INTERNATIONAL BIOETHICS COMMITTEE OF UNESCO (IBC)

SIXTH SESSION

INTERGOVERNMENTAL BIOETHICS COMMITTEE (IGBC)

FIRST SESSION

PROCEEDINGS

October 1999

Volume I

PROCEEDINGS

INTERNATIONAL BIOETHICS COMMITTEE OF UNESCO (IBC)

sixth session

INTERGOVERNMENTAL BIOETHICS COMMITTEE (IGBC)

first session

Volume I

Division of the Ethics of Science and
Technology of UNESCO

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INTRODUCTION

At the kind invitation of the Government of the Kingdom of Morocco, the Sixth Session of the International Bioethics Committee (IBC) and the First Session of the Intergovernmental Bioethics Committee (IGBC) and the first joint session of the two bodies was held in Rabat, Morocco from 7 to 13 October 1999 under the High Patronage of His Majesty King Mohammed VI and the Effective Presidency of His Royal Highness Prince Moulay Rachid, who attended the opening ceremony on 7 October, accompanied by the members of the Moroccan Government.

The Sixth Session of the IBC was devoted to the 'Follow-up of the Universal Declaration on the Human Genome and Human Rights' and to the subject of 'Confidentiality and Genetic Data'. The session devoted to the follow-up of the Declaration led to the adoption by the IBC of guidelines for the implementation of the Declaration, which were to be later approved by the IGBC. The General Conference of UNESCO endorsed these guidelines at its 30th session. Moreover, the presentation of the draft report on 'Confidentiality and Genetic Data' allowed for valuable comments and suggestions to be made.

A round-table on the topic of 'Bioethics and Public Debate: Information, Education, Participation' was also organized. It gathered together a number of representatives, in particular from the education sector, the media, non-governmental organizations, ethics committees and young people. The different interventions and debates they gave rise to brought out the paramount importance of associating all actors concerned in the public debate on bioethics and of fostering information and education at all levels of society.

The IGBC, which was meeting for the first time since its inception, was informed of the work of the IBC since the adoption of the Universal Declaration on the Human Genome and Human Rights in 1997, and more particularly its work at the sixth session and the follow-up of the Declaration.

Volume I of the Proceedings includes the reports of the Sixth Session of the IBC and of the First Session of the IGBC. It also includes the Report on Confidentiality and Genetic Data, the Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights, the speeches delivered during these meetings and the list of participants.

Volume II includes the presentations of participants in the Round-Table, together with the state-of-the-art presentations on research on cloning, xenotransplantion and research on embryonic stem cells and interspecific hybrids, given during the session reserved for the members of the IBC.

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Chapter 1

REPORT OF THE SIXTH SESSION OF THE INTERNATIONAL BIOETHICS COMMITTEE OF UNESCO (IBC)

by Yolande Tano Bouah,
Rapporteur of the IBC

I. Introduction

1. At the kind invitation of the Government of the Kingdom of Morocco, the Sixth Session of the International Bioethics Committee (IBC) was held in Rabat, Morocco, from 7 to 9 October 1999, under the High Patronage of His Majesty King Mohammed VI and the Effective Presidency of His Royal Highness Prince Moulay Rachid. This session was attended by more than 120 participants from 49 countries.

2. During an informal meeting, the IBC, in accordance with its Statutes, elected the Bureau on the basis of proposals from the Director-General of UNESCO. It re-elected the Chairperson, Mr Ryuichi Ida (Japan), the four Vice-Chairpersons (in alphabetical order), Mr Héctor Gros Espiell (Uruguay), Mr Mohammed Hamdan (Jordan), Mrs Michèle Jean (Canada), Mr Jacek Zaremba (Poland), and its Rapporteur, Mrs Yolande Tano Bouah (Côte d'Ivoire).

3. The Sixth Session reviewed the 'Follow-up of the Universal Declaration of the Human Genome and Human Rights' and discussed the theme 'Confidentiality and Genetic Data'. A Round Table, with several personalities, was also held on the theme 'Bioethics and Public Debate: Information, Education, Participation'.

4. In accordance with the wishes expressed during the Fifth Session, two meetings were reserved for members of the IBC, during which state-of-the-art presentations were made respectively on research on cloning, xenotransplantion and research on embryonic stem cells and interspecific hybrids. Moreover, a hearing was given by the Chief Executive Officer and President of *deCode genetics* (Iceland) on the project The Planned Healthcare Database in Iceland.

