



united nations educational, scientific and cultural organization
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référence : CL/3756

Subject: **Second session of the intergovernmental meeting of experts aimed at finalizing a draft of a declaration on universal norms on bioethics**
(UNESCO Headquarters, 20-24 June 2005)

Sir/Madam,

As you are aware, by Decision 3.5.1, adopted at its 170th session, the Executive Board invited me to convene intergovernmental meetings of experts (category II) aimed at finalizing a draft of a declaration on universal norms on bioethics.

The first meeting was held at UNESCO Headquarters from 4 to 6 April last. On this occasion, governmental experts recognized the complexity of the subject dealt with as well as the need for further discussions to be held among Member States. They also expressed the wish that all resources and time necessary be made available at the June 2005 meeting.

At its 171st session, after having examined the progress report I presented on this matter and having taken note of the results of the intergovernmental meeting, the Executive Board considered that, at the June 2005 meeting, the governmental experts should prepare and present a draft to me with a view to its transmission to the General Conference of UNESCO at its 33rd session in October 2005.

I accordingly have pleasure in inviting your Government to designate one or more representatives to take part in the second session of the intergovernmental meeting of experts that will be held in Paris, **from 20 to 24 June 2005** at UNESCO Headquarters, in Room XI (Fontenoy Building, entrance: 7 place de Fontenoy, 75007 Paris) at 10 a.m. Simultaneous interpretation will be provided, in addition to English and French, in Arabic, Chinese, Spanish and Russian, thanks to extrabudgetary funds.

Please find enclosed the Agenda and the Rules of Procedure as adopted at the first meeting, the Preliminary Draft Declaration drawn up by the International Bioethics Committee (IBC), together with a copy of the Final Report of the first meeting and a registration form. The Secretariat will send you all other relevant documents in due course. All relevant documents will also be available, in the six above-mentioned languages, on the Internet (www.unesco.org/bioethics).

To Ministers responsible for relations with UNESCO

I should be grateful if you could return the enclosed registration form, duly completed for each participant, to Mr Henk ten Have, Director of the Division of Ethics of Science and Technology (1 rue Miollis, 75732 Paris Cedex 15, France; e-mail: s.colombo@unesco.org; tel.: +33 (0)1 45 68 38 03 / 44 28; fax: +33 (0)1 45 68 55 15), stating the name and title of the representative(s) of your Government, most preferably **before 15 June 2005**. As is customary for meetings of this category, the travel and living expenses of the participant(s) designated will be borne by the Government they represent.

All correspondence concerning this meeting and any request for further information should be addressed to the Division of Ethics of Science and Technology at the address indicated above.

Please accept, Sir/Madam, the assurances of my highest consideration.

Koïchiro Matsuura
Director-General

Enclosures: 5

1. Agenda
2. Rules of Procedure
3. Preliminary Draft of a Declaration on Universal Norms on Bioethics
4. Report of the first intergovernmental meeting
5. Registration Form

cc: Permanent Delegations to UNESCO
National Commissions for UNESCO



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

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SHS/EST/05/CONF.204/1
Paris, 4 May 2005
Original: English / French

Second Session of the Intergovernmental Meeting of Experts Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics

UNESCO Headquarters, 20-24 June 2005
(Room XI, Fontenoy building)

AGENDA

(As adopted at the first intergovernmental meeting of experts on 4 April 2005)

1. Opening of the meeting
2. Election of the Chairperson *
3. Adoption of the Agenda *
4. Adoption of the Rules of Procedure *
5. Election of the Vice-Chairpersons and the Rapporteur *
6. Introductory statement by the Secretariat concerning the objectives of the meeting and the working documents **
7. Presentation of the preliminary draft of a declaration on universal norms on bioethics *
8. Discussion on the preliminary draft of a declaration on universal norms on bioethics (preamble and operative part) **
9. Establishment of a drafting group *
10. Results of the work of the governmental experts and adoption of the recommendations of the meeting **
11. Adoption of the final report **
12. Close of the meeting

* Item concluded at the first meeting (Paris, 4-6 April 2004).

** Item carried over to the second session of the meeting, taking into account the open-ended intersessional consultations between States.



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Second Session of the Intergovernmental Meeting of Experts Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics

UNESCO Headquarters, 20-24 June 2005
(Room XI, Fontenoy building)

RULES OF PROCEDURE

(As adopted at the first intergovernmental meeting of experts on 4 April 2005)

I. PARTICIPATION

Rule 1 – Chief participants

Experts representing the governments of the Member States and Associate Members of UNESCO invited by the Director-General in accordance with the decision of the Executive Board of UNESCO (170 EX/Dec. 3.5.1) may participate in the Meeting with the right to vote.

Rule 2 – Observers

- 2.1 States not Members of UNESCO, but members of at least one other organization of the United Nations system, and Palestine, may participate in the Meeting as observers, without the right to vote.
- 2.2 The United Nations and other organizations of the United Nations system with which UNESCO has concluded mutual representation agreements may participate in the Meeting as observers, without the right to vote.
- 2.3 International intergovernmental and non-governmental organizations invited to the Meeting by the Director-General of UNESCO in accordance with the decision of the Executive Board (170 EX/Dec. 3.5.1) may participate in the Meeting as observers, without the right to vote.
- 2.4 Bodies which may contribute to the work of the Meeting, such as national ethics committees and concerned professional associations invited to the Meeting by the Director-General of UNESCO in accordance with the decision of the Executive Board (170 EX/Dec. 3.5.1) may send observers.
- 2.5 Subject to the provisions of Rule 9.3, representatives and observers may take part in the Meeting's discussions, but without the right to vote.

(SHS-2005/CONF.204/CLD.1)

II. ORGANIZATION OF THE WORK OF THE MEETING

Rule 3 – Agenda

- 3.1 The provisional agenda of the Meeting shall be established by the Director-General of UNESCO.
- 3.2 The Meeting shall adopt the agenda at the beginning of its first plenary meeting.

Rule 4 – Bureau

- 4.1 At the beginning of its first plenary meeting, the Meeting shall elect a Chairperson, four Vice-Chairpersons and a Rapporteur, who will constitute its Bureau.
- 4.2 The Bureau shall be responsible for co-ordinating the work of the Meeting and of its subsidiary bodies, for setting the dates, times and agendas of its meetings and in general for assisting the Chairperson in carrying out his/her duties.

Rule 5 – Duties of the Chairperson

- 5.1 In addition to exercising the powers which are conferred upon him/her under any other provisions of these Rules, the Chairperson shall open and close each plenary session of the Meeting. He/she shall direct the discussions, ensure observance of these Rules of Procedure, accord the right to speak, put questions to the vote and announce decisions. He/she shall rule on points of order and, subject to the present Rules, shall control the proceedings of each session and ensure the maintenance of order. He/she shall not vote, but may instruct another expert from his/her delegation to vote in his/her place.
- 5.2 If the Chairperson ceases to represent a chief participant or finds himself/herself unable to exercise his/her role, one of the Vice-Chairpersons shall take the chair until the end of the Meeting. If that Vice-Chairperson ceases in turn to represent a chief participant, one of the other Vice-Chairpersons shall take the chair until the end of the Meeting.
- 5.3 Should the Chairperson find it necessary to be absent during a session or any part thereof, his/her place shall be taken by one of the Vice-Chairpersons, who, acting as Chairperson, shall have the same power and duties as the Chairperson.
- 5.4 The Chairperson and the Vice-Chairperson of a subsidiary body of the Meeting shall have the same duties with regard to the body over which they are called upon to preside as the Chairperson and the Vice-Chairpersons.

Rule 6 – Subsidiary bodies

- 6.1 Subject to the availability of technical facilities, the Meeting may establish such subsidiary bodies as it deems necessary for the conduct of its work.
- 6.2 Any subsidiary body so established shall elect its Chairperson and Vice-Chairperson, and, if necessary, the Rapporteur.
- 6.3 These Rules of Procedures shall apply mutatis mutandis to the Chairperson and to the debates of the subsidiary bodies, unless otherwise decided by the Meeting.

III. CONDUCT OF BUSINESS

Rule 7 – Public character of meetings

All plenary sessions shall be held in public, unless the Meeting decides otherwise.

Rule 8 – Quorum

- 8.1 At plenary sessions, a majority of the chief participants attending the Meeting shall constitute a quorum.
- 8.2 At the meetings of the subsidiary bodies of the Meeting, the quorum shall be constituted by majority of chief participants in each subsidiary body.

Rule 9 – Order of speakers and time-limit on speeches

- 9.1 The Chairperson shall call upon participants in the order in which they signify their wish to speak.
- 9.2 To facilitate the conduct of business, the Chairperson may limit the time to be allowed to each speaker.
- 9.3 Observers referred to in Rule 2 may speak with the prior consent of the Chairperson.

Rule 10 – Points of order

- 10.1 In the course of a debate on any topic, a chief participant may raise a point of order, on which the Chairperson shall immediately give a ruling.
- 10.2 An appeal may be made against the ruling of the Chairperson. Such appeal shall be put to the vote immediately, and the Chairperson's ruling shall stand unless overruled by a majority of chief participants present and voting.

Rule 11 – Procedural motions

- 11.1 A chief participant may, at any time, move the suspension or adjournment of the session, or the adjournment or closure of the debate.
- 11.2 The motions referred to in Rule 11.1 shall be put to the vote immediately. Such motions shall have precedence in the following order:
 - (a) to suspend the session;
 - (b) to adjourn the session;
 - (c) to adjourn the debate on the item under discussion;
 - (d) to close the debate on the item under discussion.

Rule 12 – Working languages

- 12.1 The working languages of the Meeting shall be English and French.
- 12.2 Statements made to the Meeting in one of the working languages shall be interpreted into the other languages.
- 12.3 The documents of the Meeting shall be issued in English and French.

Rule 13 – Vote

- 13.1 Each Member State, invited as chief participant, shall have one vote in the Meeting and in the subsidiary bodies on which they are represented, whatever the number of its representatives.
- 13.2 Subject to the provisions of Rules 16 and 17, the decisions shall be taken by a simple majority of the chief participants present and voting. Nevertheless, in all matters, participants shall endeavour to take decisions by consensus.
- 13.3 For the purpose of these Rules, the expression 'chief participants present and voting' shall mean chief participants casting an affirmative or negative vote. Chief participants abstaining from voting shall be considered as not voting.
- 13.4 Voting shall normally be by show of hands.
- 13.5 When the result of a vote by show of hands is in doubt, the Chairperson may take a second vote, by roll-call. A vote by roll-call shall also be taken if it is requested by no fewer than two chief participants before the voting takes place. When a roll-call vote is taken, the vote or abstention of each chief participant shall be recorded in the report.
- 13.6 When an amendment to a proposal is moved, the amendment shall be voted on first. When two or more amendments to a proposal are moved, the Meeting shall first vote on the amendment deemed by the Chairperson to be furthest removed in substance from the original proposal. It shall then vote on the amendment deemed by the Chairperson to be next furthest removed therefrom, and so on until all the amendments have been put to the vote.
- 13.7 If one or more amendments are adopted, the amended proposal shall then be voted upon as a whole.
- 13.8 A motion is considered an amendment to a proposal if it merely adds to, deletes from or revises part of that proposal.
- 13.9 For all elections, the vote shall be conducted by secret ballot, unless the Meeting decides otherwise if no objection is made.
- 13.10 In the case of a tie in non-electoral votes, the motion shall be deemed rejected.

