



Item 7.1 of the provisional agenda

**IMPLEMENTATION OF THE UNIVERSAL DECLARATION
ON THE HUMAN GENOME AND HUMAN RIGHTS:
REPORT BY THE DIRECTOR-GENERAL**

OUTLINE

Source: 29 C/Resolution 17.

Background: At its 29th session the General Conference adopted the Universal Declaration on the Human Genome and Human Rights, together with 29 C/Resolution 17 concerning the implementation of the Declaration.

Purpose: Pursuant to 29 C/Resolution 17, the Director-General reports to the General Conference on action taken to promote the implementation of the Universal Declaration on the Human Genome and Human Rights. As the sixth session of the International Bioethics Committee, the first session of the Intergovernmental Committee set up by Article 11 of the IBC Statutes, and a joint session of the two bodies will be held in Rabat (Morocco) from 7 to 13 October 1999, an addendum to the present report will be prepared as indicated in paragraph 34.

Decision required: A draft resolution will be submitted in the above-mentioned addendum.

I. INTRODUCTION

1. On 11 November 1997, the General Conference adopted unanimously and by acclamation the Universal Declaration on the Human Genome and Human Rights. It also adopted 29 C/Resolution 17 on the “Implementation of the Universal Declaration on the Human Genome and Human Rights”, which laid the foundations for arrangements for follow-up action.

2. The Universal Declaration on the Human Genome and Human Rights is a moral commitment to which States have subscribed. It is a starting point and not an end in itself. If the Declaration encourages the Member States of UNESCO to take steps that can put it into practice and thus ensure its continued existence, it entrusts to UNESCO the tasks that have been set out to support the action by States.

II. IMPLEMENTATION OF 29 C/RESOLUTION 17

3. In paragraph 2(a) of that resolution, the General Conference invited the Director-General:

“(a) to convene as soon as possible after the 29th session of the General Conference an ad hoc working group with balanced geographical representation, comprised of representatives of Member States, with a view to advising him on the constitution and the tasks of the International Bioethics Committee with respect to the Universal Declaration and on the conditions, including the breadth of consultations, under which it will ensure the follow-up to the said Declaration, and to report on this to the Executive Board at its 154th session;”.

4. The ad hoc working group in question met at UNESCO Headquarters from 25 to 27 March 1998. The representatives and observers of 32 Member States and two observers from non-Member States participated in the meeting. The ad hoc working group made recommendations on the constitution of the International Bioethics Committee (IBC), its tasks and on the procedures to enable it to ensure the follow-up to the Declaration. On the basis of the conclusions of the ad hoc working group and the “Report by the Director-General on the implementation of the Universal Declaration on the Human Genome and Human Rights” (154 EX/41), the Executive Board at its 154th session adopted the Statutes of the International Bioethics Committee (IBC) in 154 EX/Decision 8.4.¹

5. In accordance with its Statutes, the IBC is composed of 36 persons appointed by the Director-General. The Statutes also established an Intergovernmental Committee composed of 36 representatives of the Member States elected by the General Conference. Finally, the Statutes provide for joint sessions to foster dialogue between IBC and the Intergovernmental Committee on matters of mutual concern. Without limiting the generality of such matters, they may include consideration of any proposals to amend the Universal Declaration on the Human Genome and Human Rights or adopt any further declaration or any other international instrument within the field of competence of IBC.

¹ This document is available in the working languages of the General Conference.

6. In the above-mentioned decision, the Executive Board invited the Director-General:

“(a) to appoint the members of IBC in accordance with the [...] Statutes;

(b) to submit to the Executive Board at its 155th session the list of Member States of UNESCO and Associate Members which have put themselves forward as candidates for the Intergovernmental Committee; (...)”.

