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Committee (IBC)*

*Comité international  
de bioéthique (CIB)*

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**ELEVENTH SESSION**  
**INTERNATIONAL BIOETHICS COMMITTEE OF UNESCO (IBC)**  
UNESCO Headquarters, Paris, 23-24 August 2004

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**REPORT**

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Division of Ethics of Science and Technology

## **I. INTRODUCTION**

1. The eleventh session of the International Bioethics Committee (IBC) was held at UNESCO Headquarters in Paris on 23 and 24 August 2004, bringing together more than 250 participants from some 80 countries (List of participants in Annex I).
2. Mr Alexander McCall Smith having ceased to be a member of IBC, Mr Leonardo De Castro agreed to serve as Rapporteur of the eleventh session, in accordance with Rule 16.1 of the IBC Rules of Procedure, which stipulates that: “If the Rapporteur is unable to exercise his/her functions during a whole session of the Committee or part thereof, his/her duties shall be carried out in turn by a Vice-Chairperson, following the French alphabetical order”.
3. This eleventh session was devoted in particular to the work of preparing the future declaration on universal norms on bioethics. In accordance with its agenda (Annex II), it was marked by hearings of representatives of different religious and spiritual perspectives. IBC then examined the Second Outline of a text of the future declaration prepared by the IBC Drafting Group (27 July 2004) (Annex III).
4. At a meeting reserved for members of the Committee, IBC elected its Bureau (see Section V) and engaged in an initial exchange of views on a plan of action for implementation of the International Declaration on Human Genetic Data (2003). In this respect, the Committee examined a preliminary text of a plan of action consisting of three parts – “What to do?”, “How?” and “For whom?” – and identifying six fields of action following the provisions of the Declaration (education, training programmes, dissemination of information, genetic counselling, international cooperation and follow-up of the Declaration).

## **II. OPENING OF THE ELEVENTH SESSION OF IBC<sup>1</sup>**

5. Mr Koïchiro Matsuura, Director-General of UNESCO, presided over the opening of the eleventh session of IBC. In his address, Mr Matsuura emphasized the importance of the eleventh session, fitting in as it did with a great many consultations on the future declaration on universal norms on bioethics. By giving the floor to representatives of different religious or spiritual traditions, the session ensured the interactive, progressive and collective character of the IBC’s work. The session also provided an opportunity to gauge the progress made and difficulties encountered in the drafting of the future declaration, and to offer constructive proposals on the Second Outline of a text. Mr Matsuura then briefly presented the ensuing stages of the preparation process, recalling in particular that the text from the eleventh session of IBC would be submitted to the Executive Board at its 170th session in October 2004. Finally, while acknowledging the difficulty of the task, he reiterated his faith in IBC and expressed his view that an open and frank dialogue would help to blend traditions, to consider cultural differences and to find a common language.

6. In her address, Mrs Michèle S. Jean, Chairperson of IBC, said she was convinced that ethical reflection helped to associate science with social and political developments. As the present preamble made clear, the purpose of the future declaration was also to promote the progress of science while preventing the risks of malpractice. She then recalled the stages completed since the start of the work and stressed the importance of all the consultations conducted. In that context, the various spiritual trends having marked the development and thought of societies and continuing to pervade cultures, both collective and individual, IBC had sought to gather the points of view of various religious groups on the future declaration.

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1. All the addresses delivered during the session are reproduced in the Proceedings of the eleventh session of IBC.

### **III. HEARINGS OF REPRESENTATIVES OF DIFFERENT RELIGIOUS AND SPIRITUAL PERSPECTIVES<sup>2</sup>**

7. Mr Leonardo De Castro, Vice-Chairperson of IBC, chaired the meeting devoted to the hearings of representatives of different religious and spiritual perspectives. Six speakers were invited to take the floor, respectively from the Buddhist, Catholic, Confucian, Hindu, Islamic and Jewish traditions. Each speaker gave a presentation focusing on how their respective religious traditions viewed bioethics and some commented on the text prepared by the Drafting Group.