IV. SECRETARIAT OF THE MEETING

Rule 14 – Secretariat

- 14.1 The Director-General of UNESCO or his representatives shall participate in the work of the Meeting without the right to vote. He/she may at any time make either oral or written statements to the Meeting or to any of its subsidiary bodies on any question under consideration.
- 14.2 The Director-General of UNESCO shall appoint officials of UNESCO to constitute the Secretariat of the Meeting.
- 14.3 The Secretariat shall receive, translate and distribute all official documents of the Meeting and ensure the interpretation of the discussions, in accordance with the provisions of Rule 12 of these Rules of Procedure. It shall also perform any other duties necessary for the proper conduct of the work of the Meeting or of its subsidiary bodies.

V. ADOPTION AND AMENDMENT OF THE RULES OF PROCEDURE

Rule 15 – Adoption

The Meeting shall adopt its Rules of Procedure by a decision taken in plenary session by a simple majority of chief participants present and voting.

Rule 16 – Amendment

The Meeting may amend these Rules of Procedure by a decision taken in plenary session by a two-thirds majority of the chief participants present and voting.

Rule 17 – Suspension

The application of an article of these Rules of procedures can not be suspended except by a majority decision of two-thirds of the chief participants present and voting.



United Nations Educational, Scientific and Cultural Organization
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**Second Session of the Intergovernmental Meeting of Experts
Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics**

UNESCO Headquarters, 20-24 June 2005
(Room XI, Fontenoy building)

**Preliminary Draft Declaration
on Universal Norms on Bioethics**

This Preliminary Draft Declaration on Universal Norms on Bioethics was finalized by the International Bioethics Committee (IBC) at its Extraordinary Session on 28 January 2005 after six meetings of its Drafting Group held between April and December 2004, three sessions of IBC (April 2004, August 2004, January 2005), two written consultations (January-March 2004 and October-December 2004), numerous consultations at international, regional and national levels (including within the framework of the UN Interagency Committee on Bioethics), a session of the Intergovernmental Bioethics Committee (IGBC) and a joint session of IBC and IGBC (January 2005).

Division of Ethics of Science and Technology

PRELIMINARY DRAFT DECLARATION ON UNIVERSAL NORMS ON BIOETHICS

Recommended title:

Universal Declaration on Bioethics and Human Rights

The General Conference,

Reflecting on the rapid developments in science and technology, which increasingly affect our understanding of life and life itself, resulting in a strong demand for a global response to the ethical implications of such developments,

Conscious of the unique capacity of human beings to reflect upon their own existence and on their environment; to perceive injustice; to avoid danger; to assume responsibility; to seek cooperation and to exhibit the moral sense that gives expression to ethical principles,

Recognizing that ethical issues raised by the rapid advances in science and their technological applications should be examined with due respect to the inherent dignity of the human person and universal respect for, and observance of, human rights and fundamental freedoms,

Resolving that it is necessary and timely for the international community to state universal principles that will provide a foundation for humanity's response to the ever-increasing dilemmas and controversies that science and technology present for the human species and for the biosphere,

Recalling the Universal Declaration of Human Rights of 10 December 1948, 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 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 Standard Rules on the Equalization of Opportunities for Persons with Disabilities adopted by the United Nations General Assembly in 1993, the ILO Convention 169 concerning Indigenous and Tribal Peoples in Independent Countries of 27 June 1989, the International Treaty on Plant Genetic Resources for Food and Agriculture adopted by the FAO Conference on 3 November 2001 and entered into force on 29 June 2004, 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 other relevant international instruments adopted by the United Nations and the specialized agencies of the United Nations system, in particular the Food and Agriculture Organization of the United Nations (FAO) and the World Health Organization (WHO),

Bearing in mind international and regional instruments in the field of bioethics, including 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 national legislation and regulations in the field of bioethics and the international and regional codes of conduct and guidelines and other texts in the field of bioethics, 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, 1983, 1989, 1996 and 2000 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,

Considering that, by virtue of its Constitution, it is incumbent upon UNESCO to promote the democratic principles of the dignity, equality and respect of human beings and to reject any doctrine of inequality, and that this constitutes a duty which all nations must fulfil in a spirit of mutual assistance,

Considering also UNESCO's role in developing universal principles based on shared ethical values to guide scientific and technological development and social transformation, in order to identify emerging challenges in science and technology taking into account the responsibility of the present generation towards future generations, and that questions of bioethics, which necessarily have an international dimension, should be treated as a whole, drawing on the principles already stated in the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data, and taking account not only of the current scientific context but also of future developments,

Aware that human beings are an integral part of the biosphere and that they have responsibilities and duties towards each other and towards other forms of life,

Recognizing that scientific and technological developments have been, and can be, 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, families, groups or communities 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,

Recognizing that bioethical issues may have an impact on individuals, families, groups or communities and humankind as a whole,

Bearing in mind that cultural diversity, as a source of exchange, innovation and creativity, is necessary for humankind and, in this sense, is the common heritage of humanity, but emphasizing that it may not be invoked to contravene fundamental human rights and freedoms,

Convinced that ethical reflection should be an integral part of the process of scientific and technological developments and that bioethics should play today a predominant role in the choices that need to be made concerning issues arising from such developments,

Considering the need for a new approach to social responsibility to ensure, whenever possible, that progress in science and technology contributes to justice, equity and to the interest of humanity,

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

Proclaims the principles that follow and adopts the present Declaration.

GENERAL PROVISIONS

Article 1 – Use of Terms

For the purpose of this Declaration:

- (i) the term “bioethics” refers to the systematic, pluralistic and interdisciplinary study and resolution of ethical issues raised by medicine, life and social sciences as applied to human beings and their relationship with the biosphere, including issues related to the availability and accessibility of scientific and technological developments and their applications;
- (ii) the term “bioethical issues” refers to the issues mentioned in Article 1(i); and
- (iii) the term “decision or practice” refers to a decision or practice arising within the scope of this Declaration and involving bioethical issues.

Article 2 – Scope

The principles set out in this Declaration apply as appropriate and relevant:

- (i) to decisions or practices made or carried out in the application of medicine, life and social sciences to individuals, families, groups and communities; and
- (ii) to those who make such decisions or carry out such practices, whether they are individuals, professional groups, public or private institutions, corporations or States.

Article 3 – Aims

The aims of this Declaration are:

- (i) to provide a universal framework of fundamental principles and procedures to guide States in the formulation of their legislation and policies in the field of bioethics, and to form the basis for guidelines concerning bioethical issues for the individuals, groups and institutions concerned;
- (ii) to promote respect for human dignity and the protection and promotion of human rights and fundamental freedoms in any decision or practice involving bioethical issues, in accordance with international human rights law;
- (iii) to recognize the importance of freedom of scientific research and the benefits derived from scientific and technological developments, whilst ensuring that such developments occur within the framework of ethical principles that respect human dignity and protect human rights and fundamental freedoms;
- (iv) to foster multidisciplinary and pluralistic dialogue about bioethical issues between scientists, health professionals, lawyers, philosophers, ethicists, theologians and all the other intellectual, religious and professional groups concerned, policy makers, non-governmental organizations, representatives of civil society, the persons concerned and society as a whole;
- (v) to promote equitable access to medical, scientific and technological developments as well as the greatest possible flow and the rapid sharing of knowledge concerning those developments and the sharing of benefits, with particular attention to the needs of developing countries;
- (vi) to recognize the importance of biodiversity and the responsibilities of human beings towards other forms of life in the biosphere; and
- (vii) to safeguard and promote the interests of the present and future generations.

PRINCIPLES

Article 4 – Human Dignity and Human Rights

- a) Any decision or practice shall be made or carried out with full respect for the inherent dignity of the human person, human rights and fundamental freedoms;
- b) Any decision or practice shall respect the principle that the interests and welfare of the human person prevail over the sole interest of science or society.

Article 5 – Equality, Justice and Equity

Any decision or practice shall respect the fundamental equality of all human beings in dignity and rights and ensure that they are treated justly and equitably.

Article 6 – Benefit and Harm

Any decision or practice shall seek to benefit the person concerned and to minimize the possible harm resulting from that decision or practice.

Article 7 – Respect for Cultural Diversity and Pluralism

Any decision or practice shall take into account the cultural backgrounds, schools of thought, value systems, traditions, religious and spiritual beliefs and other relevant features of society. However, such considerations shall not be invoked to infringe upon human dignity, human rights and fundamental freedoms nor upon the principles set out in this Declaration, nor to limit their scope.

Article 8 – Non-Discrimination and Non-Stigmatization

In any decision or practice, no one shall be subjected to discrimination based on any grounds intended to infringe, or having the effect of infringing, the human dignity, human rights or fundamental freedoms of an individual, nor shall such grounds be used to stigmatize an individual, a family, a group or a community.

Article 9 – Autonomy and Individual Responsibility

Any decision or practice shall respect the autonomy of persons to make decisions and to take responsibility for those decisions while respecting the autonomy of others.

Article 10 – Informed Consent

- a) Any decision or practice in the field of scientific research shall only be made or carried out with the prior, free, informed and express consent of the persons concerned. Such consent may be withdrawn by the person concerned at any time and for any reason without any disadvantage or penalty.
- b) Any decision or practice regarding the medical diagnosis and treatment of a person shall only be made or carried out with the consent of the person concerned, based on information appropriate to the decision, and with the ongoing participation of such person.
- c) In any decision or practice involving persons who do not have the capacity to consent, special protection shall be given to such persons. Such protection shall be based on ethical and legal standards adopted by States, consistent with the principles set out in this Declaration.

Article 11 – Privacy and Confidentiality

Any decision or practice shall be made or carried out with respect for the privacy of the persons concerned and the confidentiality of their personal information. Unless irretrievably unlinked to an identifiable person, such information shall not be used or disclosed for purposes other than those for which it was collected.

Article 12 – Solidarity and Cooperation

Any decision or practice shall pay due regard to solidarity among human beings and encourage international cooperation to that end.

Article 13 – Social Responsibility

Any decision or practice shall ensure that progress in science and technology contributes, wherever possible, to the common good, including in the achievement of goals such as:

- (i) access to quality health care and essential medicines, including for reproductive health and the health of children;
- (ii) access to adequate nutrition and water;
- (iii) improvement of living conditions and the environment;
- (iv) elimination of the marginalization and the exclusion of persons on the basis of any grounds; and
- (v) reduction of poverty and illiteracy.

Article 14 – Sharing of Benefits

a) Benefits resulting from scientific research and its applications shall be shared with society as a whole and within the international community, in particular with developing countries. In giving effect to this principle, benefits may take any of the following forms:

- (i) special and sustainable assistance to the persons and groups that have taken part in the research;
- (ii) access to quality health care;
- (iii) provision of new diagnostics, facilities for new treatments or medical products stemming from the research;
- (iv) support for health services;
- (v) access to scientific and technological knowledge;
- (vi) capacity-building facilities for research purposes; and
- (vii) any other form consistent with the principles set out in this Declaration.

b) This provision may be implemented through legislation, international agreements or by other appropriate means, which shall be consistent in every case with international human rights law.

