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**REPORT BY THE DIRECTOR-GENERAL  
ON THE WORK OF THE  
INTERNATIONAL BIOETHICS COMMITTEE (IBC)  
AND OF THE  
INTERGOVERNMENTAL BIOETHICS COMMITTEE (IGBC)**

### OUTLINE

**Source:** Article 11, paragraph 2, of the Statutes of UNESCO's International Bioethics Committee (IBC).

**Background:** In accordance with Article 11, paragraph 2, of the IBC Statutes, the Director-General shall transmit to the General Conference the opinions of the Intergovernmental Bioethics Committee (IGBC), together with the advice and recommendations of IBC.

**Purpose:** This report reviews the work carried out by IBC and IGBC in 2004-2005.

**Decision required:** No decision is required on this document.

## **I. INTRODUCTION**

1. Pursuant to Article 11, paragraph 2, of the Statutes of UNESCO's International Bioethics Committee (IBC), this document reviews the work carried out by IBC and the Intergovernmental Bioethics Committee (IGBC) in 2004-2005. Since the work of the two Committees in the period considered focused mainly on the elaboration of the declaration on universal norms on bioethics, this document should be read in conjunction with document 33 C/22 submitted by the Director-General under provisional agenda item 8.2.

## **II. JOINT MEETING OF THE BUREAUX OF IBC AND IGBC<sup>1</sup>**

2. As announced at the Third Session of IGBC (June 2003), a joint meeting of the Bureaux of IBC and IGBC was convened by the Director-General in order to reflect on ways in which cooperation between these two bodies could be improved. At the kind invitation of Italy, this meeting took place on 19 December 2003 in Rome.

3. The aim of the meeting was primarily to reflect on the mechanisms for cooperation and linkage between the two Committees (IBC composed of independent experts and IGBC composed of government experts) in various areas – capacity-building, establishment of bioethics committees and education on bioethics in particular, as well as in the framework of the implementation of the instruments adopted by UNESCO in the field of bioethics and the elaboration of new ones.

4. In accordance with the agenda, the two Bureaux proceeded with an exchange of views on the follow-up to the recommendations of the Third Session of IGBC and examined and finalized together the timetable for the elaboration of a declaration on universal norms on bioethics. This timetable was then approved by the Executive Board at its 169th session (169 EX/Decision 3.6.2).

## **III. WORK OF IBC**

5. At its meeting on 18 December 2003, the Bureau considered that, since the General Conference had mandated UNESCO to draw up a draft declaration on bioethics to be submitted to the 33rd session in 2005 (32 C/Resolution 24), the work plans of IBC for 2004-2005 should be drawn up around the elaboration of the future declaration.

6. To this end and in accordance with the aforementioned timetable, in the period considered, in addition to the eleventh ordinary session, the Committee held two extraordinary sessions and set up a Drafting Group, chaired by Justice Michael Kirby (Australia). It also carried out numerous consultations (in written form, as well as in the form of conferences, etc.), at all levels (national, regional, international) and at various stages in the drafting process, involving Member States (IGBC in particular), intergovernmental organizations namely through the Interagency Committee on Bioethics) and non-governmental organizations, national bioethics committees, etc.

7. Finally, with regard to the implementation of the International Declaration on Human Genetic Data (2003), it was decided that in application of Article 25 of the Declaration the Committee would begin reflection on a plan for the implementation of the Declaration.

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<sup>1</sup> All the documents and reports related to the meetings mentioned in this document are available from the Bioethics Section of the Division of Ethics of Science and Technology and on the Internet ([www.unesco.org/bioethics](http://www.unesco.org/bioethics)).

### **Extraordinary session (Paris, 27-29 April 2004)**

8. Aware of the importance of involving the main actors in the elaboration of the future declaration, IBC held an extraordinary session entitled “Towards a Declaration on Universal Norms on Bioethics” at UNESCO Headquarters in Paris from 27 to 29 April 2004. Opened by the Director-General, this extraordinary session brought together over 200 participants from more than 70 countries.

9. The aim of this session, which followed a written consultation with Member States, was to hold consultations with the other actors concerned, initiating debate on the scope and structure of the future declaration. The session was thus organized into hearings of representatives of three different groups – intergovernmental organizations, international non-governmental organizations and national bioethics committees – followed by a question-and-answer session with IBC members and the audience.