II. Opening of the Sixth Session of the IBC

5. His Royal Highness Prince Moulay Rachid honoured with his Effective Presidency the opening ceremony of the Sixth Session, at which all the members of the Moroccan Government were present.

6. The Representative of the Director-General of UNESCO, Mr Georges Kutukdjian, thanked the Kingdom of Morocco for hosting the Sixth Session of the IBC. He cited the major transformations of the last few decades in biology and genetics and the setting up of related ethical principles. He stressed the fact that the reflection, especially in the framework of the IBC, presupposed an opening up of barriers between disciplines and a dialogue between cultures. Finally, after evoking the themes of the agenda of the sixth session, he stressed the difficult challenge for the ethical reflection to keep abreast of the tremendous advances of science and issues at stake.

7. The Minister for Higher Education, Executive Training and Scientific Research, Mr Najib Zerouali Ouariti, stressed Morocco's growing interest in bioethics and recalled the main activities in this field in his country. In the framework of the Universal Declaration on the Human Genome and Human Rights, he recalled IBC's action and stressed the role that the National Commissions for UNESCO should play at the national level, especially in promoting the ideals of the Organization.

8. The speeches made during this ceremony are included in these Proceedings.

III. Round table on 'Bioethics and Public Debate: Information, Education, Participation'

9. Bearing in mind Article 21 of the Universal Declaration on the Human Genome and Human Rights, which invites States to facilitate open discussion in the field of bioethics, the IBC decided to organize a round table on 'Bioethics and Public Debate: Information, Education, Participation'. The Round Table, chaired by Mrs Nicole Questiaux, Chairperson of the Permanent European Conference of National Ethics Committees, brought together several personalities, in particular from the educational sector, the media, non-governmental organizations (NGOs), ethics committees and young people.

10. In her preliminary address, Mrs Questiaux said that the theme of the round table was a great challenge for all institutions interested in bioethics. The ethical preoccupations raised by scientific progress has always been present, especially within the research community, and has

recently given rise to a movement of ideas tending towards the creation of independent and multidisciplinary consultative bodies. Communication between these bodies and the public, through information, education and participation, is a necessary component of this trend. Besides, their opinions, in most cases, are made public but their working sessions themselves are not public.

11. Mr Alain Perez, journalist in charge of the section *'Sciences'* in *Les Echos* (France) and the weekly supplement *'Les Echos industrie'*, spoke of the problems that scientific journalists can meet with. Firstly, he mentioned criticism levelled by scientists against approximate and insufficiently verified information. In this respect, he pointed out that journalists do not always have the possibility of or the necessary qualifications to question statements by researchers. Furthermore, he recalled the possibility that the reliability of research results might be affected by financial implications of scientific discoveries and pressure exerted on researchers by economic circles. These researchers might sometimes be tempted to announce the results of their research prematurely in order to attract interest on the part of investors. In this respect, Mr Perez took as an example the system of financing biotechnological industries, i.e. start-up firms, that involve huge sums of money without yielding any immediate returns. To keep the investors interested, these firms regularly announce agreements with major pharmaceutical groups, or discoveries, some of which may be questionable. Mr Perez felt that the financial interests at stake sometimes bias the relationship and the transmission of information between journalists and researchers.

12. Mr Farid Hakkou, Professor at the Faculty of Medicine in Casablanca and Secretary-General of the Moroccan Bioethics Committee, for his part, evoked Morocco's experience in the field of ethics, especially with the creation in 1989 of an ethics committee at the Faculty of Medicine of Casablanca, designed to respond more particularly to ethical issues in clinical trials which, at that time, were more and more numerous in the developing countries. The establishment of an institution of this kind has also been designed to cope with the lack of knowledge, on the part of health professionals, of the basic principles of bioethics. The scientific, academic and religious circles has taken part, from the very outset, in the ethical debate called for by the ethics committee while the general public appeared to be more reserved in the matter. With the appearance of illnesses such as AIDS that profoundly affect the daily lives of large numbers of people, the general public is becoming increasingly interested in the ethics debate. However, certain persons concerned by these

illnesses have sometimes made use of the forum of the ethics committee to personalize the debate. In conclusion, Mr Hakkou emphasized the need to introduce bioethics teaching in school programmes.