Article 15 – Responsibility towards the Biosphere

Any decision or practice shall have regard to its impact on all forms of life and their interconnections and to the special responsibility of human beings for the protection of the environment, biodiversity and the biosphere.

CONDITIONS FOR IMPLEMENTATION

Article 16 – Decision-Making

Any decision or practice should:

- (i) be made or carried out following full and free discussion and in accordance with fair procedures;
- (ii) be made or carried out on the best available scientific evidence and methodology;
- (iii) pay due regard to any different information on the subject reasonably available to the decision-maker;
- (iv) be considered rigorously and based on the principles set out in this Declaration;
- (v) observe, when appropriate, proper procedures of risk assessment, management and prevention; and
- (vi) be considered individually, having regard to the circumstances of the persons, groups and communities concerned.

Article 17 – Honesty and Integrity

Any decision or practice should be made or carried out with:

- (i) professionalism, honesty and integrity;
- (ii) declaration of all conflicts of interest; and
- (iii) due regard to the need to share knowledge about such decisions and practices with the persons affected, the scientific community, relevant bodies and civil society.

Article 18 – Transparency

Any decision or practice should, subject to the provisions on privacy and confidentiality in Article 11:

- (i) be made or carried out transparently and openly;
- (ii) be available for appropriate scrutiny by the persons concerned and by civil society; and
- (iii) be susceptible to informed, wide and pluralistic public debate.

Article 19 – Periodic Review

Any decision or practice, including those depending upon specialized scientific or other knowledge, should take into account the need to reconsider periodically the state of such knowledge and different opinions about it and the need to engage in a regular dialogue with:

- (i) persons affected by any such decision or practice;
- (ii) members of relevant disciplines;
- (iii) appropriate bodies; and
- (iv) civil society.

Article 20 – Ethics Committees

Independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level in order to:

- (i) assess the ethical, legal and social issues related to scientific research projects involving human beings;
- (ii) formulate recommendations and contribute to the preparation of guidelines on issues within the scope of this Declaration, in accordance with the principles set out herein; and
- (iii) foster debate and education in bioethics.

Article 21 – Promoting Public Debate

States should promote opportunities for informed, pluralistic public debate, ensuring the participation of all persons and bodies concerned, including relevant ethics committees and non-governmental organizations, and the expression of various socio-cultural, religious, philosophical and other relevant opinions.

Article 22 – Risk Assessment, Management and Prevention

- a) When evidence of serious or irreversible damage to public health or human welfare becomes available, appropriate measures should be taken in a timely manner.
- b) When there are threats of serious or irreversible damage to public health or human welfare, and there is not yet scientific certainty about such threats, provisional, adequate and proportionate measures should be taken in a timely manner. Such measures should be based on the best scientific knowledge available and on procedures that are specially designed for evaluating the ethical issues at stake. These measures should be carried out in accordance with the principles set out in this Declaration and with respect for human dignity, human rights and fundamental freedoms.

Article 23 – Transnational Practices

- a) States should take appropriate measures to ensure that any activity with bioethical implications, which is undertaken in whole or in part in different States, complies with the principles of this Declaration. Public and private institutions and professionals associated with a transnational activity should also take all appropriate measures to achieve the same end.
- b) When research is carried out in one country and funded partially or wholly by sources from one or more other countries, such research should be subjected to ethical review in all of the countries involved. This review should be based on ethical and legal standards, consistent with the principles set out in this Declaration, adopted by the States concerned.

IMPLEMENTATION AND PROMOTION OF THE DECLARATION

Article 24 – Role of States

- a) 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 spheres of education, training and public information. States should also take appropriate measures to involve young people in these activities.

- b) States should encourage the establishment of independent, multidisciplinary and pluralist ethics committees, in accordance with Article 20.
- c) States should establish processes for the assessment, management and prevention of risks. Such processes should include the identification of the issues, the characterization of risks and benefits, the development of options, the implementation of the decisions and the monitoring of the results.

Article 25 – Bioethics Education, Training and Information

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

Article 26 – International Cooperation

- a) States should foster international dissemination of scientific information and encourage the free flow and sharing of scientific and technological knowledge.
- b) Within the framework of international cooperation, States should promote cultural and scientific cooperation and enter into bilateral and multilateral agreements enabling developing countries to build up their capacity to participate in generating and sharing scientific knowledge, the related know-how and the benefits thereof.
- c) States should respect and promote solidarity between and among States, as well as individuals, families, groups and communities, with special regard for those rendered vulnerable by disease or disability or other personal, societal or environmental conditions and those with the most limited resources.

Article 27 – 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 herein. 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, on the steps they have taken, whether of a legislative, administrative or other character, to give effect to this Declaration, should be addressed every five years to the Director-General of UNESCO.

Article 28 – Follow-up action by UNESCO

- a) UNESCO shall take appropriate action to follow up this Declaration by evaluating new developments in science and technology and their applications according to the principles set out herein.

- b) UNESCO shall reaffirm its commitment to dealing with the ethical aspects of the biosphere and, if necessary, shall endeavour to elaborate guidelines and international instruments, as appropriate, on ethical principles related to the environment and other living organisms.
- c) Five years after its adoption and thereafter on a periodical basis, UNESCO shall take appropriate measures to examine this Declaration in the light of scientific and technological development and, if necessary, to ensure its revision, in accordance with UNESCO's statutory procedures.
- d) With respect to the principles set forth herein, this Declaration may be further developed through international instruments adopted by the General Conference of UNESCO, in accordance with UNESCO's statutory procedures.

OPERATION OF THE PRINCIPLES AND DECLARATION

Article 29 – Interrelation and Complementarity of the Principles

In their interpretation and application, the principles set out in this Declaration are complementary and interrelated and each principle should be construed in the context of the other principles. Where there is conflict between the principles this should be resolved by balancing all those principles that are appropriate and relevant in the circumstances.

Article 30 – Restrictions on the Principles

No restrictions shall be placed on the principles set out in this Declaration other than those prescribed by law, and which are consistent with international human rights law and necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others.

Article 31 – Denial of acts contrary to human rights, fundamental freedoms and human dignity

Nothing in this Declaration may be interpreted as implying for any State, group or person any claim to engage in any activity or to perform any act contrary to human rights, fundamental freedoms and human dignity.



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

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**First Intergovernmental Meeting of Experts
Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics**

UNESCO Headquarters, 4-6 April 2005
(Room XI, Fontenoy building)

Final Report

Division of Ethics of Science and Technology

I. INTRODUCTION

1. In accordance with the Timetable for the elaboration of the declaration, approved by the Executive Board at its 169th Session (169 EX/Dec. 3.6.2), and in application of 170 EX/Decision 3.5.1 adopted by the Executive Board at its 170th Session, the first intergovernmental meeting of experts (Category II) aimed at finalizing a draft declaration on universal norms on bioethics took place at UNESCO Headquarters in Paris, from 4 to 6 April 2005.

2. Government experts from the following 75 Member States participated in the meeting with the right to vote: Afghanistan, Algeria, Andorra, Angola, Argentina, Australia, Austria, Belgium, Benin, Bolivia, Brazil, Burkina Faso, Canada, Chile, China (People's Republic of), Cyprus, Colombia, Costa Rica, Croatia, Czech Republic, Ecuador, Egypt, El Salvador, Finland, France, Gabon, Germany, Greece, Grenada, Guatemala, Honduras, Iceland, India, Indonesia, Italy, Japan, Kazakhstan, Kenya, Lebanon, Libyan Arab Jamahiriya, Lithuania, Luxembourg, Madagascar, Malawi, Mexico, Monaco, Niger, Norway, Peru, Philippines, Poland, Portugal, Republic of Korea, Romania, Russian Federation, Saint Lucia, Saint Vincent and the Grenadines, Saudi Arabia, Senegal, Slovakia, South Africa, Switzerland, Syrian Arab Republic, Netherlands, Tunisia, Turkey, Uganda, Ukraine, United Arab Emirates, United Kingdom, United Republic of Tanzania, United States of America, Uruguay, Venezuela and Yemen.

3. Palestine and the Holy See participated in the meeting as observers. The Council of Europe, the World Trade Organization (WTO), the Organization for Economic Cooperation and Development (OECD) also sent representatives as observers and the following international non-governmental organizations also attended as observers: the World Medical Association (WMA), the International Social Science Council (ISSC), the World Academy of Biomedical Technologies (WABT), the World Federation of Scientific Workers (WFSW). Ms Michèle S. Jean, Chairperson of the International Bioethics Committee (IBC), attended the meeting as a resource person. The list of participants (SHS/EST/05/CONF.203/INF.3) is contained in Annex I of this report.

4. Before the meeting began, a minute of silence was observed in tribute to His Holiness Pope John-Paul II, deceased on Saturday 2 April 2005 and to His Serene Highness Prince Rainier III of Monaco, deceased on 6 April 2005. The meeting was opened by Mr Koïchiro Matsuura, Director-General of UNESCO, who briefly recalled the origins of the mandate entrusted by the General Conference at its 32nd session. The Director-General expressed his thanks to IBC, which had finalized the preliminary draft declaration in just one year. He underlined the transparent and participatory nature of the elaboration process which, following numerous consultations with all the actors concerned, had given rise to a text that provided a consensual basis for the work under way. The Director-General highlighted the connection between the first meeting and the second meeting, to be held in June 2005, thus leaving time for the internal consultations on the text needed to be able to complete the negotiations in June. The opening address of the Director-General is contained in Annex II (in French only).

5. After electing its Chairperson, H. E. Mr Pablo Sader (Uruguay), Ambassador of Uruguay to UNESCO, by consensus, the meeting then adopted its Agenda (SHS/EST/05/CONF.203/1), contained in Annex III, and its Rules of Procedure (SHS/EST/03/CONF.203/2).

6. In accordance with Article 4 of the Rules of Procedure, the meeting elected the members of its Bureau as follows:

Chairperson: Mr Pablo Sader (Uruguay);
Vice-Chairpersons: Mr Glenn Rivard (Canada);
Mr Umar Anggara Jenie (Indonesia);
Mrs Rima Vaitkiene (Lithuania);
Mr Ali Belhani (Tunisia)
Rapporteur: Mr Bindi Ouoba (Burkina Faso).

7. Having formed the Bureau, the Chairperson reminded the participants that this first meeting was part of a larger process that would be continued with the second meeting of government experts in June. The purpose of this first meeting was to give participants the opportunity to express different points of view, to identify major points of divergence and to determine those areas of the text where consensus seemed already to have been reached. While oral amendments would be accepted, States were asked to present their amendments in writing if possible to facilitate the work. The Chairperson also pointed out that the task of the Drafting Group, which was to be established in accordance with item 9 of the Agenda, would be one of drafting and not of negotiating.

