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*International Bioethics
Committee (IBC)*

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de bioéthique (CIB)*

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**Second meeting of the IBC Drafting Group
for the Elaboration of a Declaration
on Universal Norms on Bioethics**

UNESCO Headquarters (Paris), 2-3 June 2004

Final Report

Division of Ethics of Science and Technology

I. INTRODUCTION

1. The Drafting Group of the International Bioethics Committee (IBC), entrusted with the elaboration of a declaration on universal norms on bioethics, held its second meeting at UNESCO Headquarters, Paris, on 2 and 3 June 2004 (List of participants Annex I). The Chairperson of IBC, Mrs Michèle S. Jean, recalled that the Drafting Group had agreed to confer its presidency on Mr Michael Kirby and that the composition of the Group, for the time being restricted, will be enlarged to include other members of IBC as the text is elaborated.
2. Mr Michael Kirby, President of the Drafting Group, welcomed the participants and presented the apologies of Mr Donald Evans, Mrs Nouzha Guessous-Idrissi and Mr Michel Revel who were unable to attend.
3. Together with the Agenda (Annex II), the meeting documents included a working document drawn up to facilitate the work of the Drafting Group that compiled, in their original language, the proposals received by members of IBC, that followed the draft outline of the structure established by the Drafting Group at its first meeting (Paris, 30 April 2004). Included also was the Report of the first meeting of the Drafting Group, together with the draft outline of the structure of the declaration, a document presenting the results of the consultation with Member States, as at 24 May 2004, on the scope and structure of the declaration and the Report of IBC on the Possibility of Elaborating a Universal Instrument on Bioethics.

II. DISCUSSIONS ON THE PRINCIPLES TO BE INCLUDED IN THE DECLARATION

4. The main concern of the Drafting Group from the very outset of its reflections was to affirm in this new international instrument the need to reach a common ethical framework to harmonize positions in the field of bioethics, while recognizing that, in certain cases, plurality of viewpoints must be respected. The IBC recognized the need to respect plurality of viewpoints, the origins of which are found in different cultures, political and historical traditions and religious and philosophical beliefs, and had already adopted a pluralistic approach when deemed necessary, for example in the Report on the Use of Embryonic Stem Cells in Therapeutic Research (2001). This is why recognition of cultural diversity, which is inherent in bioethics, must be reflected throughout the entire text, from the preamble to the field of application.
5. The members of the group recognized the difficulty of dealing with bioethical issues for which, at the present time, no common position seems possible. Whilst aware that this declaration was not the place for attempting to resolve these issues, the members nevertheless felt that by not broaching these subjects, leaving everybody to act according to his own ethical considerations, would run the risk of seeing the development of practices contrary to human dignity and harmful to the human species. The question in hand therefore is to affirm principles that would be the basis for reflection and the search for common positions. In this respect, some members felt that the major, constructive contribution of the declaration to the debate on these items would be given in the procedural principles.
6. The future declaration must therefore aim essentially at establishing a common framework of principles in the field of bioethics – the term “principles” having been preferred to that of “norms” which could lead to confusion with regard to the legal force of the content of the declaration -, whilst acknowledging that, exceptionally, in certain cases where the divergence of certain viewpoints would be so great, a pluralistic approach should be advocated. This approach should not however, be used to infringe the principles set forth in the declaration nor to limit the scope of the declaration.

7. With regard to the principles to be affirmed in the declaration, an approach other than that of the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data had been preferred. It would consist of stating general principles that should be limited to a number of basic principles that would govern the entire subject and would constitute *jus cogens* principles. Then the declaration would comprise the provisions of the applications of these principles, which would consist of more specific principles that flow from general principles and finally, if need be, give concrete cases where these principles apply.

8. The future declaration will necessarily have to fall within the framework of international human rights law, fundamental freedoms, respect for human dignity and justice; some participants recalling that justice is a fundamental notion that covered all rights, both between human beings and between peoples and state institutions.