7. The Director-General constituted the International Bioethics Committee in application of the decision and in accordance with the Statutes adopted by the Executive Board, 18 of its members, designated by the drawing of lots, having a two-year mandate.²

8. Likewise, nominations were immediately requested for the Intergovernmental Committee. On the basis of the “Report by the Director-General on the follow-up to the adoption of the Statutes of the International Bioethics Committee: Election of Member States’ candidates for the Intergovernmental Committee” (155 EX/47 and Addenda), the Executive Board, by 155 EX/Decision 9.2, decided on the distribution of seats among electoral groups (cf. 30 C/NOM/8). In application of a transitional provision of the Statutes, the following 36 States were elected members of the Intergovernmental Committee: Australia, Bangladesh, Belarus, Benin, Cameroon, Canada, Chile, Congo, Côte d’Ivoire, Cuba, Dominican Republic, Egypt, Finland, France, Gabon, Germany, Ghana, Hungary, India, Indonesia, Islamic Republic of Iran, Italy, Japan, Lebanon, Lithuania, Morocco, Mexico, Netherlands, Nigeria, Peru, Republic of Korea, Russian Federation, South Africa, Tunisia, United Kingdom and Venezuela.

9. In accordance with Article 11 of the IBC Statutes, the Intergovernmental Committee will be renewed at the 30th session of the General Conference.

10. The Director-General was also invited by 29 C/Resolution 17 to take the necessary steps to enable the International Bioethics Committee to ensure the dissemination and follow-up of the Declaration, and the promotion of the principles set forth therein.

III. DISSEMINATION OF THE UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS

11. Upon adoption, the Declaration and the Resolution for its implementation were widely distributed. For instance, on 11 November 1997, they were sent to the Secretary-General of the United Nations, the Executive Heads of Specialized Agencies of the United Nations, the United Nations High Commissioner for Human Rights, the United Nations High Commissioner for Refugees, the Rector of the United Nations University, and Permanent Delegations and permanent observer missions to UNESCO.

12. Subsequently, the Universal Declaration on the Human Genome and Human Rights, accompanied by the resolution for its implementation, was published as a brochure in the working languages of the General Conference. More than 120,000 copies have been distributed to National Commissions, parliaments, ethics committees and similar institutes, academies and universities, mediators and numerous specialists. In the form of a poster, in

² The composition of the International Bioethics Committee is available, in English and French, from the Division of the Ethics of Science and Technology and is posted on the website <http://www.unesco.org/ethics>.

English, French and Spanish, the text of the Declaration has been widely distributed, in particular to educational establishments.

13. The Declaration was also sent to Specialized Agencies of the United Nations, numerous intergovernmental and non-governmental organizations, UNESCO Offices, Associated Schools and UNESCO associations, centres and clubs.

14. In addition to the six working languages of the General Conference, the Declaration and the resolution for its implementation have been translated, sometimes on the initiative of National Commissions for UNESCO or members of the International Bioethics Committee (IBC), into Catalan, Croatian, Czech, German, Greek, Hungarian, Italian, Japanese, Korean, Polish and Portuguese.

15. The Declaration has also been the subject of lectures and presentations at many national, regional and international congresses, seminars and training courses, and made available to participants in them (Argentina, Australia, Brazil, Cameroon, Canada, China, Colombia, Croatia, Cuba, Ecuador, Egypt, France, Germany, Hungary, India, Italy, Japan, Lebanon, Mexico, New Zealand, Slovakia, Spain, United Arab Emirates, United Republic of Tanzania and United States).

16. Likewise, the Declaration was reproduced and commented upon in many specialized journals (in Australia, Chile, France, Germany, Italy, Japan, Spain, United Kingdom, United States, Uruguay, and other countries). The May 1998 edition of the *UNESCO Courier* reproduced the Declaration, and published articles on it. In addition, a book retracing the origins of the Declaration was published in July 1999.³

17. With the aim of promoting the principles set forth in the Declaration and in the spirit of Article 11 of the Declaration, a kit entitled “No to human cloning” produced in English, French and Spanish, has been widely distributed, in particular to Permanent Delegations, National Commissions for UNESCO and the press worldwide.