II. PRELIMINARY PRESENTATION BY THE SECRETARIAT CONCERNING THE OBJECTIVES OF THE MEETING AND THE WORKING DOCUMENTS AND PRESENTATION OF THE PRELIMINARY DRAFT OF A DECLARATION ON UNIVERSAL NORMS ON BIOETHICS

8. Under item 6 of the Agenda, Mr Henk ten Have, Director of the Division of Ethics of Science and Technology, briefly presented the aims of the meeting and the working documents. He recalled that two meetings of government experts had been organized several months apart. This first meeting would allow for points of consensus and points of disagreement to be established in order to prepare the way for the second meeting in June and the finalization of a consensual draft declaration. The preliminary draft declaration drawn up by IBC was included in the documents provided to the participants of the meeting (see Annex IV). Mr ten Have pointed out that as the Director-General would be presenting a report on the elaboration of the declaration to the Executive Board at its 171st session two weeks after the present meeting, document 171 EX/13 which included the preliminary draft in an annex had been made available to all delegates in the six official languages of the Organization. The Draft Agenda (SHS/EST/05/CONF.203/1 (Prov.)), the Provisional Rules of Procedure of the meeting (SHS/EST/05/CONF.203/2 (Prov.)) and the Explanatory Memorandum on the Elaboration of the Preliminary Draft (SHS/EST/05/CONF.203/4) were also included in the documentation distributed to the participants.

9. Under item 7 of the Agenda, the Chairperson of the meeting invited Ms Michèle S. Jean, Chairperson of IBC, to present the preliminary draft declaration on universal norms on bioethics (SHS/EST/05/CONF.203/3). Mrs Jean briefly recalled the different drafting phases and pointed out that following the meetings in January 2005 with the Intergovernmental Bioethics Committee (IGBC), certain articles of the Preliminary Draft had been re-examined. The presentation by Ms Jean is contained in Annex V.

III. DISCUSSION ON THE PRELIMINARY DRAFT OF A DECLARATION ON UNIVERSAL NORMS ON BIOETHICS (PREAMBLE AND OPERATIVE PART)

10. Under Item 8 of the Agenda, the delegations presented their observations and comments on the preliminary draft declaration. At the suggestion of the Bureau, the delegates proceeded first of all with a presentation of general comments on the Preliminary Draft and an examination of the section on "General Provisions", and began an examination of the text article by article.

General comments

11. A number of speakers congratulated IBC for the work accomplished and for the quality of the preliminary draft. Considering the text to be well-balanced and having noted that clear improvements had been made following the consultations, particularly with IGBC, they felt that the preliminary draft constituted a solid basis for the work of the meeting. Nevertheless, some delegations expressed strong reservations with regard to the text of the preliminary draft, which did not necessarily reflect all the observations expressed by some States during the consultation process, especially developing countries.

12. The discussions dealt first of all with the scope of the declaration. Some participants said that the field of application of bioethics had been considerably extended in recent years; these participants also said that, although bioethics originally referred to ethical issues arising in the field of medicine and life sciences, over the past ten years it had gradually encompassed ethical issues associated with the environment and the biosphere; it had acquired a particularly strong social dimension, notably in developing countries.

13. Whilst this present broad field of application of bioethics was not questioned, divergences appeared with regard to the nature of the bioethical issues that should fall within the field of application of the declaration. Some wished to limit the scope of the declaration to bioethical issues related to medicine and the life sciences, at the same time expressing the wish that the text acknowledge the link between the human being and the biosphere. Others felt that the social dimension of bioethics should be at the heart of the future declaration, the principles of which should apply not only to so-called “emerging” issues, i.e. those linked to advances in science and the new technologies, but also to “persistent” issues, i.e. those linked to development, poverty, public health, access to treatment and health care, etc.

14. General comments were also expressed with regard to whom the declaration was intended, as this did not appear to be clearly defined. All agreed that the future declaration should aim to become a reference text in the field of bioethics for all the stakeholders concerned. There was a general agreement that the declaration was addressed in the first place to States. A distinction should be made with the other actors in order to define those responsible for and those who benefit from the principles set forth in the declaration.

15. Some speakers commented on the language used in the preliminary draft. With regard to the use of the words “shall” and “should”, some delegates considered that the non-binding nature of the declaration called for the use of this verb in the conditional form, since the text contained no formulation of an obligatory nature. Other delegates felt that the use of “shall” in a declaration only indicated the moral commitment of States without contesting the non-binding nature of the text. Others felt that if the provision dealt with an obligation or a right already defined in other international instruments adopted by States, the use of “shall” should be favoured, whereas, if a new obligation seemed to emerge, the use of the word “should” would allow for the nature of the declaration – where no new obligations can be created - to be respected.

16. Some delegations supported the deletion of the phrase “any decision or practice” which was considered too broad and imprecise. It was suggested that the provisions be reformulated and that the principles be stated in an impersonal manner. Other delegations supported retaining the original draft text and highlighted the importance of keeping the notion of “practice” throughout the text. As to questions of semantics, the delegates also wished to have a certain harmonization of the terms used, in particular with regard to the use of “human being” or “human person”.

Section on “General Provisions” (Articles 1 to 3)

17. Several States proposed amendments of a textual nature and of substance to this section. Nevertheless, the discussions showed that the examination of the provisions of this section were closely tied to the general discussions on the scope of the declaration. Divergent points of view were expressed with regard to the definition of bioethics and to the use of this term in the framework of the declaration and with regard to the field of application of the declaration. The meeting therefore wished to have a detailed discussion on the different perspectives of bioethics and on the way in which they could be reflected in the text.

18. Concerning more particularly Article 1 on the Use of Terms, speakers were unanimous in considering that working definitions for the purpose of the declaration were called for, rather than a theoretical definition of bioethics. Some even preferred to speak of a “description” of bioethics. Participants were reminded that the declaration should be a practical application and in no way

constitute an academic document. For some, the definition of bioethics should reflect the different concepts of bioethics expressed during the general debates. Others, faced with the difficulty of reaching an agreement on the definition, felt that these different perspectives should be brought out in the text and suggested that a definition of bioethics should not be sought.

19. Article 2 concerning the scope would need to be revised taking account of the debates being held on the field of application of the declaration. Some delegates also insisted that this provision clearly state to whom the declaration is addressed, making a distinction between the States and the other actors concerned, in accordance with the discussions held on the recipients of the text.

Section on “Principles” (Articles 4 to 10)

20. An exchange of views then took place on Articles 4 to 10 on the section on “Principles” and a number of proposed amendments were presented by States.

21. With regard to Article 4, all speakers recognized the importance of affirming human dignity, human rights and fundamental freedoms as a basic principle in the field of bioethics. Some delegates wished to include mention of the respect for human life, considering this to be the basis of human dignity and human rights. With regard to paragraph b) on the primacy of the human person, the discussion focused on the balance to be found between the interests of the individual and the interests of society. Some recalled that in accordance with Article 29 on the interrelation and complementarity of the principles, the primacy of the human person is bounded by the principles of justice and solidarity. Whilst some considered that the word “sole” constituted a balance in the formulation used, others preferred to delete the reference to society and to limit it to science. Several delegates emphasized the necessity of consistency in using terms like “human being” or “human person”. Some delegations expressed their preference for the use of the term “rights of the person” rather than “human rights” as used in the French version of Article 4. Nevertheless, they felt that this was a question of semantics that went beyond the mandate of the meeting.

22. Article 5 concerning equality, justice and equity was considered to be an Article of capital importance; particularly for developing countries. In this respect, some delegates insisted on the need to avoid double standards and to that end wished to add a reference to the right to health and access to essential medicines both in the developed and the developing countries. Others felt that that reference would be more appropriate in Articles 13 and 14 concerning social responsibility and sharing of benefits.

23. With regard to Article 6 on benefit and harm, some felt it was necessary to explain precisely that, in keeping with its origin, that principle applies to medicine and the life sciences. Others wished to introduce the idea of direct and indirect benefit to encompass all possible cases, for example drug research. Still others highlighted the importance of making explicit mention not only of persons but also of human groups as beneficiaries.

24. With regard to Article 7 on respect for cultural diversity and pluralism, everyone recognized the importance of that provision, in particular in a declaration drawn up in the framework of UNESCO. To make the text easier to read, some advocated the deletion of the list defining cultural diversity, while others on the contrary preferred to maintain it in order to make clear the factors that make up cultural diversity. In addition, some delegates wished to revise the last sentence of that provision, as it seemed to imply an opposition between respect for cultural diversity and respect for human rights, whereas respect for cultural diversity necessarily implies for human rights. Lastly, several delegates raised the issue of the position of that Article which could be grouped with Articles 6, 12 and 13, all of which deal with principles that apply to relations among human beings.

25. With regard to Article 8 on non-discrimination and non-stigmatization, emphasis was placed on the protection both of individuals and families, groups or communities. Some delegates called for the reintegration of the list of grounds for discrimination contained in the previous version of the

text in order to reinforce the principle. Furthermore, some insisted on making reference to situations of discrimination and stigmatization already existing in society so that this principle could also be applied to such situations. It was also proposed to clarify terminology, and to replace the terms “no one” and “individual” with “person”.

26. Article 10 concerning consent was considered by all as a key article of the declaration and gave rise to several questions. Some felt that that principles derived from the principle on autonomy and individual responsibility set out in Article 9 which seemed to be acceptable as it stood. Concerning the conditions for consent, some delegates wished to make explicit reference to domestic law, while others laid emphasis on Article 30 which already includes such a clause applicable to all the articles of the declaration. Comments were also made concerning exceptions to this principle. Some felt that in dealing only with people without capacity to consent, paragraph c) was too limited and preferred an explicit reference to mentally disabled people. The need to include specific high standards for the protection of persons not able to consent was also stressed. Similarly specific cases of emergency situations and collective consent could be dealt with explicitly. It was also proposed that wording on the options of withdrawing consent should be added. Others pointed out that a unanimous agreement existed on the general scope of the declaration which should set forth principles without entering into detail on the exceptions; these being already covered in a general manner by Article 30.

IV. WORK OF THE DRAFTING GROUP

27. In accordance with the Agenda, a drafting group was established. In order to ensure a fair geographical distribution, it was decided that the drafting group be composed of two Member States per region, leaving it open for other States to participate in the debates. The Member States of the drafting group were: Brazil, Croatia, France, India, Japan, Kenya, Lithuania, Mexico, Saudi Arabia, Senegal, Syria and the United States of America. The following States also participated in the drafting group as observers: Belgium, Bolivia, Burkina Faso, Canada, Germany, Luxembourg, The Netherlands and the United Kingdom.

28. The Group elected Mr Ousman Diop-Blondin, Representative of Senegal, Chairperson and Mr Christophe Valia-Kollery, Representative of France, Vice-Chairperson.

29. The task of the drafting group decided by the meeting in plenary consisted of revising the preliminary draft declaration on the basis of proposed written amendments presented by States and in the light of the debates held in plenary. The mandate was technical: on issues where consensus emerged, the group was to formulate a consensual proposal, on others, where disagreement persisted, alternative formulations could be proposed.