9. While confirming the choice to concentrate in the first place on the human being, the Group wished to see reflected in the text the fact that the human being, as an integral part of the biosphere, has responsibilities and obligations towards all other forms of life. This should be affirmed as a general principle, thus recognizing with force as a starting point the interrelation between the human being and his ecological environment. Furthermore, so that it be understood that the action of IBC, and to a larger extent UNESCO, is not limited to the human being, it appeared important to recall the various activities carried out by the Organization in the field of natural, social and human sciences, particularly the feasibility studies within the framework of the work of the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST) of an international instrument on ethics of the environment as well as the activities developed for example within the UNESCO programme of Man and the Biosphere (MAB).

10. The need also for UNESCO to pursue its standard-setting action accompanying scientific and technological progress was underlined and this should be reflected either in the resolution for the implementation of the declaration, or in the text itself in the provisions for implementation. In this regard it was pointed out that, in the present international legal corpus, no declaration had additional protocols adjoined to it. Nevertheless, it appeared necessary to foresee the inclusion of a provision in the text that would allow the declaration to be brought up to date according to advances of science and technology, thus gearing the declaration towards the future as well as envisage the possibility of future international instruments to expand the declaration.

11. Solidarity, to the extent that it covers not only solidarity between individuals but also between developed and developing countries, takes on particular importance in the context of an organization such as UNESCO. It should be recalled at several levels first of all in a general manner in the general principles, then in the recognized aims by making an explicit reference to developing countries and finally, in the implementation of the declaration within the framework of mechanisms of cooperation and national capacity-building.

12. All members were in favour of addressing specific principles in a separate part. They recognized that, if the declaration were to broach these principles at a general level, some were more particular than others and would require more detail – such as consent or the right to information. In order to secure the link between this part and the part on general principles, it appeared more suitable to speak of application of principles and to clarify in an explanatory memorandum the link between a general principle and its application and, if necessary, the interconnection between all the principles as well as the reasoning behind the drafting of the different provisions of the declaration.

13. The procedural principles will be particularly important for States wishing to set up legislation and regulations in the field of bioethics insofar as they will furnish the modalities to ensure an ethical framework for scientific and technological progress. The first procedural principle evoked concerns the need for transparent procedures in the examination of

bioethical issues, then, as modes of application of this principle, public consultation, the requirement of dialogue between scientists, health professionals, jurists, philosophers, ethicists, theologians and all other intellectual and professional groups concerned, the rationality, the need to build on empirical, verifiable and reliable data.

14. With regard to the implementation of the future declaration, provisions should define the role of UNESCO, IBC and IGBC. Like the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data, the future declaration should also include a provision encouraging States to establish independent and multidisciplinary bodies at an appropriate level as well as a provision fostering cooperation between these bodies.

15. The promotion and implementation of the declaration should also occur through education; States being called upon to make every endeavour to foster all forms of education and training in the field of bioethics at all levels, and to encourage the setting up of information programmes and the dissemination of knowledge concerning bioethics.

16. Generally speaking, the members wished to emphasize the positive contribution of scientific and technological progress that should be recognized in the declaration, while specifying that these scientific developments should be carried out within a framework of ethical principles that respect human dignity and protect human rights and fundamental freedoms, so that duties and obligations towards future generations be completed in a framework of inter-generational responsibility.

III. FINALIZATION OF A FIRST OUTLINE OF THE DECLARATION

17. The Drafting Group agreed on a first outline of a text for the declaration, the structure of which is as follows:

18. Title: Insofar as the future declaration will constitute a reference text not only for States but also for humanity as a whole, the Group felt that it was appropriate to opt for the term “universal” rather than “international”. At this stage, the title could be “Universal Declaration on Bioethics” or “Universal Declaration on Bioethics and Humanity / Humankind / Human Beings”.

19. Definitions: The Group decided to consider this part at a later date when the text is nearer finalization in order to decide whether these definitions will be necessary or not, it being understood at this stage that these definitions would be limited to scientific terms.

20. Scope: The Group preferred, for the time being, to deal on one hand with the scope of the declaration and on the other hand to deal with its aims. The part devoted to the scope pays particular attention to defining the field of application of the declaration. The following topics thus reflect, at this stage, the field of application retained for the declaration: 1) bioethics, humankind and the biosphere; 2) human dignity, human rights and fundamental freedoms; 3) consensus, diversity and pluralism.