IV. WORK OF THE INTERNATIONAL BIOETHICS COMMITTEE

18. At the kind invitation of the Government of the Kingdom of the Netherlands, the fifth session of UNESCO’s International Bioethics Committee (IBC) was held at Noordwijk from 2 to 4 December 1998, bringing together over 200 participants from 50 countries. On the proposal of the Director-General, IBC elected a Bureau composed of a Chairperson, Mr Ryuichi Ida (Japan), four Vice-Chairpersons, (in alphabetical order) Mr Héctor Gros Espiell (Uruguay), Mr Mohammad Hamdan (Jordan), Ms Michèle Jean (Canada), Mr Jacek Zaremba (Poland), and a Rapporteur, Ms Yolande Tano Bouah (Côte d’Ivoire).

19. The themes of the agenda for the fifth session were “bioethics and women’s rights” and “ethics and preventive medicine”. With reference to Article 24 of the Universal Declaration on the Human Genome and Human Rights and on the basis of a document prepared by the Secretariat, IBC devoted a working meeting to a review of the implementation of the Declaration. Finally, in view of the increasing importance the private sector attaches to ethical

³ This publication is available in English and French from the Division of the Ethics of Science and Technology.

reflection, a round table comprising several prominent figures was held on “Ethics and uses of genetic engineering in industry”.⁴

20. IBC set up two working groups, one on follow-up to the Declaration, chaired by Mr Héctor Gros Espiell (Uruguay), which met on 11 and 12 May 1999, and the other on confidentiality and genetic data, chaired by Ms Michèle Jean (Canada), which met on 21 and 22 June 1999.

21. At the conclusion of its first meeting, the working group on the follow-up to the Declaration approved the “proposals in view of the application of Article 24 of the Universal Declaration on the Human Genome and Human Rights by the International Bioethics Committee of UNESCO (IBC)”,⁵ which will be examined by IBC at its sixth session. These proposals concern the dissemination of the principles contained in the Declaration, more detailed examination of the questions posed by the application of those principles and by new developments in the techniques in question, the organization of consultations with the parties concerned (such as vulnerable groups), the formulation of recommendations to be submitted to the General Conference and opinions regarding the follow-up to the Declaration, identification of practices which may be contrary to human dignity, and topics that might be addressed by IBC in future.

22. The meeting of the working group on the confidentiality of genetic data was held for the purpose of examining the ethical questions posed by that issue and deciding on practical arrangements for the preparation of the report the working group is to submit to IBC at its sixth session. That report will deal with: identification of various types of genetic data; criteria for the application of the principle of confidentiality, pursuant to Article 7 of the Declaration; limitations to the principle of confidentiality, on the basis of Article 9; and bioethics awareness-building and education.

V. GLOBAL REPORT

23. In accordance with 29 C/Resolution 17, paragraph 2(c), on 13 March 1998 a circular letter was sent to all Member States and to non-Member States maintaining permanent observer missions to UNESCO, inviting them to take all appropriate steps, including where necessary the introduction of legislation or regulations, to promote the principles set forth in the Universal Declaration on the Human Genome and Human Rights. A second circular was sent on 3 November 1998 to those States that did not reply to the first.

24. The replies received by the Secretariat served as the basis for a document outlining the situation in the fields relevant to the Declaration in the following 41 States: Argentina, Australia, Austria, Belarus, Belgium, Benin, Brazil, Burkina Faso, Canada, China, Colombia, Denmark, Ecuador, Egypt, Estonia, Finland, France, Germany, Iceland, India, Indonesia, Ireland, Israel, Italy, Japan, Jordan, Latvia, Luxembourg, Mexico, New Zealand, Netherlands, Norway, Poland, Portugal, Russian Federation, Slovakia, Spain, Sweden, Tunisia, United Kingdom and United States.

⁴ The proceedings of the fifth session of IBC are available in English and French from the Division of the Ethics of Science and Technology.