13. Mrs Habiba Chaabouni, Head of the Department of Genetics at the Faculty of Medicine of Tunis, highlighted the results and difficulties of university teaching in bioethics which is increasingly a vital necessity in the context of recent medical progress. Training in bioethics has undoubtedly made a major contribution to awareness among doctors and, more generally, health professionals and researchers of the ethical dimension and the ethical implications of their daily activities and research. Furthermore, the interdisciplinary character and multidisciplinary approach of teaching of this kind has obvious repercussions on society as a whole; it leads to the creation, at an accelerated pace, of bioethics committees. Stressing the need to train specialists in bioethics who in turn would train students, Mrs Chaabouni concluded that it was important to create a programme for teaching bioethics in all institutions of higher education related to the life sciences.

14. Mr Darryl Macer, Director of the Eubios Ethics Institute at the University of Tsukuba (Japan), considered that bioethics could be approached in three different ways: descriptively, normatively ('prescriptive bioethics') and interactively by debates in society. While acknowledging the diversity of opinions on bioethics, he stressed the need to prepare education programmes designed especially for schools and the media in order to enable the public to make informed choices. Mr Macer considered that four elementary ethical principles - autonomy, justice, beneficence and innoxiousness - were needed to constitute a framework for the preparation of such programmes. In this respect, the media have a crucial role presenting the different viewpoints and opinions in order to bring about a real participation by the public. In conclusion, Mr Macer stressed the extraordinary possibility offered by the Internet, to a very wide public, of participating in the ethical debate, although many improvements were still desirable in this respect.

15. The presentation by Miss Diane L. Gal, Chairperson for Information and Education in the International Pharmaceutical Students' Federation, stressed the importance for young people of participating in the public debate on bioethics. Indeed, inasmuch as the decisions that are taken and the policies defined today have an impact on the daily life of young people and their future, they need to be informed and educated in order to think by themselves about the questions involved and to take informed decisions. In this respect, the public debate, by associating young people with professionals and experts in bioethics, favours this educative action.

Miss Gal said that young people could also bring a new dimension to this debate inasmuch as they are more inclined to react positively to technological progress.

16. Mr Francis P. Crawley, Chairperson of the Ethics Working Party, European Forum for Good Clinical Practice (EFGCP), stressed the role of non-governmental organizations (NGOs) in the public debate on questions of bioethics. He recalled that as soon as it was set up, the International Bioethics Committee of UNESCO has always taken care to associate the NGOs in the discussions by increasing their participation and improving their knowledge of the questions involved. Non-governmental organizations have, therefore, extremely valuable contributions to make to the public debate, since they benefit from a certain degree of independence with regard to governmental or intergovernmental organizations or institutions. Furthermore, an open and free public debate requires the participation of those who are directly concerned by questions of bioethics; the presence of NGOs, where people work together for common interests, is therefore particularly legitimate. For example, Mr Crawley recalled that the EFGCP organizes meetings between members of the academies, governments, industries and patients' organizations, to bring together their opinions and interests. He also cited the example of the *Société camerounaise de bioéthique* (SCB) [Cameroon Bioethics Society], which has played a key role in Cameroon and in Africa to promote discussion on bioethics in society. Finally, he stressed the role of the NGOs with regard to AIDS where they are particularly active not only in providing the necessary assistance to meet the needs and concerns of sick people but also in contributing to the appreciation of the ethical issues about this disease.

Discussion

17. With respect to information, particular emphasis was laid on the responsibility of the media in presenting an exact and balanced view of scientific results and resisting any tendency to dramatize them. The importance of good relations between scientists and journalists was also stressed, in order to enable the media to contribute to the education of the public at large.

18. In formal education, emphasis was laid on the importance of introducing teaching at appropriate levels and on the need to promote an international debate on this subject. Finally, the participation of youth in the ethical debate concerning life sciences was referred to several times and the question of their knowledge of the principles set out in the Universal Declaration on the Human Genome and on Human Rights was seen to be a challenge for years to come.