10. Seven intergovernmental organizations – within and outside the United Nations system –, eight international non-governmental organizations and fourteen national bioethics committees or similar bodies gave an oral presentation. Approximately 15 other non-governmental organizations and 15 other national bioethics committees and similar bodies also took part in that meeting. All organizations and institutions were invited to submit written contributions in advance, thereby providing IBC with a comprehensive overview of all the ideas and opinions expressed.

11. The written contributions as well as the results of the debate during the sessions, together with the information collected in a written consultation with Member States, constituted the starting point for IBC to begin the drafting of a text.

### **Work of the Drafting Group on the elaboration of the declaration on universal norms on bioethics**

12. At its extraordinary session in April 2004, IBC formed a Drafting Group responsible for drawing up a preliminary draft of a declaration on universal norms on bioethics, initially composed of a small number of IBC members and whose membership would be extended to other members of IBC as work on drawing up the text progressed. All the members of the Committee were nonetheless requested to contribute actively to the work, through both their expertise and actual participation.

13. The Drafting Group met six times at UNESCO Headquarters in Paris, in April, June, July, August and December 2004 respectively. Throughout its work, the Drafting Group stressed the need to devise a common ethical framework, while upholding the plurality of views, cultures, traditions and beliefs. This is why, in the finalization of the preliminary draft, it took into consideration the results of the numerous consultations carried out.

### **Eleventh session of IBC (Paris, 23-24 August 2004)**

14. The eleventh session of IBC was held in Paris on 23 and 24 August 2004. Opened in the presence of the Director-General of UNESCO, it was attended by approximately 250 participants from some 80 countries from every region of the world – members of IBC, representatives of Member States, of intergovernmental and non-governmental organizations and of national bioethics committees, experts and specialists, and representatives of young people and the media.

15. The session was devoted in particular to the drawing up of the future declaration and the examination of the second outline of the text drafted by the IBC Drafting Group. The session featured hearings of representatives of the various religious and spiritual approaches. Six speakers representing, respectively, the Buddhist, Catholic, Confucian, Hindu, Islamic and Jewish traditions

were invited to take the floor. Each speaker gave a presentation based on his or her perception of the current challenges in bioethics and commented on the text prepared by the Drafting Group.

16. In addition, at a meeting reserved for members of the Committee, IBC engaged in an initial exchange of views on a plan of action for the implementation of the International Declaration on Human Genetic Data (2003).

17. Finally, in accordance with the agenda, it was at the eleventh session that IBC was to elect its Bureau. However, for the sake of continuity in managing the work of drawing up the declaration and considering that the measure would also enable the new members to familiarize themselves more readily with the work of the Committee before a new election, the Committee decided to maintain the membership of the Bureau as it stood for one year, until its twelfth session in autumn 2005, and to elect two new members to the vacant posts of Vice-Chairperson and Rapporteur. The Bureau is accordingly composed as follows:

Chairperson:	Ms Michèle S. Jean (Canada)
Vice-Chairpersons:	Mr Leonardo de Castro (Philippines)
	Mr Alphonse Elungu (Democratic Republic of the Congo)
	Ms Nouzha Guessous Idrissi (Morocco)
	Mr Patrick Robinson (Jamaica)
Rapporteur:	Mr Claude Huriet (France)

#### **Extraordinary session of IBC (Paris, 28 January 2005)**

18. A second extraordinary session of IBC was held at UNESCO Headquarters in Paris on 28 January 2005 after the Fourth Session of IGBC (24-25 January 2005) and a Joint Session of IBC and IGBC (26-27 January 2005) (see below). Opened by the Director-General, the extraordinary session gathered together over 150 participants.

19. The session was the occasion for IBC to carry out initial public reflection on the definition of a draft plan of action for the implementation of the International Declaration on Human Genetic Data (2003). Mr Mohammad Hamdan (Jordan), who had accepted to coordinate the drafting of the preliminary proposals, presented the results of the discussions of IBC at its eleventh session. The text presented was structured around four parts – “What to do?”, “How?”, “By whom?”, “For whom?” – and six fields of action were identified along the same provisions as the Declaration: education, training programmes, dissemination of information, genetic counselling, international cooperation and follow-up of the Declaration. Generally speaking, the participants welcomed the preliminary proposals of IBC. Some expressed the wish to see conferences or workshops organized with the different role players of the implementation in order to encourage the setting up of activities. Other speakers underlined the lack of tools available for the actors concerned to allow them to carry out activities of implementation.