⁵ This document is available in English and French from the Division of the Ethics of Science and Technology.

25. The document in question presents the information provided by the States in relation to the principles set forth in the Universal Declaration on the Human Genome and Human Rights. It is thus divided into two parts, dealing respectively with the affirmation of human dignity and basic human rights, and the affirmation of freedom of scientific research within a framework of ethical references. Both parts reflect the principles set forth in the Universal Declaration on the Human Genome and Human Rights, namely:

- (i) respect for human dignity;
- (ii) non-discrimination with respect to genetic characteristics;
- (iii) guarantees of individual freedom through the prior, free and informed consent of the individual and the confidentiality of genetic data;
- (iv) the principles governing research, namely freedom of research and the responsibility of scientists;
- (v) the primacy of human dignity over research, in particular with respect to the prohibition of human cloning for purposes of reproduction and the prohibition of any practice which is contrary to human dignity.⁶

26. UNESCO has also taken action with regard to the United Nations and its relevant bodies and Specialized Agencies in the fields covered by the Universal Declaration on the Human Genome and Human Rights. General Assembly Resolution 53/152 entitled “The Human Genome and Human Rights”, adopted by consensus on 9 December 1998 by the General Assembly of the United Nations at its fifty-third session, “endorsed” the Universal Declaration on the Human Genome and Human Rights.

27. Subsequently, a document entitled “The Universal Declaration on the Human Genome and Human Rights and follow-up action” was submitted to the United Nations Commission on Human Rights at its fifty-fifth session with a view to keeping that body informed of UNESCO action for the implementation of the Declaration and the promotion of the principles contained therein.⁷ Following its presentation, the United Nations Commission on Human Rights adopted on 28 April 1999 resolution 1999/63 entitled “Human Rights and bioethics”. Referring to the Universal Declaration on the Human Genome and Human Rights, that resolution invites, *inter alia*, UNESCO, WHO, “the Office of the High Commissioner for Human Rights, and the other United Nations bodies and Specialized Agencies concerned to report to the Secretary-General on the activities conducted in their respective areas to ensure that the principles set forth in the Universal Declaration on the Human Genome and Human Rights are taken into account”. It also invites “governments to consider establishing independent, multidisciplinary and pluralist committees of ethics to assess, notably in conjunction with the International Bioethics Committee ..., the ethical, social and human questions raised by the biomedical research ...”.

28. In this connection, pursuant to Article 16 of the Declaration, a document on national bioethics committees prepared by the Secretariat was circulated to all National Commissions for UNESCO, all Permanent Delegations and all Regional Offices. Its purpose is to provide

⁶ This document, which is too long to be annexed to this report, is available in English and French from the Division of the Ethics of Science and Technology.

⁷ This document is available in English and French from the Division of the Ethics of Science and Technology.

background information Member States may need for the establishment of national ethics committees. The Secretariat has provided consultancy services to the relevant bodies of countries wishing to establish such committees (Croatia, Cuba, Ecuador, Jordan, Poland, Republic of Korea and Uruguay). In addition, a database on bioethics committees, institutes and centres has been established by the Division of the Ethics of Science and Technology, on the basis of a survey containing information on 626 such bodies in 66 different Member States.

29. The fifty-second World Health Assembly examined the issue of cloning with respect to human health on the basis of a report. Among the measures proposed is the drafting of a declaration by the World Health Organization (WHO) on genetics and its medical, ethical and public health aspects.

30. Among other relevant activities undertaken by United Nations Specialized Agencies, the Food and Agriculture Organization of the United Nations (FAO) intends to establish an international committee to examine ethical issues within its fields of competence.

31. Finally, the Secretariat is cooperating with the Joint Programme Commission on Science and Ethics of the NGO-UNESCO Liaison Committee with a view to encouraging the participation of international non-governmental organizations in the implementation of the Declaration.

