terms]

(Limited to scientific terms)

Scope

Bioethics, Humanity [Humankind / Human Beings] and the Biosphere

This Declaration states the principles of bioethics primarily affecting [related to] human beings, while recognizing that human beings, as an integral part of the biosphere, have responsibilities and duties towards all other forms of life.

Human Dignity, Human Rights and Fundamental Freedoms

The principles set out in this Declaration are founded on [are drawn from/ flow from] the respect for human dignity and the protection of human rights and fundamental freedoms [, in accordance with international human rights law].

Consensus, Diversity and Pluralism

a) This Declaration affirms [states] that, through the universal principles set out therein based on shared values, common positions [decisions / solutions] in the field of bioethics should be reached for the benefit of humanity as a whole.

b) This Declaration acknowledges that ethical issues raised by scientific and technological development are set [reflected] in the cultural, philosophical and religious bedrock of the various human communities and that in some cases they should be addressed in the spirit of cultural pluralism inherent in bioethics.

Aims

The aims of this Declaration are:

- to promote respect for life in all its diversity and in particular [including] respect for human life;
- to ensure the respect for human dignity and the protection of human rights and fundamental freedoms in [the sphere of] bioethical decision making, in accordance with international human rights law;
- to recognize an understanding of the great benefit derived from scientific and technological development, whilst ensuring that such development occurs within the framework of ethical principles that respect human dignity and protect human rights and fundamental freedoms;
- to provide a universal framework of fundamental values, [core principles] and basic procedures designed to guide States in the formulation of their legislation and their policies in the field of bioethics, and to form the basis for guidelines in bioethical matters for the institutions, groups and individuals concerned;
- to foster dialogue between scientists, health professionals, lawyers, philosophers, ethicists, theologians and all the other intellectual and professional groups concerned, policy makers and society as a whole;
- to prevent practices contrary to human dignity such as those that undermine the respect for individuals and for the diversity of humankind;
- to promote the sharing and the greatest possible flow of knowledge concerning the scientific and technological development as well as the sharing of benefits, in particular with developing countries;
- to safeguard the interests of present and future generations.

General Principles

Ecological Responsibility [Bioethical Responsibility]

Any decision or practice in the field of bioethics [at all levels] shall have due regard for the impact on the interconnections of all life forms and the special responsibility of human beings for the protection of life in its diversity and of the biosphere within which human beings exist.

Human Dignity, Human Rights and Justice

Any decision or practice in the field of bioethics [at all levels] shall be made in the respect of the human dignity and in accordance with the universal principles of justice, human rights and fundamental freedoms.

Diversity and Tolerance

Any decision or practice in the field of bioethics [at all levels] shall take into account the various schools of thought, value systems, historical and cultural backgrounds, and philosophical and religious traditions that make up our societies. However, cultural diversity shall not be invoked to infringe upon the principles set out in this Declaration, nor to limit their scope.

Solidarity, Equity and Cooperation

Any decision or practice in the field of bioethics [at all levels] shall be guided by [founded on] the solidarity of humanity, in order to avoid discrimination and stigmatization of an individual, a family or a group, to ensure equity and to encourage the sharing of scientific knowledge and cooperation.

Application of the General Principles

The list of the application of principles is still being developed. It may include:

- Primacy of the human person
- Non-discrimination and non stigmatization
- Consent
- Confidentiality
- Right to information
- Right to health care
- Benefit sharing
- Non-commercialization of the human body and its parts
- Scientific research
- Research involving human subjects

Procedures

Provision on procedures which should be followed at national and international level in science and technology, in particular:

- the need for democratic and transparent procedures,
- rationality and agreement,
- intellectual honesty and integrity of research,
- principles governing the dissemination of scientific knowledge,
- dialogue between specialists, policy-makers and society,
- the promotion and establishment of national bioethics committees and review boards at appropriate levels,
- the need for public consultations,
- the regulation of transnational practices

Promotion and Implementation

- Education and Awareness-raising
- Solidarity and International Cooperation
- Implementation (including a reporting mechanism and an evaluation system and periodical revision)
- Denial of acts contrary to human rights, fundamental freedoms and human dignity