8. Mr Soheib Bencheikh, the Mufti of Marseille (France), began his statement by saying that bioethical reflection was relatively recent in the Muslim world and that it stemmed mainly from work by individual researchers. He then illustrated some specific subjects such as organ or tissue transplants, which do not seem to present any major ethical problem, particularly if the person is dead, since the human body is regarded in Muslim tradition as the mere envelope of the soul. With respect to the end of life, palliative care should come first and any form of euthanasia be banned, given that life belongs not to humans but to Allah. Concerning voluntary termination of pregnancy, with Muslim tradition considering the woman to have a “real life” and the foetus a “probable life”, the practice is accepted if a physical or psychological danger, attested by a physician, is incurred by the pregnant woman.

9. Mr Ruiiping Fan, Professor in the Department of Public and Social Administration, City University of Hong Kong (China), presented the perspective of Confucianism, recalling that in the Confucian tradition, in order to lead a healthy life, the individual has to seek unity with other individuals in respect for the husband/wife, parent/child and governed/governing relationship. He then presented some specific suggestions on the Second Outline, aimed in particular at ensuring that the notion of “human dignity”, turned towards the individual and implying rights, is accompanied by that of “virtue”, which is turned towards relations with others and involved obligations. The two notions consequently form the basis of human rights and justice that should guide practice in the scientific and technological field. He also suggested that such subjects as human cloning for reproductive purposes – which would be banned in accordance with Confucianism – and stem cell research – which would be permitted – should be addressed in the text.

10. Mr Swami Jitatmananda, Shri Ramakrishna Ashram (Rajkot, India), presented the Hindu perspective, derived from two postulates: that ethics underlies any human civilization and that it is based on the unity of earthly existence. That implied, first, that ethics can not be based on individualism but on the contrary has to seek universalism and, second, that all forms of life are interconnected. That being so, science should pursue two goals: promote the welfare of human beings and establish a sustainable universal civilization. That notion of universalism, he concluded, does not presuppose uniformity and, consequently, such practices as cloning for reproductive purposes should be condemned.

11. The Reverend Gonzalo Miranda, President of the Bioethics Centre, Pontifical Athenaeum Regina Apostolorum (Rome, Italy), reiterated the interest taken by the Catholic Church both in bioethical issues and in scientific and technological advances. For the Catholic Church, he recalled, the basis of any ethical reflection has to be human dignity. Furthermore, he considered that in order to formulate universal principles, on the one hand, cultural and religious diversity should be respected and, on the other, special attention should be given to the rights set forth in the Universal Declaration of Human Rights of 1948, particularly the right to life. In addition, he wished the text to avoid any indirect and implicit affirmation, which might for example lead to approval of cloning for therapeutic purposes if the instrument were to include only a provision condemning human cloning for reproductive purposes.

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2 The statements are given in their original languages in the Proceedings of the eleventh session of IBC.

12. Mr Pinit Ratanakul, Director of the College of Religious Studies, Mahidol University (Bangkok, Thailand), commented on the Second Outline in the light of the Buddhist tradition. The future declaration should, he considered, recognize the interdependence of all forms of life. According to the Buddhist tradition, the individual enjoys the right to self-determination but, as a person living in an interdependent world, has to exercise that right with due regard to other forms of life. The reference to the biosphere is thus very important, even though there should be greater emphasis on animals and the environment. With interdependence also operating at the level of States, harmony among peoples and cooperation are critically important human values; the principle of solidarity, equity and cooperation is therefore perfectly in place in the declaration, notably with a view to guaranteeing the sharing of scientific knowledge. Furthermore, the principle of protecting life in all its diversity should be developed to ensure the protection of human life regardless of its state of development, which implies condemnation of voluntary termination of pregnancy, euthanasia and stem cell research. In conclusion, he took the view that the provision on cultural diversity, pluralism and tolerance is all-important since it enables the various societies to seek solutions in keeping with their own moral traditions.

13. Mr Avraham Steinberg, Director of the Medical Ethics Centre of the Hebrew University – Hadassah Medical School (Jerusalem, Israel), presented comments on the Second Outline in accordance with the Judaic outlook. Generally speaking, with the Jewish religion favouring the casuistic approach, he wished the declaration not merely to prescribe major principles in the absolute but to take account of their relative value, which stems from the declaration's multicultural context. The declaration should consequently provide for a mechanism enabling a balance to be found when apparently conflicting values are at issue. Furthermore, he considered that while the future declaration should affirm the supremacy of human life and the principle of autonomy, it should also recognize the limits of autonomy, which, in Jewish tradition, are based on respect for other human beings and on solidarity and shared obligations.