30. The drafting group met once, on Tuesday 5 April, after the afternoon plenary session. Nevertheless, given the content of the debates during the first two days, the group faced difficulties in carrying out its technical drafting task, because it became apparent that discussions of substance were still necessary. The group felt that to fulfil its mandate, it was preferable that the plenary meet again so that further in-depth discussions could be pursued, notably on the issue of the scope of the declaration.

V. RECOMMENDATIONS

31. The States represented at the first intergovernmental meeting of experts aimed at finalizing a draft declaration on universal norms on bioethics on the basis of the Preliminary Draft of the International Bioethics Committee:

1. *Recognize* the complexity of the subject dealt with and the value of the exchanges held during this first meeting and *note* that it is necessary for further discussions to be held among Member States on fundamental issues such as the scope of the future declaration, its recipients and the definition of bioethics;
2. *Aware* of the crucial role that the government experts play in the process of elaborating the declaration, *confirm* their willingness to engage in a constructive process of negotiation on the different positions expressed;
3. *Invite* the Chairperson of the meeting to encourage and to lead open-ended intersessional consultations between States on diverging views in order to prepare and facilitate the work of the second intergovernmental meeting of experts in June 2005 and, on these occasions, to play the role of facilitator between the different parties;
4. *Consider* it essential to have additional time at the June 2005 meeting, with the availability of documents and interpretation in all official languages of the Organization, to be able to attempt to finalize a draft declaration for the 33rd session of the General Conference in October 2005 and *express* their concern as to the availability of all material resources necessary for the conduct of their work under the best possible conditions.
5. *Thank* the Government of Italy for its generous financial offer with regard to the funding of the interpretation of the remaining official languages.
6. *Request* the Chairperson of the meeting to bring the above to the attention of the Director-General and of the Chair of the Executive Board.

VI. ADOPTION OF THE REPORT AND CLOSURE OF THE MEETING

32. The Rapporteur, Mr Bindi Ouoba (Burkina Faso), presented his draft report and highlighted the major lines of the discussions held in plenary and in the drafting group. He stated that the report would be finalized in the light of the final discussions of the last plenary session. Some delegations presented proposals for amendments and these have been taken into account in the finalization of the report.

**Première réunion intergouvernementale d'experts
destinée à mettre au point un projet de déclaration relative à
des normes universelles en matière de bioéthique**

Siège de l'UNESCO, 4 – 6 avril 2005
(salle XI, bâtiment Fontenoy)

**First Intergovernmental Meeting of Experts Aimed at
Finalizing a Draft of a Declaration on Universal Norms on Bioethics**

UNESCO Headquarters, 4 – 6 April 2005
(Room XI, Fontenoy building)

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**Discours de M. Koïchiro Matsuura,
Directeur général de l'UNESCO,
à l'ouverture de la Réunion intergouvernementale d'experts
destinée à mettre au point le projet de déclaration
relative à des normes universelles en matière de bioéthique**

UNESCO, le 4 avril 2005

Excellences,
Mesdames, Messieurs
[Minute de silence d'hommage au Pape]

C'est avec une profonde émotion que j'ai appris la disparition du pape Jean-Paul II, un guide spirituel qui a mis son énergie peu commune, son charisme et ses talents d'orateur au service de la paix et du dialogue inter-religieux.

Dans le communiqué de presse que j'ai publié aussitôt, j'ai rappelé les temps forts de l'action du pape Jean-Paul II en faveur du dialogue inter-religieux, dont il avait fait une des priorités de son pontificat et auquel l'UNESCO est si attachée. Les relations du pape avec l'UNESCO ont donc été marquées par cette détermination. En juin 1980, ici même, il a prononcé un discours qui a fait date. Il fut aussi un ardent messenger de paix : au-delà de la communauté catholique, c'est donc le monde entier qui rend hommage à cet homme qui restera l'une des grandes figures de notre époque.

Permettez-moi de souhaiter la bienvenue à tous les experts réunis dans cette enceinte pour participer aux débats sur le projet de déclaration relative à des normes universelles en matière de bioéthique.

Je souhaite tout d'abord remercier très vivement les délégations des pays de langue espagnole du GRULAC pour leur contribution financière tout à fait exceptionnelle qui permettra, tout au long de ces journées, une interprétation passive en espagnol.

Je ne peux que me réjouir de constater à quel point les Etats membres, qui ont été à l'origine du processus d'élaboration de cette Déclaration, en me demandant, lors de la Conférence générale d'octobre 2001, par la résolution 31C/22, d'étudier la possibilité d'élaborer des normes universelles sur la bioéthique, ont suivi avec attention l'évolution de ce texte, qui est au cœur des préoccupations de la communauté internationale, et nous invite à réfléchir ensemble sur des principes fondamentaux qui touchent à l'essence même de la vie.

Je suis également heureux de constater que nous sommes à présent en mesure de mieux répondre à l'attente des Ministres de la science, réunis eux aussi en octobre 2001 à l'occasion d'une table ronde sur les enjeux internationaux de la bioéthique au Siège de l'UNESCO, qui avaient alors rappelé « l'inaliénable primauté du respect de la dignité, de l'intégrité et de la liberté de la personne humaine », et invité l'UNESCO « à examiner la possibilité d'élaborer, en prenant comme point de départ la Déclaration universelle sur le génome humain et les droits de l'homme, un instrument universel sur la bioéthique ».

Tout au long de ces dernières cinq années, il est remarquable que nous ayons ainsi su réunir les conditions de travail, d'écoute et de dialogue aptes à répondre à cette demande pressante de la communauté internationale, et que nous puissions ainsi vous présenter aujourd'hui un premier projet de déclaration, conformément à la résolution 32C/24, adoptée lors de la 32^{ème} Conférence générale, en octobre 2003.

Comme vous le savez, c'est tout naturellement au Comité international de bioéthique (CIB), dont les compétences, la sagacité et l'intégrité sont unanimement reconnues, que j'ai demandé d'engager le processus de consultation et de rédaction, dans le cadre d'un calendrier rigoureux approuvé par le Conseil exécutif lors de sa 169^e session, en avril 2004. Respectant scrupuleusement les délais impartis, le CIB m'a transmis il y a un mois, après un an de travail intensif, six réunions de son Groupe de rédaction et de nombreuses consultations, un Avant-projet de déclaration.

Je saisis cette occasion pour adresser de nouveau mes plus sincères remerciements à Madame Michèle Jean, Présidente du CIB, et à M. Michael Kirby, Président du Groupe de rédaction du CIB. Ils ont joué un rôle décisif pour parvenir avec les experts consultés à un texte consensuel, que les membres du Comité intergouvernemental de bioéthique (CIGB) ont, pour leur part, considéré comme une excellente base pour les négociations gouvernementales à venir. De fait, je crois que la qualité du texte qui présenté aujourd'hui repose en grande partie sur le caractère ouvert, pluraliste, transparent et participatif des discussions qui ont accompagné son élaboration.

Je tiens à rappeler que les Etats, les premiers, ont été consultés par écrit à deux reprises au cours de l'année 2004 sur la portée et la structure du futur instrument. Puis ce sont les organisations intergouvernementales, les organisations non gouvernementales ainsi que les comités nationaux de bioéthique qui ont été entendus lors d'auditions organisées dans le cadre d'une session extraordinaire du CIB en avril 2004 puis d'une consultation écrite. Le Comité interinstitutions des Nations Unies sur la bioéthique, pour sa part, a attentivement suivi et discuté les travaux du CIB, dont il a pu rencontrer les membres du Groupe de rédaction en décembre dernier.

Par ailleurs, une grande attention a été accordée aux remarques et suggestions du CIGB, dont la dernière session ordinaire, en janvier dernier, a été très utilement suivie d'une session conjointe avec le CIB. Je veux également rappeler combien ont été utiles les conférences itinérantes, organisées tout au long de l'année passée par l'UNESCO dans les différentes régions du monde, pour susciter la constitution d'un espace élargi d'échange et de discussion sur les thèmes abordés par le projet de déclaration. Enfin, il est important de rappeler que le CIB a pu bénéficier de remarques et commentaires multiples sur les différentes versions du texte tout long du processus de consultation, grâce à une mise en ligne sur l'Internet qui a permis de rendre public au jour le jour les résultats de chaque réunion ou consultation tenue.

Au total, je crois pouvoir dire que l'UNESCO a réussi à maintenir un dialogue d'une grande qualité entre organisations gouvernementales et non gouvernementales, membres du CIB et du CIGB, membres du Comité interinstitutions et représentants de la société civile. Je m'en réjouis très vivement, car c'est là une preuve importante de la capacité de l'UNESCO à entretenir un dialogue structuré, cohérent et participatif en matière de bioéthique avec ses nombreux partenaires.

Mesdames et Messieurs,

La communauté internationale a ressenti le besoin de se doter aujourd'hui d'un cadre universel en matière de normes et de principes en bioéthique, tout en inscrivant celui-ci dans un rapport évolutif aux avancées des sciences et des technologies.

Ce texte n'a donc pas pour ambition de résoudre toutes les questions de bioéthique, mais bien plutôt d'offrir des principes directeurs à l'usage des individus, groupes et institutions concernées, tout en guidant les États dans la formulation de législations et de politiques en matière de bioéthique. C'est donc un texte à visée normative et prospective à la fois, qui devrait permettre d'envisager, grâce à un socle de principes et procédures définies d'un commun accord, les contours possibles de la réflexion bioéthique au niveau international.

S'agissant de ces principes, je dois dire que l'Avant-projet a fait un réel effort de clarification en choisissant de définir les responsabilités de l'être humain, notamment vis-à-vis de la biosphère, tout en articulant son texte autour de principes fondamentaux tels que la dignité humaine et les droits de l'homme, le consentement éclairé, l'autonomie, la responsabilité individuelle ou la confidentialité.

Plus encore, le projet a pris soin, dans le cadre d'une approche systémique, de mettre en corrélation quelques grands principes régissant les relations entre les êtres humains, tels que la solidarité, la coopération, l'équité, la justice, la diversité culturelle ou la responsabilité sociale. Cette dernière notion, bien accueillie lors des réunions du CIB et du CIGB en janvier dernier, apparaît tout particulièrement utile, car elle met en jeu, à travers les questions de l'accès à une alimentation, à un environnement ou à des systèmes de santé de qualité, le lien très fort qui unit l'interrogation éthique, la question du développement et le souci du bien-être des générations futures. La future déclaration ouvre ainsi des perspectives d'action qui dépassent largement la seule éthique médicale et réinsèrent la bioéthique dans le cadre d'une réflexion ouverte sur les questions de la lutte contre la pauvreté et du partage des bienfaits, en particulier à l'égard des pays en développement.

En prévoyant une révision périodique de la Déclaration, permettant d'intégrer des sujets ou principes nouveaux en fonction de l'état des connaissances scientifiques, l'Avant-projet montre une très haute conscience du besoin d'une telle ouverture aux questions de société. En ce sens, la Déclaration doit être regardée comme l'amorce d'une réglementation internationale, capable d'insérer dans son champ d'application, en temps voulu, des cadres pratiques et conceptuels utiles pour tous.