V. CONCLUSION

32. It is clear that bioethics offers much scope for reflection and action worldwide. It is attracting more and more attention in all societies, in particular that of public and private decision-makers, and arousing the interest of the broad public. The Director-General is therefore proposing in document 30 C/5 the possible preparation and publication of a "world bioethics report".

33. The success of any strategy to ensure implementation of the Universal Declaration on the Human Genome and Human Rights will depend on the firm commitment of States to implementing the Declaration and their ability to mobilize the necessary resources. States have a key role to play in promoting the principles set forth in the Declaration and ensuring the relevance and effectiveness of all measures taken to achieve that end. It would therefore be useful to identify lines of action designed to promote the implementation of the Declaration and evaluate its impact.

34. An addendum to this report will present the results of the work of the sixth session of IBC, the first session of the Intergovernmental Committee and the joint meeting of those two bodies, to be held in Rabat from 7 to 13 October 1999 at the kind invitation of the Government of the Kingdom of Morocco.



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OUTLINE

Source: 29 C/Resolution 17.

Background: At its 29th session the General Conference adopted the Universal Declaration on the Human Genome and Human Rights, together with 29 C/Resolution 17 concerning the implementation of the Declaration.

Purpose: The sixth session of the International Bioethics Committee (IBC), the first session of the Intergovernmental Bioethics Committee (IGBC) set up by Article 11 of the IBC Statutes, and a joint session of the two bodies were held in Rabat (Morocco) from 7 to 13 October 1999. The joint session recommended that the Director-General present for adoption by the General Conference at its 30th session the Draft Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights as amended by the IBC and in the light of the comments made by the Intergovernmental Bioethics Committee. The draft guidelines annexed to this document take into account the amendments proposed by the IBC and the comments made by the IGBC. This Addendum, which supplements the Director-General's report (30 C/26), contains a resolution proposed to the General Conference for adoption.

Decision required: paragraph 10.

I. INTRODUCTION

1. At the kind invitation of the Government of the Kingdom of Morocco, the sixth session of the International Bioethics Committee (IBC) (7-9 October 1999), the first session of the Intergovernmental Bioethics Committee (IGBC) (11-12 October 1999) and the first meeting of the joint session (13 October 1999), were held in Rabat, under the high patronage of His Majesty King Mohammed VI and the effective presidency of His Royal Highness Prince Moulay Rachid. The opening ceremony was attended by His Royal Highness Prince Moulay Rachid and the Moroccan Government. Over 140 participants from 52 countries attended the three meetings.

II. SIXTH SESSION OF THE INTERNATIONAL BIOETHICS COMMITTEE (IBC)

2. The IBC re-elected its Bureau, with Mr Ryuichi Ida (Japan) Chairperson and the following four Vice-Chairpersons (in alphabetical order): Mr Héctor Gros Espiell (Uruguay), Mr Mohammad Hamdan (Jordan), Ms Michèle Jean (Canada), Mr Jacek Zaremba (Poland) and Mr Yolande Tano Bouah (Côte d'Ivoire) Rapporteur.

3. The work of the sixth session focused on two themes, the Follow-up of the Universal Declaration on the Human Genome and Human Rights and Ethics and confidentiality of genetic data. Several prominent figures also attended a round table on ethics and public debate: information, education, participation.

4. In accordance with the wishes expressed by the IBC at its fifth session, two meetings were reserved for IBC members at which specialists gave progress reports on research relating, respectively, to cloning, xenotransplantations and embryonic stem cells. The IBC also held a hearing of the Chairman and Chief Executive Officer of *de Code genetics* (Iceland) on the planned health care database set up by law in Iceland.

5. At the conclusion of its work the IBC approved, with amendments, the Draft Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights, accompanied by a draft resolution proposed for adoption by the General Conference at its 30th session. The text was then transmitted to the IGBC at its meeting.

