



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



*International Bioethics  
Committee (IBC)*

*Comité international  
de bioéthique (CIB)*

Distribution : limited

SHS/EST/04/CIB-Gred-1/1  
Paris, 24 May 2004  
Original : French

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

UNESCO Headquarters (Paris), 30 April 2004

**Final Report**

Division of Ethics of Science and Technology

## **I. INTRODUCTION**

1. The Drafting Group of the International Bioethics Committee (IBC) which has been entrusted with the elaboration of a declaration on universal norms on bioethics, held its first meeting at UNESCO Headquarters, Paris, on 30 April 2004 (List of participants Annex I).

2. To begin the work, the group comprises a limited number of IBC members whose primary task, with the assistance of the Secretariat, is the actual drafting of the text. Its composition will be gradually enlarged to other members of IBC as the elaboration of the text progresses. The initial composition of the group is as follows: Mr Leonardo De Castro (Philippines), Mr Donald Evans (New Zealand), Mr Héctor Gros Espiell (Uruguay), Mrs Nouzha Guessous-Idrissi (Morocco), Mrs Michèle S. Jean (Canada), Mr Michael Kirby (Australia), Mr Alexander McCall Smith (United Kingdom), Mr Edmond Pellegrino (United States of America), Mr Michel Revel (Israel) and Mr Patrick Robinson (Jamaica).

3. All members of the Committee have nevertheless been invited to contribute actively to this undertaking by lending their expertise and ideas, their reflections or suggestions on the text and by being associated with the work of the group. Several members have already expressed their desire to join the group at a later stage. At the proposal of the Chairperson, the group agreed to confer the chairmanship upon Justice Michael Kirby. In the absence of Mr Kirby, Mrs Jean chaired the meeting.

4. In order to take account of the results of the Extraordinary Session of IBC (Paris, 27-29 April 2004) and to lay down some guidelines for the Drafting Group, IBC met in its entirety the day before the meeting of the Drafting Group and exchanged views on the scope and structure of the declaration. The present report reflects the debates and discussions at both the meeting of IBC and the meeting of the Drafting Group.

## **II. DEBATE ON THE AIMS, SCOPE, STRUCTURE AND CONTENT OF THE FUTURE DECLARATION**

### **A. Title**

5. Several members raised the question of the present wording “Declaration on universal norms on bioethics”. It was pointed out that this is the term employed in 32 C/Resolution 24, adopted by the General Conference at its 32nd session in October 2003, but that it does not as such constitute the title of the declaration. This will be determined later on in the elaboration of the text.

### **B. Aims and scope of the declaration**

6. Some members felt that as the ultimate objective of bioethics is to accompany advances in science in order to ensure that this progress serves the well-being of humankind and the development of humanity, the declaration should highlight the positive aspect of advances in science and technology. It should be an instrument that would help bring back the confidence of society in the life sciences. With this in mind, a balance would need to be struck between the legal approach, which consists of establishing a framework of present practices, and a necessarily flexibility of the declaration so that it could become applicable to future evolutions in science and technology.

7. Insofar as the future declaration will be adopted by States, it will be unique of its kind in the international legal corpus and will stand out from other agreements and existing guidelines. It is therefore not out of the question to repeat the principles already established and asserted in international texts, for example in texts of non-governmental organizations or professional associations.

8. The future declaration should nevertheless be comprehensible and accessible to everyone, the members having insisted on the fact that it should be a reference text at all levels in the field of bioethics. It should therefore be addressed to both Member States and to researchers, scientists, decision-makers and citizens.

9. With regard to the scope of the declaration, members took account of the discussions held during the Extraordinary Session on the question of whether the declaration should be limited to the human being: quite a number of interventions had tended towards a broad scope that would include other fields. It was pointed out that the scope of the declaration corresponds to its field of application and in this respect a distinction should be made between the subject of rights – the human being – and the object of rights – animals, plants – towards which the subject of rights has obligations.