### ***Debate***

14. Taking the example of the Muslim religion, where lack of a sole institutional body is no barrier to a common ethic, the participants first considered that universal principles could be formulated with a reconciling of the various points of view.

15. One of the questions prompting discussion was the balance to be struck between the principle of autonomy, whereby only individuals can decide for themselves, and the place accorded to family and solidarity among human beings by particular religious and cultural traditions. The future declaration would therefore have to reflect that dichotomy to a greater extent.

16. Also debated was the interdependence of all forms of life, which led to emphasizing not only human rights but also human responsibilities and duties, notably towards the biosphere.

17. Mr De Castro concluded the session by thanking all speakers and participants, who had given rise to a rewarding debate and had highlighted the need to give special attention to the points of divergence between the various religious and spiritual traditions in a quest for common values.

#### **IV. ELABORATION OF THE DECLARATION ON UNIVERSAL NORMS ON BIOETHICS: PROGRESS REPORT ON THE WORK OF THE IBC DRAFTING GROUP AND PRESENTATION OF THE OUTLINE**

18. At a meeting chaired by Mrs Jean, Mr Michael Kirby, Chairperson of the Drafting Group, presented the main thrust of the Second Outline of a text. With regard to the title of the future declaration, he recalled that the Group had preferred, at the current stage, to keep to the terms of the General Conference mandate (“Declaration on Universal Norms on Bioethics”) while recommending a broader title (“Universal Declaration on Bioethics”). As to the preamble, he specified that it followed a traditional drafting style within the United Nations system by placing the declaration in its international context, historically and legally speaking, notably with the recapitulation of a number of relevant international and regional instruments. Regarding principles, their order in the section on general principles had been revised as against the first draft of the text: the provision on human dignity and human rights now came first, constituting the basis of the entire declaration.

19. He then mentioned two difficult points that remained to be settled, namely how on the one hand to set forth the general principles and their applications while avoiding any rank-ordered classification and, on the other, how to address specific subjects. On the latter issue, the point was whether the future declaration was the right instrument for addressing all the specific subjects, and whether the prescribed time limits so permitted. He stressed the need to be able to broach such subjects satisfactorily and suggested considering a mechanism whereby in-depth study of those questions would be conducted at a later stage. An explanatory note would, he concluded, be drafted and constitute an important document for understanding and interpreting the declaration.

##### ***Debate***

20. The discussion highlighted the need to pursue the debate on some matters within the Drafting Group. With regard to the title, for example, the participants engaged in discussion of the use of the word “norms”. As some saw it, retaining the mandate of the General Conference would pave the way for future instruments covering more specific subjects within the ambit of the principles set forth in the present declaration. For others, preferring a broader title without any linguistic ambiguity as to the nature of the document, and in view of the various meanings of the word “norm” in differing linguistic cultures, it seemed more appropriate not to use the word in the title.

21. With regard to the preamble, insofar as the future declaration is intended not only for States but also for a broad general public, it was suggested that a few introductory paragraphs be included to present, concisely and clearly, the context of the drafting of the declaration. Furthermore, some considered that if regional instruments were cited, such as the 1997 Convention on Human Rights and Biomedicine of the Council of Europe, it would also be desirable to mention comparable texts from other regions of the world.

22. Concerning the section on definitions, while some participants felt that all the ethical terms should be defined, others considered that some notions should remain undefined and that, consequently, the definitions should be confined to scientific terms as necessary.

23. As to the section on general provisions, taking the view that the future declaration applied to individual human beings in their relationship with other human beings, some participants wished to delete the reference to responsibilities and duties towards other forms of life in the biosphere, while others, considering the text too anthropocentric, argued for giving more attention to the biosphere.

24. With regard to the section on general principles, it was suggested to review the structure of this part and its link with the section on the implications of the general principles. Some considered that, rather than following a logical order, an attempt should be made to conceptualize the global structure of the principles. Furthermore, suggestions were made for new principles such as those of equality, proportionality, scientific responsibility, paternalism or the non-instrumentalization of the human being.