III. FIRST SESSION OF THE INTERGOVERNMENTAL BIOETHICS COMMITTEE (IGBC)

6. After electing as its Chairperson His Excellency Mr Najib Zerouali Ouariti, Minister of Higher Education, Executive Training and Scientific Research of Morocco, representing Morocco on the IGBC, the IGBC adopted its agenda and rules of procedure. It then elected as Vice-Chairpersons the representatives of the Dominican Republic, Germany, the Republic of Korea and South Africa, and as Rapporteur the representative of Hungary.

7. The following Member States of the IGBC were represented at this first session: Belarus, Benin, Canada, Chile, Côte d'Ivoire, Cuba, Dominican Republic, Egypt, Finland, France, Germany, Hungary, Indonesia, Italy, Japan, Lithuania, Morocco, Netherlands, Republic of Korea, South Africa and Tunisia.

8. After presentations concerning the work and conclusions of the sixth session of the IBC, in particular the Draft Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights, the IGBC adopted the following conclusions:

8.1 The Intergovernmental Bioethics Committee (IGBC), in the presence of the International Bioethics Committee, and in an atmosphere of mutual respect, recognizing the magnitude of the scientific, ethical, political and educational tasks to be accomplished and adopting a spirit of openness in its approach to its work, held its first session in Rabat on 11 and 12 October 1999. Its discussions were characterized by constructive collaboration and mutual support.

8.2 The IGBC noted with satisfaction the Draft Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights approved by the IBC on 8 October 1999. During its debates, however, the following comments were made:

- (i) as regards the establishment of a dynamic relationship between the different actors (subparagraph 2.4), it would be helpful to include vulnerable groups among the latter;
- (ii) the evaluation referred to in Section 5 should be carried out in accordance with the procedures established by the Executive Board and the General Conference, in particular because of its budgetary implications.

8.3 The IGBC made the following comments on the proposals in view of the application of Article 24 of the Universal Declaration on the Human Genome and Human Rights by the International Bioethics Committee of UNESCO (IBC):

- (i) regarding the dissemination of the principles set out in the Universal Declaration on the Human Genome and Human Rights (I.6) specific arrangements should be made to take into account the level of education of the target groups concerned. Furthermore, the relevant international non-governmental organizations and the higher education establishments should be regarded as privileged points of relay, in the same way as the national ethics committees;
- (ii) within the framework further examination of issues raised by the application of the principles set out in the Declaration (II.2), a World Report on Bioethics should be disseminated by electronic means. Some members of the IGBC, however, expressed reservations concerning the advisability of preparing such a report;
- (iii) the formulation of advice and recommendations concerning the follow-up of the Declaration (IV.1) should be seen in the context of Articles 7 and 11 (2) of the IBC Statutes. Thus the advice and recommendations of the IBC are made public promptly and widely disseminated. The IGBC, for its part, examines the result of the deliberations of the IBC and adds its comments to the IBC. The reports of the two Committees are submitted to the Director-General in parallel. Finally, it is for the Director-General to transmit the advice and recommendations of the IBC, together with those of the IGBC, to the Member States, the Executive Board and the General Conference;
- (iv) the IGBC considered that all practices should be taken into consideration, even if, in certain cases, the IBC concluded that the practices in question did not have a sound scientific basis.

8.4 The Intergovernmental Committee expressed the hope that, in establishing its programme of work, the IBC would be guided by the following criteria:

- (i) priority given to the identification of practices which might be contrary to human dignity, such as germ-line interventions, as referred to in Article 24 of the Universal Declaration on the Human Genome and Human Rights;
- (ii) the specific fields covered by UNESCO's mandate (education, science, culture, information and communication);
- (iii) the relevance of the subjects covered to the Universal Declaration on the Human Genome and Human Rights;
- (iv) the establishment of cooperation with other bodies and Specialized Agencies of the United Nations system and other independent bodies, and the taking into account of their activities in the life sciences, when necessary seeking the cooperation of these institutions.

8.5 As far as the working methods of the IBC in the preparation of its thematic reports are concerned, the IGBC welcomed the intention of the IBC to organize appropriate consultations with parties concerned, including vulnerable groups such as, *inter alia*, ethnic minorities and indigenous peoples.