10. While recognizing that the human being is an element of biodiversity and as such his/her well-being and development are closely linked to the ecosystem in which he/she lives, some members drew attention to a risk of conflict of competence with other organizations of the United Nations system, as well as with the feasibility studies in progress for the elaboration of guidelines on subjects such as the environment in the framework of UNESCO's programme of ethics of science and technology.

11. Given the time limit imposed by the General Conference of UNESCO, the Drafting Group therefore decided to concentrate in the first place on the human being, while leaving open the possibility, if necessary, to refer to other fields and/or to cover them in the future. The possibility of protocols to the declaration was taken into consideration, however some members pointed out that this procedure was not in keeping with international juridical tradition concerning texts of a declaratory nature.

### **C. Structure and content of the declaration**

12. A number of members put forward proposals concerning the structure of the text and everyone seemed to agree that the declaration should be constructed with a preamble, a section devoted to definitions if necessary, followed by provisions concerning the objectives of the declaration, its scope, general principles, procedural principles and the implementation of the declaration.

13. With regard to the preamble, it should set out the framework within which the instrument lies. In keeping with usual practice, a first part should be devoted to the international legal context, making reference to existing international texts in the field of bioethics, not only those adopted within the framework of the United Nations, but all other agreements or relevant guidelines promulgated by other organizations or institutions, and a second part should recall the philosophical, scientific and political context within which the declaration falls.

14. As far as the definition of terms used in the text is concerned, the Group felt that if indeed definitions were to be included, they should come after the preamble, as in the International Declaration on Human Genetic Data (2003), and should be definitions of technical and scientific terms used and not definitions of legal or philosophical principles.

#### **D. Content of the declaration**

15. The debate centred on the connection between general principles and specific subjects and the way to treat specific subjects. Some members suggested dealing with general principles on one hand and their applications on the other, but, for the time being, the Group preferred to structuralize the declaration around general principles and, if need be, make reference to concrete applications, using IBC Reports as a basis in certain instances.

16. Several sorts of distinction between principles were raised, general and particular, derogable and non-derogable, and more particularly, well established, recognized principles and new and emergent principles – for example the principle of accountability. The respect for human dignity should of course be woven throughout the entire text.

17. It was unanimously recognized that recourse to any hierarchisation of principles should be avoided. Based on the principles given in the questionnaire sent to Member States in the framework of the written consultation, some had already been identified: respect for human rights, justice, equality, non-discrimination (as a consequence of justice), autonomy and tolerance (with pluralism as a means of approach extending from the principle of tolerance). It appeared important to make it clear also that the identity of a person may not be reduced to genetic characteristics and that the diversity of human beings in the unity of the human family must be respected. Several members felt that certain principles, such as consent, may need to have an entire section devoted to them. It was decided that the list of principles should be determined at the next meeting.

18. Regarding the specific subjects to which reference could be made, several members raised the problem of controversial issues, where, quite clearly, a unique position cannot be considered at the present time. Some members proposed that these issues be referred to in an explanatory note, others suggested they be dealt with in a separate section containing so-called descriptive provisions that would present the different approaches to the subject taking into account the diversity of cultures, practices and ways of thinking, yet others contemplated the possibility that they be broached throughout the list of principles as an illustration of the pluralistic approach to bioethics.

19. Some cross-cutting themes were raised such as trans-border research, access to health care, benefit sharing, even more especially as this declaration should not only target topical, heated issues widely covered by the media, but also and above all respond to the concerns of developing countries. In this respect, some members underlined the importance of certain interventions during the Extraordinary Session that emphasized the priorities and different approaches to bioethical issues in developing countries.

20. The question of so-called “vulnerable” groups – such as women, children, disabled persons – was discussed at length and it was proposed that this question be dealt with either in a separate section or throughout the text whenever it seemed appropriate in relation to the subject dealt with, to the extent that these groups are not in themselves vulnerable but it is the situations in which they find themselves that make them vulnerable.