Je voudrais également souligner que si les Etats sont bien entendu les premiers responsables de la mise en œuvre des principes futurs de la Déclaration, l'application de ceux-ci, notamment la mise en œuvre spécifique des dispositions et réglementations de bioéthique au niveau national, repose d'abord et avant tout sur l'implication de tous les acteurs concernés. Je me réjouis donc de constater que le projet consacre une grande partie de ses articles à la promotion du débat public, aux politiques d'éducation et de formation, à la coopération internationale, ainsi qu'au suivi nécessaire de la mise en œuvre de la déclaration. Les recommandations très concrètes de l'Avant-projet, comme l'établissement de comités d'éthique indépendants, de programmes d'éducation en éthique ou de procédures d'évaluation et de prévention des risques, plaident ainsi en faveur d'un dialogue renouvelé entre scientifiques, décideurs et société civile, que l'UNESCO ne peut qu'encourager.

Mesdames et Messieurs,

Fort de l'expérience précédente liée à l'élaboration de la Déclaration universelle sur le génome humain et les droits de l'homme et la Déclaration internationale sur les données génétiques humaines, les Etats ont souhaité que deux réunions intergouvernementales d'experts soient organisées, la seconde devant se tenir du 21 au 23 juin prochain. Je souhaite naturellement que ces deux réunions puissent s'inscrire dans la continuité. Dès lors qu'ils auront identifié les points fondamentaux d'accord ou de divergence, les Etats auront ainsi de nouveau quelques mois pour mener les consultations internes nécessaires sur le texte et revenir en juin pour achever leurs négociations avant que je soumette le projet pour adoption à la prochaine session de Conférence générale, en octobre 2005.

Pour terminer, je voudrais appeler votre attention sur la recommandation des experts du CIB, proposant comme nouveau titre de la déclaration « Déclaration universelle sur la bioéthique et les droits de l'homme ». Je crois savoir que les opinions restent encore partagées sur ce sujet, il vous reviendra donc de trouver une base de consensus acceptable pour tous. Il m'apparaît cependant remarquable de constater que la mondialisation des questions d'éthique et la recherche de points de repères communs contribuent à mettre toujours plus l'accent sur la protection des droits de l'homme, de la dignité humaine et des libertés fondamentales, permettant ainsi de promouvoir une vision de l'humanité fondée sur l'intérêt et le bien-être de la personne humaine.

Il me reste à présent à vous souhaiter des journées de travail très fructueuses. Nous savons tous combien sont grandes les attentes de la communauté internationale sur ce sujet, je ne doute pas que vous aurez à cœur, avec toutes les compétences et qualités de négociation qui vous sont reconnues, de faire émerger, dans un climat constructif de confiance et respect mutuels, un texte de très grande qualité.

Je vous remercie de votre attention.

**First Intergovernmental Meeting of Experts
Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics**

UNESCO Headquarters, 4-6 April 2005
(Room XI, Fontenoy building)

Agenda

1. Opening of the meeting
2. Election of the Chairperson
3. Adoption of the Agenda
4. Adoption of the Rules of Procedure
5. Election of the Vice-Chairpersons and the Rapporteur
6. Introductory statement by the Secretariat concerning the objectives of the meeting and the working documents
7. Presentation of the preliminary draft of a declaration on universal norms on bioethics
8. Discussion on the preliminary draft of a declaration on universal norms on bioethics (preamble and operative part)
9. Establishment of a drafting group
10. Results of the work of the governmental experts and adoption of the recommendations of the meeting
11. Adoption of the final report
12. Close of the meeting

Preliminary Draft Declaration on Universal Norms on Bioethics

This Preliminary Draft Declaration on Universal Norms on Bioethics was finalized by the International Bioethics Committee (IBC) at its Extraordinary Session on 28 January 2005 after six meetings of its Drafting Group held between April and December 2004, three sessions of IBC (April 2004, August 2004, January 2005), two written consultations (January-March 2004 and October-December 2004), numerous consultations at international, regional and national levels (including within the framework of the UN Interagency Committee on Bioethics), a session of the Intergovernmental Bioethics Committee (IGBC) and a joint session of IBC and IGBC (January 2005).

Recommended title:

Universal Declaration on Bioethics and Human Rights

The General Conference,

Reflecting on the rapid developments in science and technology, which increasingly affect our understanding of life and life itself, resulting in a strong demand for a global response to the ethical implications of such developments,

Conscious of the unique capacity of human beings to reflect upon their own existence and on their environment; to perceive injustice; to avoid danger; to assume responsibility; to seek cooperation and to exhibit the moral sense that gives expression to ethical principles,

Recognizing that ethical issues raised by the rapid advances in science and their technological applications should be examined with due respect to the inherent dignity of the human person and universal respect for, and observance of, human rights and fundamental freedoms,

Resolving that it is necessary and timely for the international community to state universal principles that will provide a foundation for humanity's response to the ever-increasing dilemmas and controversies that science and technology present for the human species and for the biosphere,

Recalling the Universal Declaration of Human Rights of 10 December 1948, 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 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 Standard Rules on the Equalization of Opportunities for Persons with Disabilities adopted by the United Nations General Assembly in 1993, the ILO Convention 169 concerning Indigenous and Tribal Peoples in Independent Countries of 27 June 1989, the International Treaty on Plant Genetic Resources for Food and Agriculture adopted by the FAO Conference on 3 November 2001 and entered into force

on 29 June 2004, 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 other relevant international instruments adopted by the United Nations and the specialized agencies of the United Nations system, in particular the Food and Agriculture Organization of the United Nations (FAO) and the World Health Organization (WHO),

Bearing in mind international and regional instruments in the field of bioethics, including 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 national legislation and regulations in the field of bioethics and the international and regional codes of conduct and guidelines and other texts in the field of bioethics, 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, 1983, 1989, 1996 and 2000 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,

Considering that, by virtue of its Constitution, it is incumbent upon UNESCO to promote the democratic principles of the dignity, equality and respect of human beings and to reject any doctrine of inequality, and that this constitutes a duty which all nations must fulfil in a spirit of mutual assistance,

Considering also UNESCO's role in developing universal principles based on shared ethical values to guide scientific and technological development and social transformation, in order to identify emerging challenges in science and technology taking into account the responsibility of the present generation towards future generations, and that questions of bioethics, which necessarily have an international dimension, should be treated as a whole, drawing on the principles already stated in the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data, and taking account not only of the current scientific context but also of future developments,

Aware that human beings are an integral part of the biosphere and that they have responsibilities and duties towards each other and towards other forms of life,

Recognizing that scientific and technological developments have been, and can be, 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, families, groups or communities 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,

Recognizing that bioethical issues may have an impact on individuals, families, groups or communities and humankind as a whole,

Bearing in mind that cultural diversity, as a source of exchange, innovation and creativity, is necessary for humankind and, in this sense, is the common heritage of humanity, but emphasizing that it may not be invoked to contravene fundamental human rights and freedoms,

Convinced that ethical reflection should be an integral part of the process of scientific and technological developments and that bioethics should play today a predominant role in the choices that need to be made concerning issues arising from such developments,

Considering the need for a new approach to social responsibility to ensure, whenever possible, that progress in science and technology contributes to justice, equity and to the interest of humanity,

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

Proclaims the principles that follow and adopts the present Declaration.

GENERAL PROVISIONS

Article 1 – Use of Terms

For the purpose of this Declaration:

- (i) the term “bioethics” refers to the systematic, pluralistic and interdisciplinary study and resolution of ethical issues raised by medicine, life and social sciences as applied to human beings and their relationship with the biosphere, including issues related to the availability and accessibility of scientific and technological developments and their applications;
- (ii) the term “bioethical issues” refers to the issues mentioned in Article 1(i); and
- (iii) the term “decision or practice” refers to a decision or practice arising within the scope of this Declaration and involving bioethical issues.

Article 2 – Scope

The principles set out in this Declaration apply as appropriate and relevant:

- (i) to decisions or practices made or carried out in the application of medicine, life and social sciences to individuals, families, groups and communities; and
- (ii) to those who make such decisions or carry out such practices, whether they are individuals, professional groups, public or private institutions, corporations or States.

Article 3 – Aims

The aims of this Declaration are:

- (i) to provide a universal framework of fundamental principles and procedures to guide States in the formulation of their legislation and policies in the field of bioethics, and to form the basis for guidelines concerning bioethical issues for the individuals, groups and institutions concerned;
- (ii) to promote respect for human dignity and the protection and promotion of human rights and fundamental freedoms in any decision or practice involving bioethical issues, in accordance with international human rights law;
- (iii) to recognize the importance of freedom of scientific research and the benefits derived from scientific and technological developments, whilst ensuring that such developments occur within the framework of ethical principles that respect human dignity and protect human rights and fundamental freedoms;
- (iv) to foster multidisciplinary and pluralistic dialogue about bioethical issues between scientists, health professionals, lawyers, philosophers, ethicists, theologians and all the other intellectual, religious and professional groups concerned, policy makers, non-governmental organizations, representatives of civil society, the persons concerned and society as a whole;

- (v) to promote equitable access to medical, scientific and technological developments as well as the greatest possible flow and the rapid sharing of knowledge concerning those developments and the sharing of benefits, with particular attention to the needs of developing countries;
- (vi) to recognize the importance of biodiversity and the responsibilities of human beings towards other forms of life in the biosphere; and
- (vii) to safeguard and promote the interests of the present and future generations.

PRINCIPLES

Article 4 – Human Dignity and Human Rights

- a) Any decision or practice shall be made or carried out with full respect for the inherent dignity of the human person, human rights and fundamental freedoms.
- b) Any decision or practice shall respect the principle that the interests and welfare of the human person prevail over the sole interest of science or society.

Article 5 – Equality, Justice and Equity

Any decision or practice shall respect the fundamental equality of all human beings in dignity and rights and ensure that they are treated justly and equitably.

Article 6 – Benefit and Harm

Any decision or practice shall seek to benefit the person concerned and to minimize the possible harm resulting from that decision or practice.

Article 7 – Respect for Cultural Diversity and Pluralism

Any decision or practice shall take into account the cultural backgrounds, schools of thought, value systems, traditions, religious and spiritual beliefs and other relevant features of society. However, such considerations shall not be invoked to infringe upon human dignity, human rights and fundamental freedoms nor upon the principles set out in this Declaration, nor to limit their scope.

Article 8 – Non-Discrimination and Non-Stigmatization

In any decision or practice, no one shall be subjected to discrimination based on any grounds intended to infringe, or having the effect of infringing, the human dignity, human rights or fundamental freedoms of an individual, nor shall such grounds be used to stigmatize an individual, a family, a group or a community.

Article 9 – Autonomy and Individual Responsibility

Any decision or practice shall respect the autonomy of persons to make decisions and to take responsibility for those decisions while respecting the autonomy of others.

Article 10 – Informed Consent

- a) Any decision or practice in the field of scientific research shall only be made or carried out with the prior, free, informed and express consent of the persons concerned. Such consent may be withdrawn by the person concerned at any time and for any reason without any disadvantage or penalty.
- b) Any decision or practice regarding the medical diagnosis and treatment of a person shall only be made or carried out with the consent of the person concerned, based on information appropriate to the decision, and with the ongoing participation of such person.

c) In any decision or practice involving persons who do not have the capacity to consent, special protection shall be given to such persons. Such protection shall be based on ethical and legal standards adopted by States, consistent with the principles set out in this Declaration.

