



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



*International Bioethics
Committee (IBC)*

*Comité international
de bioéthique (CIB)*

Distribution limited

BIO-503/99/CIB-6/GT-1/1
Paris 20 May 1999
Original : French

**WORKING GROUP ON THE
FOLLOW-UP OF THE UNIVERSAL DECLARATION ON
THE HUMAN GENOME AND HUMAN RIGHTS**

Paris, 11 and 12 May 1999

**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)**

Before opening the discussions, the Working Group on the follow-up of the Universal Declaration on the Human Genome and Human Rights expressed its gratitude to Mr Héctor Gros Espiell, its Chairperson, for the quality and clarity of the working document he had drafted, entitled "An Outline Interpretation of Article 24 of the Universal Declaration on the Human Genome and Human Rights with a view to its implementation by the International Bioethics Committee of UNESCO (IBC)".

I. DISSEMINATION OF THE PRINCIPLES SET OUT IN THE UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS

1. The Working Group on the follow-up of the Universal Declaration on the Human Genome and Human Rights felt that, as the only text in the field of biology and genetics having been adopted through universal agreement, the unique character of the Declaration should be highlighted.
2. The Group expressed its satisfaction at the work carried out by the Secretariat in the dissemination of the Universal Declaration and in following up the decisions of the General Conference¹.

1. Document dated 12 April 1999 prepared by the UNESCO Secretariat for the 55th Session of the United Nations Commission on Human Rights, entitled "The Universal Declaration on the Human Genome and Human Rights and Follow-up Action".

3. The Group expressed its satisfaction at the Resolution “Human Rights and Bioethics” of 23 April 1999, adopted by the United Nations Commission on Human Rights at its 55th session² and expressed its interest for the possible invitation that ECOSOC could address to UNESCO to present a periodic report related to bioethics.
4. In welcoming the initiative taken by several National Commissions for UNESCO to translate the Universal Declaration into different languages, sometimes at the instigation of members of the IBC, the Working Group stressed the need to translate the Declaration into numerous other national languages in order to ensure as broad a dissemination as possible.
5. The Group welcomed the publication of a book on the genesis of the Universal Declaration by UNESCO Publishing, in English and in French.
6. The Group considered that, within the framework of the dissemination of the principles set out in the Universal Declaration, national ethics committees constituted a privileged point of relay.
7. The Group expressed its wish that the Universal Declaration be made better known to scientific circles, in particular during:
 - (i) the First Inter-institutional Meeting on Bioethics and Biosecurity, organised by the National Scientific and Technological Research Council (CONICIT) in Caracas, Venezuela, from 21 to 23 June 1999;
 - (ii) the Seminar on “The European Convention on Biomedicine at Human Rights : Towards a New Generation of Human Rights?”, organized by the *Association internationale Droit, Ethique et Science (IALES)* in Bratislava, Slovakia, from 25 to 27 June 1999;
 - (iii) the World Conference on Science (Budapest, Hungary, from 26 June to 1 July 1999) organized by UNESCO and the International Council of Science (ICSU) (including the possible reference to the Universal Declaration on the Human Genome and Human Rights to be included in the Draft Declaration to be adopted);
 - (iv) the International Symposium on “Constitutions and Bioethics” organised in Rotterdam, on 15 and 16 July 1999, by the International Association of Constitutional Law;
 - (v) The Second International Seminar on Interferon and on Biotechnology, organized in Havana, Cuba, from 29 November to 3 December 1999, by the Center of Genetic Engineering and Biotechnology;
 - (vi) the World Human Genetics Congress which will be held in the United Kingdom in 2001 (the Secretariat could examine the possibility of organising, in collaboration with the Human Genome Organization (HUGO), a Symposium within the framework of this Congress).
8. The Working Group envisaged proposing that the Interparliamentary Union devote a session to the implementation of the Universal Declaration, in compliance with the Resolution it adopted in Madrid in March-April 1995. A similar invitation could be addressed to the Latin-American Parliament.
9. The Working Group noted with interest that a preliminary report on “Bioethics and International Law” will be presented by Judge Mohammed Bedjaoui, member of the Working Group, at the forthcoming session of the Institute of International Law (Berlin, Germany, August 1999).

2. Document (reference E/CN.4/1999/L.95), distributed to the members of the IBC Working Group on the follow-up of the Universal Declaration on the Human Genome and Human Rights.

10. The Working Group considered that discussions on the Universal Declaration should be further encouraged in Universities. Three or four people per country, in particular members of the IBC, could be given the responsibility of organising symposia, presentations and seminars.
11. In any case, apart from the work carried out on an international level by the IBC, in order to define a strategy in bioethics at regional and national level, the Working Group proposed the organisation of regional and national seminars on bioethics.
12. The Working Group felt that the IBC members and other specialists should be invited to provide comments on the Declaration, article by article, with a view to a brief publication aiming at a facilitated comprehension by the non-specialised public.
13. Furthermore, the Working Group proposed that manuals on the Universal Declaration adapted to the different professional circles concerned, be drawn up.