20. This session was also the occasion for all observers to express opinions publicly one last time on the Fourth Outline of the future declaration finalized by the Drafting Group of IBC at its sixth meeting (December 2004). At the end of the discussions, IBC finalized the Preliminary Draft Declaration subsequently transmitted by the Chairperson to the Director-General for the work of the governmental experts who were to meet on two occasions in April and in June 2005 in order to finalize the draft declaration for submission to the General Conference at its 33rd session in October 2005 (see document 33 C/22).

### **III. WORK OF IGBC**

#### **Information meeting with IGBC (Paris, 7 July 2004)**

21. In accordance with the timetable for the elaboration of the Declaration, a meeting to inform IGBC of the progress achieved in drawing up a declaration on universal norms on bioethics was held at UNESCO Headquarters in Paris on 7 July 2004.

22. The meeting, chaired by Ms Cinzia Caporale (Italy), Vice-Chairperson of IGBC, brought together more than 100 participants and aimed to inform IGBC of the progress of the work undertaken and to receive its views on the ongoing discussions and on the text drawn up by the IBC Drafting Group.

23. The participants congratulated IBC on the work accomplished and commended the transparency of the work carried out. They also emphasized that the text could be improved and expanded over the coming months, not only within the framework of IBC's work but also on the occasion of the meetings of governmental experts to be convened in 2005.

24. In giving the opportunity to engage a dialogue on the structure and the content of the future declaration, the meeting allowed IGBC to play an active part in the debate in a spirit of openness and cooperation, whilst respecting the independence of IBC.

#### **Fourth session of IGBC (Paris, 24-25 January 2005)**

25. The fourth session of IGBC was held at UNESCO Headquarters in Paris on 24 and 25 January 2005. The following Member States of IGBC were represented: Belgium, Brazil, Canada, Chile, China, Costa Rica, Egypt, Finland, France, Germany, Ghana, India, Indonesia, Islamic Republic of Iran, Italy, Kenya, Latvia, Libyan Arab Jamahiriya, Malawi, Mexico, Mozambique, Nigeria, Republic of Korea, Russian Federation, Saudi Arabia, Thailand, Togo, Tunisia, Uganda, United States of America, Uruguay and Venezuela. The Chairperson of IBC and the Chairperson of the IBC Drafting Group also took part in the debates while many IBC members attended as observers.

26. The Committee proceeded with the election of its Bureau. On the proposals put forward by the electoral groups, Ms Cinzia Caporale (Italy) was unanimously elected Chairperson of IGBC. Mr Abdulaziz Mohammed Al-Swailem (Saudi Arabia), Mr Elmars Grens (Latvia), Mr Huanming Yang (People's Republic of China) and Mr Pablo Sader (Uruguay) were elected Vice-Chairpersons and Ms Esther Kakonge (Kenya), Rapporteur.

27. The session was mainly devoted to the drawing up of the future declaration and to a discussion on the Fourth Outline of the text, as finalized by the IBC Drafting Group, and was immediately followed by a joint session of IBC and IGBC and an extraordinary session of IBC (see paras. 34-35 and paras. 21-23 respectively).

28. In addition, in accordance with 32 C/Resolution 23 "Implementation of the International Declaration on Human Genetic Data" and in application of Article 25 of the Declaration, which stipulates that IBC and IGBC "shall contribute to the implementation of this Declaration and the dissemination of the principles set out therein", IGBC discussed the preliminary proposals examined by IBC during its eleventh session.