8.6 The members of the IGBC considered that it would be appropriate that its next session be convened by the Director-General, alternately with the session of the IBC and after sufficient time had elapsed to enable its members to examine the IBC's conclusions.

IV. JOINT SESSION

9. The joint session, attended by members of the IBC and of the IGBC, recommended that the Director-General submit for adoption by the General Conference at its 30th session the "Draft Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights" annexed to this Addendum, together with a resolution proposed to the General Conference for adoption.

V. CONCLUSION

10. In accordance with the outcome of the aforesaid proceedings, the Director-General submits to the General Conference the "Draft Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights", which take into account amendments proposed by the IBC and comments made by the IGBC. He also proposes the following draft resolution for adoption by the General Conference:

The General Conference,

Recalling the Universal Declaration on the Human Genome and Human Rights,

Bearing in mind 29 C/Resolution 17 entitled "Implementation of the Universal Declaration on the Human Genome and Human Rights" and resolution A/RES/53/152 entitled "The human genome and human rights" adopted by the General Assembly of the United Nations at its 53rd session,

Having noted resolution 1999/63 entitled "Human Rights and Bioethics", adopted by the United Nations Commission on Human Rights at its 55th session,

Having noted the Director-General's report on the implementation of the Declaration (30 C/26 and Addendum),

1. Approves the "Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights" (30 C/26 Add.);
2. Invites the Director-General to transmit them to the Secretary-General of the United Nations, with a view to the 54th session of the General Assembly of the United Nations and to the work of the relevant bodies, in particular the United Nations Commission on Human Rights;
3. Further invites the Director-General to transmit them to the United Nations Specialized Agencies and to other relevant international, intergovernmental and non-governmental organizations and to disseminate them as widely as possible;
4. Invites Member States, international, intergovernmental and non-governmental organizations and all identified partners to take all the necessary steps to implement the guidelines in question.

ANNEX

DRAFT GUIDELINES FOR THE IMPLEMENTATION OF THE UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS

1. Why guidelines?

The Universal Declaration on the Human Genome and Human Rights sets forth the basic principles bearing on research in genetics and biology and their applications. In order to guarantee the respect of these principles, the Declaration recommends that they be made known, disseminated and given shape as measures, especially in the form of legislation or regulations. The Declaration also specifies the measures that Member States should take for its application.

The implementation of the Declaration is all the more urgent since scientific progress in genetics and biology is accelerating and giving humankind both hope and creating ethical dilemmas.

These guidelines seek to identify not only the tasks devolving on the different actors in the implementation of the Declaration but also modalities of action for their achievement.

2. What to do?

2.1 The dissemination of the principles set forth in the Universal Declaration on the Human Genome and Human Rights is a priority and a preliminary condition for their effective application. Thus, this dissemination must be as wide as possible and especially oriented towards scientific and intellectual circles, people involved in education and training, especially in universities, and decision-making bodies such as parliaments.

3. How?

- 3.1.1 The translation of the Declaration into the largest possible number of national languages.
- 3.1.2 The organization of seminars, symposia and conferences (in Benin, Croatia, Monaco, United Republic of Tanzania, Uruguay, etc.) at the international, regional, subregional and national levels.

4. For whom are these guidelines intended?

Experience shows that to implement an international instrument, a synergy needs to be created between all actors at the different levels. Today, international action is characterized by partnership in which each actor, while retaining his identity and specific nature, complements the role played by the others.