IV. Follow-up of the Universal Declaration on the Human Genome and Human Rights

19. Mrs Elisabeth Pognon, Magistrate, Former President of the Constitutional Court of Benin, chaired the session on the Follow-up of the Universal Declaration on the Human Genome and Human Rights, which was designed especially to identify the modalities of promotion of the principles set out in the Declaration.

20. At its Fifth Session in December 1998, the IBC had decided to set up a Working Group on the Follow-up of the Declaration. The chairmanship of this working group had been entrusted to H. E. Mr Héctor Gros Espiell, Vice-Chairperson of the IBC (see Annex I for the composition of the Working Group). The group had met at UNESCO Headquarters in Paris, on 11 and 12 May 1999. During this meeting, the Working Group had finalized a document entitled '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)' (BIO-503/99/CIB-6/GT-1/1). This document was presented by Mr Gros Espiell along with the report of the meeting of the Working Group (BIO-503/99/CIB-6/GT-1/2).

A. Presentation of the Report of the Meeting of the Working Group on the Follow-up of the Universal Declaration on the Human Genome and Human Rights and 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)'

21. After an introductory part, Chapter II of the Report, entitled 'Interpretation of Article 24 of the Universal Declaration on the Human Genome and Human Rights with a view to its Application by the International Bioethics Committee', dealt with the discussions on: the dissemination of the principles set out in the Declaration; the further examination of issues raised by the application of these principles and the evolution of the technologies in question; the organization of appropriate consultations with parties concerned such as vulnerable groups; the 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; and the identification of practices that could be contrary to human dignity. A third part was devoted to suggested subjects that could be dealt with by the International Bioethics Committee in plenary.

22. As part of the background information needed by the IBC to focus its future work, Mr Gros Espiell recalled the nature of the Declaration which, as such, was not a source of legal obligations imposing constraints on States. However, the fact that the United Nations General Assembly has for the first time 'endorsed' a declaration coming from a specialized agencies of the United Nations suggests that, in the future, the Declaration could be a source of international law along the lines already laid down by the evolution of the interpretation of the Universal Declaration of Human Rights of 1948. Mr Gros Espiell also stressed the innovative character of the Universal Declaration on the Human Genome and Human Rights, in the sense that it is the first document of a declarative nature that envisages the existence of a system for its follow-up and implementation (Art. 24).

23. Mr Gros Espiell then presented 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)'. These proposals follow, like the report, Article 24 of the Declaration:

- the dissemination of the principles set out in the Declaration;
- the further examination of issues raised by the application of the principles set out in the Declaration and the evolution of the technologies in question, with the proposal to prepare a state-of-the-art report on the different issues covered by the Declaration;
- the organization of appropriate consultations with parties concerned such as vulnerable groups. In this respect, the Proposals specify that the notion of 'vulnerable groups' should be understood with reference to that of prior, free and informed consent, to the possibilities offered by genetic screening, to the risk of discrimination based on genetic characteristics, to questions related to the owernship of genetic material and the cultural representations of identity. The Proposals also stress the fact that this notion should be envisaged in a spatio-temporal context, because it could evolve or change along these two axes;
- the 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, with the need to identify 'modules' for submitting questions to the IBC;

- the identification of practices that could be contrary to human dignity. This notion has been examined by the Working Group from three points: the non instrumentalization of human beings, his singularity and the respect to every human being, whatever his/her disabilities or his/her genetic characteristics;
- the suggested subjects which could be dealt with by the IBC in plenary.

24. It appears that the field of application of the principles set out in the Universal Declaration on the Human Genome and Human Rights goes beyond the context of the human genome itself. These are general principles that the scientific community and society as a whole deem to be basic principles for the life sciences as a whole.

Discussion

25. The discussion were mainly on the dissemination of the principles set out in the Declaration, the importance of national ethics committees, the notion of 'vulnerable groups' and the question of practices contrary to human dignity.

Dissemination of the Principles Set out in the Universal Declaration on the Human Genome and Human Rights

26. While the scale of the work of dissemination already undertaken by UNESCO was acknowledged, it was suggested that the Organization should further develop its activities in this field, especially in developing countries, by using all the existing structures at the local level and also by working through the National Commissions for UNESCO of the Member States.