Article 11 – Privacy and Confidentiality

Any decision or practice shall be made or carried out with respect for the privacy of the persons concerned and the confidentiality of their personal information. Unless irretrievably unlinked to an identifiable person, such information shall not be used or disclosed for purposes other than those for which it was collected.

Article 12 – Solidarity and Cooperation

Any decision or practice shall pay due regard to solidarity among human beings and encourage international cooperation to that end.

Article 13 – Social Responsibility

Any decision or practice shall ensure that progress in science and technology contributes, wherever possible, to the common good, including in the achievement of goals such as:

- (i) access to quality health care and essential medicines, including for reproductive health and the health of children;
- (ii) access to adequate nutrition and water;
- (iii) improvement of living conditions and the environment;
- (iv) elimination of the marginalization and the exclusion of persons on the basis of any grounds; and
- (v) reduction of poverty and illiteracy.

Article 14 – Sharing of Benefits

a) Benefits resulting from scientific research and its applications shall be shared with society as a whole and within the international community, in particular with developing countries. In giving effect to this principle, benefits may take any of the following forms:

- (i) special and sustainable assistance to the persons and groups that have taken part in the research;
- (ii) access to quality health care;
- (iii) provision of new diagnostics, facilities for new treatments or medical products stemming from the research;
- (iv) support for health services;
- (v) access to scientific and technological knowledge;
- (vi) capacity-building facilities for research purposes; and
- (vii) any other form consistent with the principles set out in this Declaration.

b) This provision may be implemented through legislation, international agreements or by other appropriate means, which shall be consistent in every case with international human rights law.

Article 15 – Responsibility towards the Biosphere

Any decision or practice shall have regard to its impact on all forms of life and their interconnections and to the special responsibility of human beings for the protection of the environment, biodiversity and the biosphere.

CONDITIONS FOR IMPLEMENTATION

Article 16 – Decision-Making

Any decision or practice should:

- (i) be made or carried out following full and free discussion and in accordance with fair procedures;
- (ii) be made or carried out on the best available scientific evidence and methodology;
- (iii) pay due regard to any different information on the subject reasonably available to the decision-maker;
- (iv) be considered rigorously and based on the principles set out in this Declaration;
- (v) observe, when appropriate, proper procedures of risk assessment, management and prevention; and
- (vi) be considered individually, having regard to the circumstances of the persons, groups and communities concerned.

Article 17 – Honesty and Integrity

Any decision or practice should be made or carried out with:

- (i) professionalism, honesty and integrity;
- (ii) declaration of all conflicts of interest; and
- (iii) due regard to the need to share knowledge about such decisions and practices with the persons affected, the scientific community, relevant bodies and civil society.

Article 18 – Transparency

Any decision or practice should, subject to the provisions on privacy and confidentiality in Article 11:

- (i) be made or carried out transparently and openly;
- (ii) be available for appropriate scrutiny by the persons concerned and by civil society; and
- (iii) be susceptible to informed, wide and pluralistic public debate.

Article 19 – Periodic Review

Any decision or practice, including those depending upon specialized scientific or other knowledge, should take into account the need to reconsider periodically the state of such knowledge and different opinions about it and the need to engage in a regular dialogue with:

- (i) persons affected by any such decision or practice;
- (ii) members of relevant disciplines;
- (iii) appropriate bodies; and
- (iv) civil society.

Article 20 – Ethics Committees

Independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level in order to:

- (i) assess the ethical, legal and social issues related to scientific research projects involving human beings;
- (ii) formulate recommendations and contribute to the preparation of guidelines on issues within the scope of this Declaration, in accordance with the principles set out herein; and
- (iii) foster debate and education in bioethics.

Article 21 – Promoting Public Debate

States should promote opportunities for informed, pluralistic public debate, ensuring the participation of all persons and bodies concerned, including relevant ethics committees and non-governmental organizations, and the expression of various socio-cultural, religious, philosophical and other relevant opinions.

Article 22 – Risk Assessment, Management and Prevention

- a) When evidence of serious or irreversible damage to public health or human welfare becomes available, appropriate measures should be taken in a timely manner.
- b) When there are threats of serious or irreversible damage to public health or human welfare, and there is not yet scientific certainty about such threats, provisional, adequate and proportionate measures should be taken in a timely manner. Such measures should be based on the best scientific knowledge available and on procedures that are specially designed for evaluating the ethical issues at stake. These measures should be carried out in accordance with the principles set out in this Declaration and with respect for human dignity, human rights and fundamental freedoms.

Article 23 – Transnational Practices

- a) States should take appropriate measures to ensure that any activity with bioethical implications, which is undertaken in whole or in part in different States, complies with the principles of this Declaration. Public and private institutions and professionals associated with a transnational activity should also take all appropriate measures to achieve the same end.
- b) When research is carried out in one country and funded partially or wholly by sources from one or more other countries, such research should be subjected to ethical review in all of the countries involved. This review should be based on ethical and legal standards, consistent with the principles set out in this Declaration, adopted by the States concerned.

IMPLEMENTATION AND PROMOTION OF THE DECLARATION

Article 24 – Role of States

- a) 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 spheres of education, training and public information. States should also take appropriate measures to involve young people in these activities.
- b) States should encourage the establishment of independent, multidisciplinary and pluralist ethics committees, in accordance with Article 20.

c) States should establish processes for the assessment, management and prevention of risks. Such processes should include the identification of the issues, the characterization of risks and benefits, the development of options, the implementation of the decisions and the monitoring of the results.

Article 25 – Bioethics Education, Training and Information

a) In order to implement and 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.

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

Article 26 – International Cooperation

a) States should foster international dissemination of scientific information and encourage the free flow and sharing of scientific and technological knowledge.

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

c) States should respect and promote solidarity between and among States, as well as individuals, families, groups and communities, with special regard for those rendered vulnerable by disease or disability or other personal, societal or environmental conditions and those with the most limited resources.

Article 27 – 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 herein. 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, on the steps they have taken, whether of a legislative, administrative or other character, to give effect to this Declaration, should be addressed every five years to the Director-General of UNESCO.

Article 28 – Follow-up action by UNESCO

a) UNESCO shall take appropriate action to follow up this Declaration by evaluating new developments in science and technology and their applications according to the principles set out herein.

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

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

d) With respect to the principles set forth herein, this Declaration may be further developed through international instruments adopted by the General Conference of UNESCO, in accordance with UNESCO's statutory procedures.

OPERATION OF THE PRINCIPLES AND DECLARATION

Article 29 – Interrelation and Complementarity of the Principles

In their interpretation and application, the principles set out in this Declaration are complementary and interrelated and each principle should be construed in the context of the other principles. Where there is conflict between the principles this should be resolved by balancing all those principles that are appropriate and relevant in the circumstances.

Article 30 – Restrictions on the Principles

No restrictions shall be placed on the principles set out in this Declaration other than those prescribed by law, and which are consistent with international human rights law and necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others.

Article 31 – Denial of acts contrary to human rights, fundamental freedoms and human dignity

Nothing in this Declaration may be interpreted as implying for any State, group or person any claim to engage in any activity or to perform any act contrary to human rights, fundamental freedoms and human dignity.

**Première réunion intergouvernementale d'experts destinée
à mettre au point un projet de déclaration relative à des
normes universelles en matière de bioéthique**
(Siège de l'UNESCO, 4-6 avril 2005)

Point 7 de l'ordre du jour
« Présentation de l'avant-projet d'une déclaration
relative à des normes universelles en matière de bioéthique »

par Mme Michèle S. Jean,
Présidente du CIB

Mesdames et Messieurs,

Je voudrais tout d'abord remercier le Directeur général de m'avoir invitée à participer à cette première réunion intergouvernementale d'experts destinée à mettre au point un projet de déclaration relative à des normes universelles en matière de bioéthique.

Ma tâche aujourd'hui, au titre du point 7 de l'ordre du jour, est de vous présenter l'Avant-projet de déclaration mis au point par le Comité international de bioéthique (CIB), que j'ai transmis au Directeur général en février dernier. J'espère par ailleurs pouvoir vous être utile tout au long de cette réunion en apportant si vous le souhaitez des éclaircissements sur certains points du texte qui vous paraîtraient obscurs, en vous livrant également le cas échéant le raisonnement suivi par le CIB lors de la rédaction de tel ou tel article, enfin en répondant à toute question que vous jugerez utile.

Le chemin qui nous a menés à l'Avant-projet de déclaration a été ardu mais passionnant. Au risque d'être répétitive pour tous ceux qui ont suivi le processus dès le début – et je sais que vous avez été nombreux à suivre nos travaux pas à pas –, permettez-moi tout d'abord de retracer très brièvement les différentes étapes qui nous ont conduits à ce texte.

I would like to recall that following the mandate given to the DG by the 31st session of the General Conference, he had asked the IBC to study the opportunity and the feasibility of producing a universal instrument on bioethics. The IBC produced this study in June 2003 which stated how such an instrument could contribute to the international efforts necessary to produce guiding ethical principles in matters related to scientific the actual scientific progresses. This study also dealt with certain bioethical topics susceptible of being included in such an instrument. Based on this study, in October 2003, the General Conference.

UNESCO for sure, could not engage by itself in such an endeavour. All the interested parties had to be involved. Thus, following the timetable approved by the executive council at his 169th session. Broad consultations and auditions have been engaged very soon in the process to ensure first, the participation of member states end also other specialized institutions of the United Nations system, other intergovernmental organizations, NGOS, appropriate national organizations and specialists in bioethics. The IBC wanted a transparent and participatory process that unfold as follow.

Plusieurs conférences itinérantes organisées dans une douzaine de pays tout au long du processus ont également permis de consulter des experts au niveau national et régional.

Le CIB a analysé tous les commentaires qui lui ont été fournis au fur et à mesure des consultations ainsi que les commentaires du Comité interinstitutions.

La semaine de réunion avec le CIGB a été particulièrement fructueuse et constructive et au sein du CIB nous avons tous beaucoup apprécié ce moment d'interaction. Je crois qu'on peut reconnaître aujourd'hui que la session conjointe entre les deux comités à ce stade du processus a véritablement constitué un pont entre les travaux du CIB et vos travaux aujourd'hui.

Chacune des moutures de la future déclaration a été rendue publique sur le site Internet de l'UNESCO, de même que toutes les réunions et consultations tenues, ce qui a permis au grand public de suivre au jour le jour l'état d'avancement des travaux.

On nous a dit que ce processus de préparation d'une déclaration est l'un des plus participatif qu'ait connu l'UNESCO dans la préparation d'un instrument international. De mon côté, j'ose croire que notre démarche a été une démarche d'éthique délibérative. Le CIB composé de 36 membres venant de culture et d'horizons professionnels différents a travaillé dans le respect des opinions exprimées et a cherché, avec le plus de rigueur possible, à en arriver à un texte consensuel mais significatif bien conscient de l'importance du mandat qui lui a été confié et des délais courts qui lui avaient été impartis.