21. Some members voiced the need to foresee provisions concerning the procedure to be followed at national and international level in the framework of science and technology, particularly with regard to recourse to democratic and transparent procedures - for example the creation of national bioethics committees and review boards should be called for and encouraged, as well as a system of responsibility at national and regional level, and, on an international level reflection on procedures regulating trans-border flows.

22. The Group stressed the importance for a section to be devoted to the implementation of the declaration, recalling that this new approach in international declarations had been instigated with the Universal Declaration on the Human Genome and Human Rights (1997) and further developed with the International Declaration on Human Genetic Data (2003), which provides for a system of reporting by States. Some members expressed the wish for the declaration to include a similar system of periodic reporting by States to a body or committee whose task would be to examine and give an opinion, but not in the sense of a judicial or quasi judicial body. The principles of solidarity, international cooperation, education and awareness-raising should also be included in the section devoted to the implementation of the declaration.

23. Finally, because of the rapid advances in science and technology and in order to ensure the perennality of the declaration, a system of evaluation and periodic review could be put in place. This could pave the way towards the development of the declaration and possible future instruments.

### **III. CONCLUSION**

24. In conclusion, the Drafting Group, drew up a preliminary outline of the structure of the declaration which, once finalized by the Secretariat will serve as a basis for the second meeting which will be held at UNESCO Headquarters in Paris on 2 and 3 June 2004 (see Annex II).

25. Certain members offered to send propositions for the text to the Secretariat, in particular, Mr Héctor Gros Espiell expressed his willingness to draft a first outline for the preamble and the implementation of the declaration. Other members were invited to send their contributions to the Secretariat, especially with regard to the positive approach of science and technology and the question of women. The Secretariat requested that these contributions be received by 21 May at the latest.

**First Meeting of the  
Drafting Group of IBC**

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**Première réunion du  
Groupe de rédaction du CIB**

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**LIST OF PARTICIPANTS / LISTE DES PARTICIPANTS**

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Mrs/Mme Nouzha Guessous-Idrissi (Morocco / Maroc)  
Mrs/Mme Michèle S. Jean (Canada), Chairperson of IBC / Présidente du CIB  
Mr/M. Michel Revel (Israel / Israël)  
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**OTHER MEMBERS OF IBC / AUTRES MEMBRES DU CIB**

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Distribution: limited

Paris, 29 April 2004  
Original: English / French

**DRAFT OUTLINE OF THE STRUCTURE  
OF THE DECLARATION ON UNIVERSAL NORMS ON BIOETHICS**  
(established at the first meeting of the IBC drafting group, on 29 April 2004)

**Preamble**

- Reference to existing pertinent international instruments, agreements and guidelines, within and outside the United Nations system
- philosophical, scientific and political context

**[Use of Terms]**

Limited to scientific terms

**Aims and Scope**

- To ensure the application of science for the welfare of human beings and the development of humanity.
- The declaration should underline the positive aspects of science and technology progress
- The scope should be oriented towards the human being

**Procedures**

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

- the need for democratic and transparent procedures,
- the promotion and establishment of national bioethics committees and review boards at appropriate levels
- the regulation of transnational practices.

**General Principles** (together with provisions on specific areas when applicable)

- justice
- equality
- respect for human dignity
- non-discrimination (as a consequence of justice)
- autonomy
- tolerance (with pluralism as modality of approach to controversial issues)

others :

- benefit sharing
- confidentiality
- freedom of research
- informed and free consent
- integrity of research
- respect for privacy
- solidarity
- transparency
- truth-telling

**[Descriptive Section]**

- on controversial issues requesting a pluralistic approach (this part could contain a prosaic description of these issues and set out the positions of parties where there is no agreement)

**Promotion and Implementation**

- Education and Awareness-raising
- Solidarity and International Cooperation
- Implementation (including a reporting mechanism and an evaluation system and periodical revision )