27. The principles of the Declaration need to be disseminated among decision-making institutions as well as in civil society as a whole. In this respect, the national ethics committees have a special role as points of relays. At the same time, the local ethics committees, especially those in research centres and institutions as well as in the health establishments, also have a major role to play, more especially in the scientific community in order to sensitize it to ethical questions. In addition to the ethics committees, the non-governmental organizations must play a role in disseminating the principles of the Declaration.

28. Other ways of disseminating the principles of the Declaration must be considered. In particular, the organization of regional and national seminars would make the principles set out in the Declaration more widely known and allow them to be analysed in the light of the perceptions and sensitivities proper to each culture.

29. Furthermore, the brochure with commentaries on the Declaration, article by article, is being prepared by the Secretariat and would be a valuable tool for disseminating the principles of the Declaration to a very wide public.

The National Ethics Committees

30. Given the importance attached by the Declaration to the national ethics committees and the absence of these committees in many countries, UNESCO must help the States to create such bodies. Reference was also made to the initiative undertaken by the Organization to promote the establishment and networking of ethics committees, especially with the creation of a database pooling information on ethics committees and/or institutions throughout the world.

31. It was recalled that, under Article 16 of the Declaration, the national ethics committees should be independent, multidisciplinary and pluralistic. It is necessary to avoid any confusion in their functions that could affect their credibility: far from being decision-making bodies, the national ethics committees have the task of preparing opinions - grounded in scientific, legal and political principles - to be used as a basis for action by the lawmaker. It is up to political leaders to assume their responsibilities in acting to reflect these opinions in legislation.

Vulnerable Groups

32. The vulnerable groups mentioned in Article 24 of the Declaration are one of the components of parties concerned with which the IBC should organize consultations. This notion of 'vulnerable groups', which is not limited to the concept of incapable, has been perceived as equivocal since, with the present development of genetic knowledge, it can be considerably widened. When groups and/or minorities within populations show particular or specific genetic characteristics, they could form a vulnerable group as understood under the Declaration. Thus, the suitability of defining this notion, in order to promote an understanding of it and prevent an excessively limited interpretation, was evoked inasmuch as it is an explicit part of a specific space/time framework.

Practices Contrary to Human Dignity

33. Within the context of Article 24 of the Declaration, participants stressed that certain germ-line interventions might not be contrary to human dignity. Furthermore, the Declaration condemned reproductive cloning of human beings. Some participants felt that, by an *a contrario* interpretation, cloning for non-reproductive purposes could not be ruled out and that such a possibility had to be studied in greater depth by the IBC.

B. Draft Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights (BIO-503/99/CIB-4/4)

34. In view of the importance of defining an action framework for the follow-up of the Declaration, Mr Gros Espiell had prepared a set of 'Draft Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights' in view of this Sixth Session of the IBC. The guidelines seek to identify not only the tasks devolving on the different actors in the implementation but also modalities of action for their achievement.

35. Mr Gros Espiell first of all stressed the close link between the Proposals finalized by the Working Group and the Draft Guidelines. He also recalled that the Draft Guidelines, once approved by the IBC with amendments if any, would be sent to the Director-General of UNESCO for submission to the General Conference at its 30th session (October-November 1999). He then read out the Draft.

Discussion

36. During the discussion, some participants asked that specific action of the IBC should be made clearer, especially as regards to co-operation between countries of the North and the South and for the organization of international and/or regional workshops designed to provide a standard framework of laws and regulations in bioethics. He also suggested that Section IV, entitled 'For whom are these Guidelines intended?', should mention the Intergovernmental Bioethics Committee as well as the National Commissions for UNESCO.

37. Furthermore, the Committee wished that certain points be added or reformulated in Section III on the modalities of action, especially in education. In particular, point 3.5.1 was revised in order to take account of the need for a deeper analysis of the conditions that foster freedom of research or run counter to it, rather than being limited to a 'periodic examination of co-operation between the countries of the North and the South'. Similarly, a point 3.2.4 was added, referring to the preparation of programmes for training in bioethics, designed especially for teachers and educators.

38. In conclusion, the IBC approved the draft guidelines as amended during the debate.

V. Confidentiality and Genetic Data

39. Following the discussions at its Fifth Session and on the basis of suggestions made by its members, the IBC had set up a Working Group on Confidentiality and Genetic Data which had met at UNESCO Headquarters in Paris, on 21 and 22 June 1999, under the chairmanship of Mrs Michèle Jean (Canada), Vice-Chairperson of the IBC (see Annex II giving composition of the group). At this meeting, the Working Group had examined the ethical questions raised by the confidentiality of genetic data and defined the modalities of preparing the report on this subject (BIO-503/99/CIB-6/GT-2/3).