21. Aims: The part devoted to aims illustrates the goals targeted in the principles set forth in the declaration, even though this may be at the risk of repetition. Also included in the aims are: ensuring the respect for human dignity and the protection of human rights and fundamental freedoms in the sphere of bioethical decision making; promoting respect for life in all its forms and in particular respect for human life; recognizing and understanding of the great benefits derived from scientific and technological development; providing a universal framework of principles and fundamental procedures to guide States in the formulation of their legislation and their policies in the field of bioethics; fostering dialogue between all actors in bioethics; promoting the sharing of benefits and knowledge and safeguarding the interests of present and future generations.

22. General principles: The general principles formulated at this stage are: 1) the responsibility and obligations of the human being towards the biosphere – thus contributing to the development of international law; 2) respect for human dignity, human rights and justice – thus reflecting customary international law; 3) respect for diversity and the principle of tolerance – that nonetheless cannot be invoked to infringe upon human dignity and human rights, nor to limit the scope of the declaration - ; the principle of solidarity, equity and cooperation.

23. Applications of the principles: The list of applications of the principles has not yet been developed but could include: the primacy of the human person, non-discrimination and non-stigmatisation, consent, confidentiality, the right to information, the right to health care, benefit sharing, the non-commercialization of the human body and its parts, scientific research, research involving human subjects.

24. Principles of procedure: This part will include provisions related to the need for transparent and democratic procedures, rationality and argumentation, dialogue with specialists and society, encouragement to set up national bioethics committees and other similar bodies and regulations concerning transnational practices.

25. Promotion and implementation: Finally, the aim of this part will be to ensure, at different levels, the application of the declaration and the principles set forth therein. It will thus address education and awareness-raising, international solidarity and cooperation, a reporting mechanism as well as a system of evaluation and periodic revision, and the exclusion of any act contrary to human rights, fundamental freedoms and human dignity.

III. CONCLUSION

26. In conclusion, the Drafting Group entrusted the Secretariat, in close consultation with Mrs Jean and Mr Kirby, with the editorial finalization of the first outline of the text of the declaration. Upon completion, the text (see Annex III) will be sent to all members of IBC and, in view of the Information meeting with the Intergovernmental Bioethics Committee (IGBC) on the progress of the elaboration of the declaration (Paris, 7 July 2004) to all members of IGBC.

**SECOND MEETING OF THE IBC DRAFTING GROUP
FOR THE ELABORATION OF A DECLARATION
ON UNIVERSAL NORMS ON BIOETHICS**

(UNESCO Headquarters, Paris, 2-3 June 2004)

LIST OF PARTICIPANTS

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Justice of the High Court of Australia

Member of the Ethics Committee, the Human Genome Organization (HUGO)

Former President of the Courts of Appeal of New South Wales and Solomon Islands

Former President of the International Commission of Jurists

Members

Mr Leonardo De Castro (Philippines)

Professor of Philosophy, University of the Philippines

National Coordinator of the Philippine Bioethics Network

Secretary of the International Association of Bioethics /

Vice-President of the Asian Bioethics Association

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Mr Hector Gros Espiell (Uruguay)

Professor of International Law

Chairperson of the UNESCO Consultative Committee on the Teaching of Human Rights,

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Mrs Michèle S. Jean (Canada), *Chairperson of IBC*

Adviser in programme development, Faculty of Higher Education, University of Montreal

Vice-President of the Administrative Council of the *Fonds de la recherche en santé du Québec*

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Judge Patrick Robinson (Jamaica)

Judge at the International Criminal Tribunal for the former Yugoslavia
Former Member of the United Nations International Law Commission
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(UNESCO Headquarters, Paris, 2-3 June 2004)

Agenda

- Introduction by the Chairperson of IBC
- Discussions on the principles to be included in the declaration
- Examination of wording proposals formulated by members of IBC and finalization of a first outline of the declaration