- 2.2 The creation of awareness, education, and training in the principles contained in the Declaration are especially important goals so that each and every member of society can grasp the ethical issues at stake in genetics and biology.
- 3.2.1 The drafting of the simplest and most explicit possible commentary on each of the articles of the Declaration.
- 3.2.2 The publishing of books on the subject, designed both for a non-specialist public or intended for various professional groups concerned (scientists, philosophers, jurists, judges, journalists, etc.).
- 3.2.3 The preparation of programmes of education and training in bioethics designed for the secondary and university level.
- 3.2.4 The preparation of training programmes in bioethics designed for teachers and trainers.
- 3.2.5 The preparation of information kits on defined subjects and their dissemination among public and private decision-makers and press institutions.
- 3.2.6 The production of audiovisual materials on bioethics for the general public.
- 3.2.7 Multimedia exhibitions designed especially for young people.
- 2.3 Exchanges of studies and analyses pertaining to questions of bioethics, and
- 3.3.1 The creation of institutions such as independent, pluralist and
- Thus, all these guidelines are intended for:
- States and National Commissions for UNESCO;
 - UNESCO (Headquarters and field offices);
 - the International Bioethics Committee (IBC);
 - the Intergovernmental Bioethics Committee (IGBC);
 - bodies and specialized institutions of the United Nations system;
 - competent intergovernmental and non-governmental organizations at the international, regional and national levels;
 - public and private decision-makers, especially in scientific policy;
 - lawmakers;
 - ethics committees and similar bodies;
 - scientists and research workers;
 - individuals, families and populations with genetic mutations that may lead to illnesses or disabilities.

- programmes of information on this subject must be organized at the international and regional levels, especially in order to identify practices that could be contrary to human dignity.
- 2.4 The establishment of a dynamic relationship between the different actors is desirable in order to promote dialogue among industrialists, members of the civil society, vulnerable groups, scientists and political leaders.
- 2.5 Freedom of research, especially in genetics and biology, should be respected and scientific and cultural cooperation encouraged and broadened, especially between the countries of the North and the South.
- multidisciplinary ethics committees which constitute the special partners of decision-makers, the scientific community and the civil society.
- 3.3.2 The networking of these institutions so as to facilitate communication and exchanges of experiences among them, especially for carrying out joint activities.
- 3.4.1 The involvement of the economic actors, especially from industry, and of social organizations such as associations of vulnerable persons or families and friends of vulnerable persons.
- 3.4.2 The organization of public debates on issues covered by the Declaration and the exploration of various approaches (conferences for consensus, public consultation, etc.).
- 3.5.1 The in-depth analysis of the conditions which encourage freedom of research or which hamper it.
- 3.5.2 The periodic examination by the IBC of cooperation between the countries of the North and the South and an examination of the obstacles, if any, in order to overcome them.

- 2.6 Examples of legislation and regulations that embody the principles set out in the Declaration should be prepared in order to serve as a source of inspiration to States.
- 3.6.1 The organization by the IBC of international and/or regional workshops aimed at providing a standard framework of legislation and regulations in the field of bioethics.
- 3.6.2 The collection and processing of information on the international and regional instruments pertaining to bioethics as well as on national legislation and/or regulations.
- 2.7 As most of the issues covered by the Declaration are at the interface of the fields which fall within the assigned tasks of the various organizations, it is through effective cooperation that they will be able to deal with issues in a concerted manner.
- 3.7.1 The setting up of an inter-agency committee within the United Nations system open to other interested intergovernmental organizations and responsible for the coordination of activities related to bioethics.

- See paragraph 3 of Resolution 1999/63 entitled “Human Rights and Bioethics” adopted by the United Nations Commission on Human Rights at its 55th session.

5. Evaluation

Five years after the adoption of the Declaration, i.e. in 2002, UNESCO should evaluate both the results obtained through the guidelines defined here above and the impact of the Universal Declaration on the Human Genome and Human Rights worldwide (States, intellectual communities, institutions of the United Nations system, intergovernmental organizations - international and regional - competent non-governmental organizations, etc.).

The evaluation, which should be carried out according to the procedures established by the Executive Board and the General Conference, in particular because of its budgetary implications, will be examined at a joint session of IBC and IGBC and will be presented by the Director-General in 2003 to the statutory bodies of the Organization along with, as the case may be, relevant recommendations.