40. Mrs Sylvia Rumball (New Zealand), Director of the Science Education and Policy Unit of the University of Massey, chaired the session on 'Confidentiality and Genetic Data'. In her introduction, she recalled that the confidentiality of medical data was at the very core of the doctor-patient relationship and was also an imperative in the field of biomedical research. The improvement of computer systems, the advances made in the knowledge of the human genome and the specific character of genetic data are leading to new thinking about the boundaries of this confidentiality at the level of the individual, the family and the society as a whole. Mrs Rumball also stressed the disparities between countries in the protection of the confidentiality of genetic and medical data in general, which is not always necessarily envisaged from the viewpoint of the individual. She regretted the absence in many cases of guidelines in this field or, when such guidelines existed, their unsuitability for new situations. However, initiatives are being taken to promote a set of recommendations to protect the confidentiality of genetic data in research. In this respect, the Universal Declaration on the Human Genome and Human Rights, and especially its Articles 7 and 9, are undoubtedly a reference.

41. Mrs Rumball concluded by stressing the fact that, owing to the particular nature and importance of genetic information, it was essential that each and every person should arrive at an understanding, through public debate, of the implications of the uses of genetic knowledge, whatever these uses might be. Ultimately, given that the question of the confidentiality of genetic data was a complex one, the responses that would be brought to it would vary according to the cultural context.

42. Mrs Michèle Jean then presented the report which consisted of five parts. The first part, by way of introduction, recalls some of the texts that underlie the issue of confidentiality. It dwells particularly on Article 7 of the

Universal Declaration on the Human Genome and Human Rights as well as Article 12 of the Universal Declaration of Human Rights of 1948 and also refers to other international and regional texts.

43. The second part, entitled 'Identification of the Different Kinds of Genetic Data', seeks to present the characteristics of this data which, while it is proper to an individual, may also concern a group of individuals or populations. This part also gives the various uses (medical and non-medical) that may be made of this data.

44. The third part of the report deals more specifically with the principle of confidentiality as applied to genetic data. Although genetic data may be qualified as medical information, it should be brought under a specific framework inasmuch as it provides sensitive information not only about an individual but also about his family. This part also includes a detailed analysis of Article 7 of the Universal Declaration on the Human Genome and Human Rights according to which data must be 'associated with an identifiable person and held confidential in the conditions set by law'.

45. The fourth part deals with limitations on the principle of confidentiality covered by Article 9 of the Declaration. The conditions of application of this article are specified in the sense that, since the principle of confidentiality is the standard, any limits that may be placed on it should be exceptional in character and 'may only be prescribed by law, for compelling reasons within the bounds of public international law and the international law of human rights'. The right of the person tested not to be informed of the results of a genetic examination is also cited. Furthermore, the report presents examples of applications of limitations, namely with respect to the family, third parties, researchers and justice.

46. Finally, the fifth part is devoted to awareness-raising and education. In this respect, Mrs Jean recalled that the need to raise awareness and educate public opinion was especially relevant to the UNESCO's whole mission. The heightening of awareness and education shall enable the individual concerned to understand the implications of genetic data, take informed decisions and to fully exercise his/her rights.

Discussion

47. The discussions that followed Mrs Jean's presentation highlighted certain aspects of the draft report on 'Confidentiality and Genetic Data' that needed further development and clarification.

The Principle of Confidentiality and Genetic Data

48. Certain participants felt that it was important to refer not only to various existing international and regional texts concerning the confidentiality of data resulting from scientific research (such as the Nuremberg Code, the Helsinki Declaration and the European Convention on Human Rights and Biomedicine), but also legal documents protecting the confidentiality of personal and sensitive data.

49. Furthermore, although many countries have already passed laws to protect personal data and privacy, the need for specific legislation to protect the confidentiality of genetic data was emphasized. Indeed, the novelty of genetic information - which provides information on the individual, his health, his predisposition as well as on his family and descendants - and the specific risks of misuse resulting therefrom, access to this information must be covered by special protection. Furthermore, the transgenerational aspect of genetic data deserves to be made clearer.