25. Concerning more particularly the specific subjects, it emerged from the debates that continued reflection was needed on how they should be developed, taking into consideration on the one hand the divergent positions in the world on some subjects and, on the other, the limited drafting time available. In this respect, regarding the section on promotion and implementation, the possibility was contemplated of providing for a scheme opening the way for UNESCO, and IBC in particular, to conduct more thorough studies in the future on specific matters that might, as appropriate, lead to other international instruments.

26. Textual observations and general comments were also made, particularly on the necessity of fuller provision in the text for vulnerable persons, particularly disabled persons, and of recognition of the role played by civil society in the bioethics debate.

27. In conclusion, Mr Kirby thanked all participants in the debate, which had produced valuable observations on that part of the text already developed by the Drafting Group, together with possible guidance for the drafting work ahead.

## V. CONCLUSIONS

28. The comments and observations made on the Second Outline on the occasion of the eleventh session were taken into consideration by the Drafting Group, which met immediately after the session, from 25 to 27 August 2004, in order to finalize the Third Outline, for submission to the Executive Board of UNESCO in October 2004.

29. In accordance with the agenda, at a reserved meeting the Committee elected its new Bureau. For the sake of continuity in managing the work of drafting a declaration on universal norms on bioethics, IBC decided to renew the members of the present Bureau until the twelfth session in Autumn 2005 (as Chairperson, Mrs Michèle S. Jean, Canada; as Vice-Chairpersons, Mr Leonardo De Castro, Philippines; Mrs Nouzha Guessous Idrissi, Morocco; and Mr Patrick Robinson, Jamaica) while electing two new members to the vacant positions of Vice-Chairperson and Rapporteur. As customary, the members wished the membership of the Bureau to reflect cultural diversity and equitable geographical distribution.

30. The membership of the new Bureau in office until the twelfth session of IBC in Autumn 2005 is as follows:

Chairperson: Mrs Michèle S. Jean (Canada)

Vice-Chairpersons: Mr Leonardo De Castro (Philippines)  
 Mr Alphonse Elungu (Democratic Republic of the Congo)  
 Mrs Nouzha Guessous Idrissi (Morocco)  
 Mr Patrick Robinson (Jamaica)

Rapporteur: Mr Claude Huriet (France)

**VI. CLOSURE OF THE ELEVENTH SESSION OF IBC**

31. At the end of the eleventh session of IBC, on behalf of the Director-General, Mr ten Have, Secretary General of IBC, congratulated the new Bureau and thanked all speakers for their active and constructive participation, evidence indeed that collective reflection was always very productive. The eleventh session had highlighted the complexity of the task but also the confidence placed in IBC for rising to the challenge.

32. Mrs Jean thanked all participants who had spoken and, through the diversity of their points of view, had permitted a debate of substance. After mentioning the subsequent stages of the drafting, she concluded by emphasizing the significant contribution of public debate and of cultural diversity to any ethical reflection, as the eleventh session had once more shown.



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Maison de l'UNESCO, 23 – 24 août 2004**

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**Eleventh Session  
International Bioethics Committee (IBC)  
UNESCO House, 23 – 24 August 2004**

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Member of the Human Genome Organization (HUGO)  
Membre de l'Académie des sciences du tiers monde /  
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Chairperson of the Bioethics Committee of the Turkish National Commission for UNESCO

Membre de la Société européenne de génétique humaine /

Member of the European Society for Human Genetics

Membre du Comité d'évaluation des biotechnologies, Conseil de la recherche scientifique  
et technique de Turquie (TUBITAK) / Member of the Committee on Biotechnology

Assessment, Scientific and Technical Research Council of Turkey (TUBITAK)

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Directeur scientifique, Interpharm / Chief Scientist, Interpharm

Président du Comité de bioéthique de l'Académie nationale israélienne des sciences  
et humanités / President of the Bioethics Committee of the National Academy

of Sciences and Humanities of Israel

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**ROBINSON Juge / Judge (M. / Mr) Patrick** (Jamaïque / Jamaica)

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Ancien Membre de la Commission de droit international des Nations Unies /

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Organisation des Nations Unies pour l'éducation, la science et la culture  
United Nations Educational, Scientific and Cultural Organisation



*Comité international  
de bioéthique (CIB)*

*International Bioethics  
Committee (IBC)*

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**ELEVENTH SESSION OF THE  
INTERNATIONAL BIOETHICS COMMITTEE OF UNESCO (IBC)  
UNESCO House (Room II), 23-24 August 2004**