II. FURTHER EXAMINATION OF ISSUES RAISED BY THE APPLICATION OF THE PRINCIPLES SET OUT IN THE DECLARATION AND BY THE EVOLUTION OF THE TECHNOLOGIES IN QUESTION

1. The Working Group considered that it would be appropriate to establish “states of the art” on the different questions covered by the Universal Declaration.
2. The Working Group supported the proposal of the Director-General in the “Draft Programme and Budget for 2000-2001” (30 C/5) for the publication of a World Report on Bioethics, by suggesting that the report in question should not be limited to genetics but should encompass other fields, such as reproductive techniques, tissue and organ transplantation, transgenesis, etc.
3. In particular, the Working Group felt that national ethics committees could contribute to the identification of concrete situations likely to raise ethical issues.

III. ORGANISATION OF APPROPRIATE CONSULTATIONS WITH PARTIES CONCERNED, SUCH AS VULNERABLE GROUPS

1. The concept of “vulnerable groups” should be seen in the context of articles 5(e) and 17 of the Declaration, in relation to:
 - (i) prior, free and informed consent,
 - (ii) genetic screening,
 - (iii) discrimination based on genetic characteristics,
 - (iv) ownership of genetic material, and
 - (v) cultural representation of identity.
2. The concept of “vulnerable groups” should be set in a spatio-temporal context, because it could evolve or change following these two axis. In particular, it includes: children, the legally incapable, prisoners, indigenous populations, handicapped persons, patient or patient family groups, etc.

IV. FORMULATION, IN ACCORDANCE WITH UNESCO'S STATUTORY PROCEDURES, OF RECOMMENDATIONS ADDRESSED TO THE GENERAL CONFERENCE AND OF ADVICE CONCERNING THE FOLLOW-UP OF THE DECLARATION

1. The recommendations of the IBC are addressed to the Director-General of UNESCO, who presents them to the Executive Board with his proposals. After examination, the Executive Board may submit them to the General Conference, if need be, with its observations.

2. The Working Group felt that it should be concrete and precise concerning the follow-up of the Universal Declaration, in particular by distinguishing the general follow-up from that of special situations. In the first case, the publication of the World Report on Bioethics, previously mentioned, could apply. In the second case, the follow-up of special situations could be of an advisory form, without excluding other possibilities.
3. The Working Group felt that on the occasion of one of its future sessions, it should establish rules concerning the submission of an issue to the IBC. Nevertheless, a first exchange of opinions was held on the possible rules of competence of the IBC and its admissibility on issues submitted to it. It wondered in particular which bodies would have the faculty to submit an issue to the IBC, the characteristics of the examination of such an issue, the time delay allowed, etc.³

V. IDENTIFICATION OF PRACTICES THAT COULD BE CONTRARY TO HUMAN DIGNITY

1. The Working Group broached discussions on this issue, particularly concerning germ-line interventions and human cloning for non reproductive purposes. The IBC members, as well as outside experts, will be invited to present a state of the art on these questions.
2. The Working Group examined the concept of human dignity from three points:
 - (i) the non instrumentalisation of human beings,
 - (ii) the singularity (unique character of each human being), and
 - (iii) the respect of every human being regardless of his/her handicaps or his/her genetic characteristics.

VI. SUGGESTED SUBJECTS WHICH COULD BE DEALT WITH BY THE INTERNATIONAL BIOETHICS COMMISSION IN PLENARY

1. Concerning present research in the field of human genetics, focus should be made on the major trends in research : multifactorial diseases (cardio-vascular disease, cancer, arthroses), Alzheimer's disease, etc., and not on "peripheral" practices, which sometimes give rise to sensational announcements.
2. It would be opportune for certain subjects to be discussed within the IBC, in particular questions linked to:
 - (i) research on embryonic stem-cells and interspecific hybrids (human-animal, animal-vegetal transgenesis, etc.);
 - (ii) the "post-mapping" of the human genome (ethical issues of post-genomic research);
 - (iii) the protection of the human embryo;
 - (iv) the possible use of genetic research results for non-peaceful purposes (biological weapons);
 - (v) North-South international co-operation and solidarity;
 - (vi) a trend, more defined than in the past, to secrecy in scientific research; and,

3. On this point refer to Gros Espiell, Héctor : "Mechanism for Monitoring the Future Universal Declaration on the Human Genome and Human Rights" UNESCO Document, CIP/BIO/96/COMJUR.7/3, Paris 1 July, 1996, paragraphs 73 to 81.

- (vii) the consequences of changes in priority of public and private funding of research.