50. Several participants wished that the question of prior, free and informed consent, which is the subject of Article 5 of the Declaration, should be more fully developed. Indeed, there is need for specific consent based on knowledge of the use of genetic data, especially in the communication of genetic data to third parties. At the same time, the risks of divulgation or, on the contrary, of refusal to divulge genetic information to third parties should also be more fully examined. Since confidentiality was being dealt with at the level of the individual only, it was suggested that it might be appropriate to consider it at the level of groups of populations, ethnic minorities or entire regions.

51. Finally, it was pointed out that the notion of law, which is referred to in Article 7 of the Declaration, should be understood as that of formal law adopted by legislative authority and promulgated by governments.

The Storage and Processing of Genetic Data

52. The storage and computer processing of genetic data and DNA samples, which can be kept for several years before being processed, raise questions that have major ethical repercussions and need to be emphasized.

53. In this respect, the need to guarantee the anonymity of information contained for example in a data and/or sample bank was acknowledged. However, some participants felt that all information should be able to be identified as pertaining to a specific person, for example by means of a dual recording system. This possibility raises the question of knowing who is responsible for managing this data bank and/or using this information and who is responsible for deciding on its decoding if necessary.

Limitations on the Principle of Confidentiality

54. In general, the entire part of the report devoted to the limitations on the principle of confidentiality was perceived as being far too permissive as compared with the existing legislation in certain countries. Many speakers therefore sought to restrict or at least shade the scope of these limitations.

55. In this respect, the notion of 'compelling reasons' mentioned in Article 9 of the Declaration was presented in the report as referring to reasons of public interest warranting limits on the principle of confidentiality. However, certain participants felt that a more restrictive vision of limitations needed to prevail and proposed that such compelling reasons be related rather to the danger for third parties or threats to human life. Other participants felt that this interpretation was too restrictive and cited the example of legislation in some States, which might serve as a basis to define guidelines in this respect.

56. Some participants pointed out that the legislation in some countries provided better protection to individuals against intrusion by public authority than against intrusion by the private sector. Inquiries made by employers or insurance companies could also constitute a threat to confidentiality.

57. In conclusion, Mrs Jean recalled that it would be necessary to take account of all the observations formulated during the debate, in the finalizing of the report on 'Confidentiality and Genetic Data'.

VI. Closing of the Sixth Session of the IBC

58. The Chairperson of the IBC briefly summarized the discussions of the Sixth Session. He also presented the contents of the programme for the next session of the IBC, which will be organized around certain subjects, of which he gave a provisional list, and draft actions. Having noted the observations made by some participants, while recognizing the need to devote more time to public sessions, he recalled that the organization of the work of the IBC in public sessions and sessions reserved for the members would be maintained and improved.

59. In his closing speech, he recalled the spirit of harmony that should prevail in all bioethical considerations. Thus, the IBC does not intend to pursue a Manichean approach, but strives to propose the best possible way for each and every individual and for humanity as a whole.

ANNEX I

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

List of Members

CHAIRPERSON

GROS ESPIELL **Prof. (Mr) Héctor** (Uruguay)
Professor of International Law
Former Ambassador of Uruguay in France and to UNESCO
Former Minister of Foreign Affairs of Uruguay
Former President of the Inter-American Court of Human Rights

MEMBERS

ANDORNO **Dr. (Mr) Roberto Luis** (Argentina)
Professor of Civil Law

GALJAARD **Prof. (Mr) Hans** (The Netherlands)
Professor of Human Genetics
Head of the Department of Clinical Genetics, University Hospital Rotterdam

IDA **Prof. (Mr) Ryuichi** (Japan)
Chairperson of the IBC
Professor of International Law
Rapporteur of the Committee of Regional Economic Development Law of the International Law Association

McCALL SMITH **Prof. (Mr) Alexander** (United Kingdom)
Professor of Private Law

NOMBELA **Prof. (Mr) D. César** (Spain)
President of the *Consejo Superior de Investigaciones Científicas*

Pak **Prof. (Mrs) Un-jung** (Republic of Korea)
Professor of Law
President of the Korean Association of Legal Philosophy
Vice-President, Korean Bioethics Association