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**Agenda**

1. Opening of the Eleventh Session of IBC;
2. Presentation by the Chairperson of IBC of the work of the Committee since its Extraordinary Session (Paris, 27-29 April 2004);
3. Hearings of representatives of different religious and spiritual perspectives on the future declaration on universal norms on bioethics;
4. Declaration on universal norms on bioethics: progress report on the work of the IBC Drafting Group and presentation of an outline;
5. International Declaration on Human Genetic Data: first exchange of view on a plan of action for its implementation<sup>(\*)</sup>;
6. Election of the Bureau of IBC<sup>(\*)</sup>;
7. Closure of the Eleventh Session of IBC.

\*

Items 52 and 6 will be dealt with during meetings reserved for the members of the IBC.



United Nations Educational, Scientific and Cultural Organisation  
Organisation des Nations Unies pour l'éducation, la science et la culture



*International Bioethics  
Committee (IBC)*

*Comité international  
de bioéthique (CIB)*

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## **Elaboration of the Declaration on Universal Norms on Bioethics : Second Outline of a Text**

This second version of an outline of a declaration on universal norms on bioethics has been elaborated by the Drafting Group for consideration by the International Bioethics Committee (IBC) at its Eleventh Session (Paris, 23-24 August 2004).

It was revised following a preliminary review by the IBC Drafting Group at its third meeting (Paris, 8-9 July 2004), taking into consideration the observations formulated during the information meeting of the Intergovernmental Bioethics Committee (IGBC) (Paris, 7 July 2004) and the third meeting of the UN Interagency Committee on Bioethics (Paris, 24-25 June 2004).



# **Declaration on Universal Norms on Bioethics**

***or***

## **Universal Declaration on Bioethics and Humanity [Humankind / Human Beings]<sup>\*</sup>**

*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,

Also recalling 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 1997 and entered into force in 1999, as well as the other international and regional instruments, national legislation and regulations in the field of bioethics,

Also recalling the international and regional codes of conduct and guidelines and other ethical texts in the field of science and technology

Considering that, by virtue of its Constitution, it is incumbent upon UNESCO to promote “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 this constitutes a sacred duty which all the nations must fulfil in a spirit of mutual assistance,

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

Considering also that it is the mission of UNESCO to develop universal principles and norms based on shared values to guide scientific and technological development and social transformation, in order to meet emerging challenges in science 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 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 they have responsibilities and duties towards other forms of life,

Recognizing that scientific and technological developments have been of great benefit to humankind in increasing *inter alia* life expectancy and improving quality of life and emphasizing that such developments should always promote the welfare of individuals and humankind as a whole in the recognition of the inherent dignity of the human person and the universal respect for, and observance of human rights and fundamental freedoms,

Bearing in mind that, without prejudice to the universal respect for, and observance of human rights and fundamental freedoms, 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)

## **General Provisions**

### Scope

The principles set out in this Declaration:

- (i) apply to human beings, while recognizing that human beings have responsibilities and duties towards other forms of life in the biosphere, and
- (ii) apply to issues raised by scientific and technological developments and their applications, as well as their availability and access.

## Aims

The aims of this Declaration are:

- to provide a universal framework of fundamental 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 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 human rights law;
- to promote respect for biodiversity;
- to recognize the great benefit derived from scientific and technological developments, whilst ensuring that such development occurs within the framework of ethical principles that respect human dignity and protect human rights and fundamental freedoms, and to prevent practices contrary to human dignity;
- 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 promote the sharing and the greatest possible flow of knowledge concerning scientific and technological developments as well as the sharing of benefits, in particular with developing countries;
- to safeguard the interests of present and future generations.

## **General [Fundamental] Principles**

### Human Dignity, Human Rights and Justice

Bearing in mind that the principles set out in this Declaration derive [are drawn / flow] from the inherent dignity of the human person and the duty to promote universal respect for, and observance of human rights and fundamental freedoms, any decision or practice within the scope of this Declaration [to which this Declaration applies] shall be made or carried out in the respect of the inherent dignity of the human person, and in accordance with the universal principles of justice, human rights and fundamental freedoms.

### Responsibility for [towards] the Biosphere

Any decision or practice within the scope of this Declaration [to which this Declaration applies] 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.