29. At the outcome of the session, IGBC adopted the following recommendations:

**In relation to item 7 “Elaboration of a Declaration on Universal Norms on Bioethics: Report on the Work of IBC and discussion on the Fourth Outline of a Declaration”,**

1. Thanks and congratulates the International Bioethics Committee (IBC) and its Drafting Group for the high quality of the work carried out in the framework of the elaboration of a declaration on universal norms on bioethics (32 C/Resolution 24);
2. Welcomes the efforts deployed by IBC and the Secretariat to ensure the transparency of the elaboration process of the draft declaration as well as the active participation of all stakeholders concerned in the framework of all consultations carried out throughout the elaboration process, in particular States, the United Nations and the other specialized agencies of the United Nations system, other intergovernmental and non-governmental organizations, appropriate national bodies and specialists;
3. Also welcomes the initiatives taken to foster dialogue between IBC and IGBC and to improve cooperation and interaction of their work;
4. Takes note with satisfaction of the substantial improvements that have led to the Fourth Outline and appreciates its spirit and structure;
5. Considers nevertheless that many crucial issues and principles need to be considered further, including but not limited to those related to autonomy, informed consent, social responsibility, risk assessment, sharing of benefits, transnational practices and ethics committees, and invites IBC, in the framework of the finalization of a preliminary draft declaration, to reconsider the relevant articles;
6. Also invites IBC to reconsider the provisions concerning the use of terms, scope, aims, implementation principles, procedures and promotion and implementation of the declaration, in order to clarify to whom various provisions apply and are addressed;
7. Further invites IBC, *inter alia*:
  - (i) to reconsider the formulation of Article 5 on restrictions and its location in the text;
  - (ii) to reconsider the wording of the title of Article 8 as well as the formulation of Article 9;
  - (iii) to make an appropriate reference to the freedom of research; and
  - (iv) where appropriate, to bring language in line with other UNESCO instruments;
8. Recognizes the quality of the text elaborated by IBC and, subject to modifications which could be made on the basis of the discussions of the fourth session of IGBC and the joint session of IBC and IGBC (26-27 January 2005), considers that it will constitute an excellent basis for further governmental negotiations aiming at improving the draft declaration;
9. Considers that, at the meetings in April and June 2005, the government experts should attempt to finalize a draft that can be presented to the 33rd session of the General Conference of UNESCO in October 2005.

**In relation to item 9 “International Declaration on Human Genetic Data: Preliminary Exchange of view on a Plan of Action for its Implementation”,**

10. Takes note of the preliminary proposals of IBC for the implementation of the International Declaration on Human Genetic Data as a basis for further reflection and

suggests that the discussion be continued in the appropriate institutions and in Member States.

#### **IV. JOINT SESSION OF IBC AND IGBC (Paris, 26-27 January 2005)**

30. The Director-General convened a joint session of IBC and IGBC on 26 and 27 January 2005 in Paris, in accordance with Rule 11.7 of the Statutes of IBC in order to “foster dialogue between the IBC and the IGBC on matters of mutual concern”, namely, the drawing up of the future declaration. By providing an opportunity for an exchange of views between the two committees, the joint session of IBC and IGBC helped to clarify and enlarge upon the commentaries and remarks of the Member States and to enrich the final reflections of IBC.

31. The Joint Session, which gathered together some 200 participants, was co-chaired by the Chairpersons of IBC and IGBC. Through a free and open exchange of views between the two committees, the Joint Session allowed for clarification and further examination of comments and proposals formulated by Member States on the text of the future declaration elaborated by the IBC Drafting Group, and provided nourishment for the ultimate reflections of IBC before the finalization of a preliminary draft and the examination of the text by government experts.

#### **V. CONCLUSIONS**

32. Because of the mandate given by the General Conference in the period considered, IBC and IGBC focused their respective work mainly on the elaboration of a declaration on universal norms on bioethics. The timetable for the elaboration of the declaration approved by the Executive Board allowed for a balance to be achieved between the drafting work of IBC and the political role of IGBC.

33. The constructive contribution of IGBC in the process of the elaboration of the declaration, the spirit of cooperation and the fruitful exchange that characterized the information meeting in July 2004, the Fourth Session of IGBC and the Joint Session of IBC and IGBC in January 2005, confirms that the existence of the two Committees constitutes a distinct advantage for the Organization in particular with regard to its normative action.

34. The future work programme of IBC will be defined during the twelfth session of IBC scheduled to take place in Japan in December 2005 and the participatory process that has characterized the work of the two Committees during the 2004-2005 period should continue throughout the coming biennial exercise.