On my behalf, I would like to repeat what I said during the first extraordinary session: I think that the process is as important as the result. In fact, this consultation has allowed us to be involved in an important communication and awareness raising strategy, a real deliberative ethics process. I think that the IBC with its 36 members coming from diversified cultures and professional background has worked with the respect of the opinions that have been expressed and has search, with honesty to arrive at a consensual, but substantial and meaningful text, being well aware of the importance of the task and of the short timeframe allocated to produce this draft.

Ladies en gentlemen,

I would now like to talk briefly about the text per se and to provide you with some explanations about our work leading to this preliminary draft which is the fifth version of the text. This version is very different from the first one following our willingness to take into consideration the comments that were made specially following the January meeting with the IGBC.

- The text contains 31 articles divided in six sections.

Avant de dérouler le texte, j'aimerais évoquer ici quelques points généraux qui me semblent importants pour bien comprendre le texte :

- 1) Prenant en considération les discussions tenues lors des premières consultations, le CIB a décidé, dans les délais impartis par la Conférence générale et dans le respect du champ de compétence des différentes organisations intergouvernementales, de focaliser la future déclaration sur **l'être humain** tout en accordant une certaine place à la biosphère, c'est-à-dire en reconnaissant la responsabilité particulière qui incombe aux êtres humains de protéger l'environnement, la biodiversité et la biosphère. Cette approche est ainsi le résultat d'un équilibre que le CIB a essayé de trouver entre ceux qui auraient souhaité un texte couvrant tous les aspects éthiques de la médecine et de l'environnement et ceux qui préféreraient dès le départ un texte plus ciblé sur les pratiques médicales et scientifiques.
- 2) Concernant les **sujets spécifiques**, le CIB a longuement débattu et des positions divergentes au sein même du Comité ont été exprimées entre ceux souhaitant inclure des sujets concrets, ceux préférant rester à un niveau général et d'autres enfin souhaitant au minimum traiter de la santé et de la recherche. Finalement, en raison des délais impartis et dans un souci de consensus, le CIB a estimé que la déclaration devait se situer à un niveau plus général en posant les grands principes en matière de bioéthique. Pour autant, le Comité a souhaité prévoir dans l'Avant-projet une révision périodique de la Déclaration, afin d'intégrer à

l'avenir des sujets sur lesquels un consensus pourrait émerger. De plus, l'Avant-projet laisse la porte ouverte à l'élaboration, sur la base des principes énoncés dans la Déclaration, de futurs instruments internationaux sur des sujets plus concrets.

- 3) Si les principes sont formulés de manière générale, la section « Application des principes et de la Déclaration » en constitue une grille de lecture. En effet, le CIB est d'avis que quand un problème éthique se pose, c'est généralement quand deux ou plusieurs principes éthiques entrent en conflit. Il est question alors de trouver un équilibre entre ceux-ci pour résoudre le conflit. Les principes doivent donc être considérés dans leur ensemble comme **complémentaires et interdépendants** : c'est l'idée qui est reflétée dans l'article sur « Interdépendance et complémentarité ». En outre, cette section comprend une disposition relative aux **exceptions**. Le CIB a choisi de pas aborder les exceptions dans chaque article mais de les traiter de manière globale dans un article commun.
- 4) Les principes ont été organisés selon une certaine **logique**, à savoir d'abord sont énoncés les principes relatifs à l'individu (articles 4 à 11) puis les principes qui se rapportent aux relations entre les êtres humains (articles 12 à 14) et enfin les principes concernant les relations de l'être humain avec les autres formes de vie et la biosphère (article 15). Il n'existe aucune hiérarchisation entre les principes dans la mesure où ceux-ci sont complémentaires et peuvent prévaloir l'un sur l'autre suivant les situations concrètes.
- 5) Tout au long du processus, le CIB a été à l'écoute des différentes approches de la bioéthique. En particulier, le Comité a tenu à refléter dans cette déclaration la place accordée à la **famille** et à la **communauté** dans certaines cultures. La déclaration reconnaît ainsi la dimension sociétale et collective des questions de bioéthique qui, dans certaines régions du monde, prime sur la dimension individuelle.
- 6) As far as the use of "**shall**" and "**should**" is concerned, after having listened the different positions on this matter during the January meetings, IBC decided to stick to its approach, i.e. to consider that the use of the word "shall" underlines the moral commitment without questioning the non-binding nature of the text. It seemed appropriate therefore to use the word "shall" only in the statement of the principles and in the implementation provisions addressed to UNESCO. I may recall here that the same approach was already adopted in the Universal Declaration on the Human Genome and Human Rights.
- 7) Lastly, a lot of comments were made requesting to clarify **to whom the declaration is addressed**. Whilst IBC agrees that States are the main responsible for the implementation of the declaration, IBC considers that the role of the declaration is to address all actors involved in bioethical decision or practice: individuals, professional groups, public or private institutions, corporations, States. Naturally, all provisions of the declaration do not apply to all these addresses at the same time. That is why we put "as appropriate and relevant" in the headline of the article 2 on the "Scope".

I will not go over the text article by article but touch on certain articles and mention some of the changes made following the January meeting with the IGBC.

Les définitions (article 1) : nous avons inclus une définition opérationnelle de la bioéthique, des questions de bioéthique et des décisions ou pratiques en matière de bioéthique. Je dis bien opérationnelle car il s'agit uniquement d'une définition sur laquelle nous nous sommes entendus aux fins de la déclaration. Comme vous le savez, il existe de multiples définitions de la bioéthique.

Beaucoup de commentaires sur les dispositions relatives à la **portée (article 2)** ont été formulés. Nous avons donc essayé de rendre cet article plus clair, plus bref et plus simple en le divisant en deux parties, la première (i) s'adressant à la mise en œuvre et à l'application des décisions et pratiques et la deuxième (ii) à ceux qui sont amenés à prendre ces décisions ou à mettre en œuvre ces pratiques.

Lors des réunions de janvier, beaucoup de participants ont souhaité que la déclaration fasse une référence explicite à la promotion de la **liberté de la recherche**. Certains avaient toutefois insisté pour inscrire la liberté de la recherche dans le cadre des principes éthiques qui respectent la dignité humaine et protègent les droits de l'homme et les libertés fondamentales. La liberté de la recherche figure désormais au niveau des objectifs (**article 3**).

Parmi les principes (articles 4 à 15 inclus), j'aimerais mentionner plus particulièrement celui relatif au **consentement éclairé (article 10)** dont la formulation a été revue suite aux réunions de janvier. Il se divise en trois parties, l'alinéa a) étant consacré aux conditions du consentement en cas de recherche scientifique, l'alinéa b) aux pratiques médicales, qui requièrent des conditions différentes, et l'alinéa c) aux personnes incapables. Il s'agit d'un des rares principes pour lequel nous sommes entrés un peu plus dans le détail tant le consentement éclairé est important dans le débat bioéthique.

Le principe sur la **responsabilité sociale (article 13)** constitue l'une des innovations majeures de l'Avant-projet. Il a été inclus suite à de nombreux commentaires recueillis dans le cadre des consultations régionales, à savoir que la bioéthique s'inscrivait dans un contexte social plus large que lors de la création du concept dans les années 70. Cet article permet de refléter le lien qui existe aujourd'hui entre la bioéthique et les problèmes mondiaux tels que l'accès à des soins de santé de qualité, la nutrition, l'eau potable, la pauvreté et l'analphabétisme. Nous avons été peut-être un peu « prétentieux » dans cet article mais n'est-ce pas comme cela qu'on avance?

La section sur les « **Conditions de mise en œuvre** » (**articles 16 à 23**) a été revue et allégée et les dispositions ont été articulées de manière plus cohérente. En particulier, **l'article 22 relatif à l'évaluation, la gestion et la prévention des risques** a certainement évolué et distingue désormais deux cas, celui où les risques sont connus et scientifiquement établis et ceux où il existe une menace de préjudice grave ou irréversible, sans pour autant qu'on ait encore de certitude scientifique.

Je sais que **l'article 23 sur les pratiques transnationales** est cher à beaucoup d'entre vous car il se fait l'écho de nombreuses situations où une activité scientifique implique plusieurs pays et prévoit que dans tous les cas, les principes de la déclaration doivent être respectés et appliqués. Cet article a la prétention par ailleurs de s'adresser non seulement aux Etats mais aussi aux autres acteurs concernés, les institutions publiques et privées et les professionnels associés à une activité transnationale.

Concernant la section sur la mise en œuvre des principes et de la Déclaration, le CIB souhaitait qu'un instrument relatif à la bioéthique appelle fermement l'attention sur l'importance de la **sensibilisation, de l'information, de l'éducation**, de la consultation et du débat public. Car, à quoi servirait un tel instrument sans une compréhension et une reconnaissance commune de l'importance de la vie humaine et de la responsabilité que nous avons tous de la rendre meilleure d'une façon démocratique et responsable.

Concernant la mise en œuvre par les Etats, outre les articles 24 et 26 relatifs respectivement au rôle des Etats et à la coopération internationale, **un mécanisme de rapports** a été prévu à **l'article 27 b)**. Le CIB a entendu et pris en compte les réserves exprimées par les Etats en janvier sur cette disposition. Le Comité, tout en estimant important de conserver ce mécanisme, a alors décidé de supprimer la référence au CIB et au CIGB dans l'examen de ces rapports et de laisser à la discrétion du Directeur général et des organes directeurs de l'Organisation le soin d'explorer les mécanismes les plus appropriés quant à la suite à donner à ces rapports. Nous pensons que la mise en place d'un tel mécanisme est capital pour la mise en œuvre de la déclaration et s'inscrit d'ailleurs dans la lignée de la Déclaration universelles sur le génome humain et les droits de l'homme et la Déclaration internationale sur les données génétiques humaines.

Je rappelle également que l'Avant-projet comporte un article substantiel sur **les activités de suivi de l'UNESCO (article 28)** dans lequel le CIB a souhaité réaffirmer l'importance de bien suivre les développements scientifiques et, au besoin, d'élaborer de nouveaux instruments concernant des questions spécifiques ou encore la biosphère.

Nous avons ensuite regroupé à la fin sous le titre d'**application des principes et de la déclaration** les articles concernant l'interdépendance et la complémentarité des principes, les restrictions aux principes et l'article sur l'exclusion d'actes contraires aux droits de l'homme, aux libertés fondamentales et à la dignité humaine (**articles 29-30-31**).

Finally, **the title**: IBC accepts the title set out in the resolution of the General Conference: *Declaration on universal norms on bioethics* but is more in favour of and therefore recommends: *Universal Declaration on Bioethics and Human Rights*. Thus, IBC stresses the importance of taking international human rights legislation as the essential framework and starting point for the development of bioethical principles, as was the case with the Universal Declaration on the Human Genome and Human Rights of UNESCO.



**Deuxième session de la réunion intergouvernementale d'experts
destinée à mettre au point un projet de déclaration relative à
des normes universelles en matière de bioéthique**

**Second session of the intergovernmental meeting of experts aimed
at finalizing a draft declaration on universal norms on bioethics**

(Siège de l'UNESCO, 20 – 24 juin 2005 / UNESCO Headquarters, 20-24 June 2005)
Salle XI / Room XI

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