### Beneficence

Any decision or practice within the scope of this Declaration [to which this Declaration applies] shall optimize the positive benefits and reduce the possible harms of such decision or practice.

### Cultural Diversity, Pluralism and Tolerance

Any decision or practice within the scope of this Declaration [to which this Declaration applies] 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 within the scope of this Declaration [to which this Declaration applies] shall be guided by 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.

## **Implication of the [Fundamental] General Principles**

Primacy of the human person

Non-discrimination and non stigmatization

Autonomy

Consent

Confidentiality and Right to Information

Benefit sharing

## **Specific Issues**

Scientific research

Research involving human subjects

Healthcare

Human Reproduction and the Beginning of Life

Reproductive human cloning

End of Life

Palliative care

Tissue and Organ Transplantation

Genetic and other Personal Healthcare Data

Germ-line interventions

Sex Selection

Pharmacogenetics

Non-commercialization of the human body and its parts

Generic drugs

Right to healthy food

Right to a healthy environment

## **Procedures [Procedural Principles]**

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**

Bioethics education, training and information

a) In order to promote the principles set out in this Declaration and to achieve a better understanding of the ethical implications of scientific and technological developments, States should endeavour to foster all forms of bioethics education and training at all levels as well as to encourage information and knowledge dissemination programmes about bioethics. These measures should aim at specific audiences, in particular researchers and members of ethics committees, or be addressed to the public at large.

b) States should encourage the participation of international and regional intergovernmental organizations and international, regional and national non-governmental organizations in this endeavour.

Solidarity and International Cooperation

a) States should respect and promote solidarity towards individuals, families, populations and groups, with special regard for those rendered vulnerable by health or other personal, societal or environmental conditions and those with the most limited resources.

b) States should foster the international dissemination of scientific information and make every effort to guarantee the free flow and sharing of scientific and technological knowledge [namely throughout the creation of research and education structures in the developing countries as well as the transfer of technology].

c) In the framework of international cooperation, States should promote cultural and scientific cooperation, endeavouring to enter into bilateral and multilateral agreements enabling developing countries to build up their capacity to participate in generating and sharing scientific knowledge and of the related know-how.

#### Role of States

States should take all appropriate measures, whether of a legislative, administrative or other character, to give effect to the principles set out in this Declaration, in accordance with international human rights law. Such measures should be supported by action in the sphere of education, training and public information.

#### Roles of the International Bioethics Committee (IBC) and the Intergovernmental Bioethics Committee (IGBC)

a) The International Bioethics Committee (IBC) and the Intergovernmental Bioethics Committee (IGBC) shall contribute to the implementation of this Declaration and the dissemination of the principles set out therein. On a collaborative basis, the two Committees should be responsible for its monitoring and for the evaluation of its implementation, in particular on the basis of reports provided by States. The two Committees should be responsible in particular for the formulation of any opinion or proposal likely to further the effectiveness of this Declaration. They should make recommendations in accordance with UNESCO's statutory procedures, addressed to the General Conference.

b) Reports provided by States will be addressed every two years to the International Bioethics Committee, which, after having examined them, will give its advice following the statutory procedures of UNESCO. After having examined the advice of IBC and the reports provided by States, the Intergovernmental Bioethics Committee will submit its opinion to the Director-General for transmission, together with the advice and recommendations of IBC, to the Member States, the Executive Board and the General Conference.

#### Follow-up action by UNESCO

a) UNESCO shall take appropriate action to follow up this Declaration so as to foster progress of the life sciences and their applications through technologies, based on respect for human dignity and the exercise and observance of human rights and fundamental freedoms.

b) UNESCO shall reaffirm its commitment to dealing with all aspects of the biosphere and, if necessary, shall elaborate guidelines and international instruments, as appropriate, on ethical principles related to the environment and other living organisms.

c) Five year after its adoption [*and thereafter on a periodical basis*], UNESCO shall take appropriate measures to examine the Declaration in the light of scientific and technological development and, if necessary, to ensure its revision, in accordance with UNESCO's statutory procedures.

#### Denial of acts contrary to human rights, fundamental freedoms and human dignity

Nothing in this Declaration may be interpreted as implying for any States, group or person any claim to engage in any activity or to perform any act contrary to human rights, fundamental freedoms and human dignity, including, in particular, the principles set out in this Declaration.