Questiaux **(Mrs) Nicole** (France)
Honorary Chairperson of Section of the State Council
Vice-Chairperson of the National Consultative Ethics Committee for Health and Life Sciences
Chairperson of the Permanent European Conference of National Ethics Committees
Former Minister of Social Affairs

Roucounas **Prof. (Mr) Emmanuel** (Greece)
Professor of International Law
Member of the Academy of Athens
Member of the Institute of International Law, Geneva
Chairman , National Commission of Patients' Rights
Former member of the United Nations International Law Commission

Rumball **Prof. (Mrs) Sylvia** (New Zealand)
Professor of Chemistry
Director, Science Education and Policy Unit, Massey University

Tadjudin **Prof. (Mr) Muhammad Kamil** (Indonesia)
Professor of Biology
Former Rector of the University of Indonesia

Tano Bouah **Prof. (Mrs) Yolande Evelyne** (Côte d'Ivoire)
Professor of Law
Vice Chairperson of the University of Abobo-Adjamé

Yang **Prof. (Mr) Huanming** (China)
Professor of Genetics
Director of the Human Genome Center, Chinese Academy of Medical Sciences

ANNEX II

WORKING GROUP OF THE IBC ON CONFIDENTIALITY AND GENETIC DATA

List of Members

CHAIRPERSON

JEAN **(Mrs) Michèle** (Canada)
Special Adviser to the Minister of Foreign Affairs of Canada
to the European Commission
Former Vice-Minister of Health

MEMBERS

BOMPIANI **Prof. (Mr) Adriano** (Italy)
Professor of Gynaecology
Former Senator
Former Minister for Social Affairs
Former President of the Italian National Bioethics Committee

CRUZ-COKE **Prof. (Mr) Ricardo** (Chile)
Professor of Medicine and Clinical Genetics
Former President of the Latin American Programme
on the Human Genome
Former Director of the Genetic Unit, J.J. Aguirre Hospital,
University of Chile

FOX **Prof. (Mr) Maurice** (United states of America)
Lester Wolfe Professor of Molecular Biology

HAMDAN **Dr (Mr) Mohammad** (Jordania)
Rector of the Arab Open University
Vice-Chairperson of the Jordanian National Bioethics Committee
Former Secretary General of the Higher Council for Science
and Technology
Former President of the Hashemite University
Former Minister of Education and Higher Education

***IDA* Prof. (Mr) Ryuichi** (Japan)
Chairperson of the IBC
Professor of International Law
Rapporteur of the Committee of Regional Economic Development Law of the International Law Association

***ÖZTÜRK* Prof. (Mr) Mehmet** (Turkey)
Chairperson, Department of Molecular Biology and Genetics, Bilkent University

***PETROV* Academician (Mr) Rem V.** (Russian Federation)
Vice-President of the Academy of Sciences
Member of the Russian Academy of Medical Sciences

***POGNON* (Mrs) Elisabeth** (Benin)
Magistrate
Former President of the Constitutional Court of Benin

***QUESTIAUX* (Mrs) Nicole** (France)
Honorary Chairperson of Section of the State Council
Vice-President of the National Consultative Ethics Committee for Health and Life Sciences
Chairperson of the Permanent European Conference of National Ethics Committees
Former Minister of Social Affairs

***ROBINSON* (Mr) Patrick** (Jamaica)
Judge to the International Criminal Tribunal for the former Yugoslavia
Member of the United Nations International Law Commission
Former Deputy Solicitor-General
Former Chairperson of the Inter-American Commission on Human Rights

***ZAREMBA* Prof. (Mr) Jacek Stanislaw** (Poland)
Professor, Head of Department of Genetics, Institute of Psychiatry and Neurology

Chapter 2

REPORT OF THE FIRST SESSION OF THE INTERGOVERNMENTAL BIOETHICS COMMITTEE (IGBC)

by Ferenc Oberfrank,
Rapporteur of the IGBC

I Introduction

1. At the kind invitation of the Government of the Kingdom of Morocco, the First Session of the Intergovernmental Bioethics Committee (IGBC) was held in Rabat, Morocco, on 11 and 12 October 1999, under the High Patronage of His Majesty King Mohammed VI and the Effective Presidency of His Royal Highness Prince Moulay Rachid. The following Member States of the Intergovernmental Committee 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.

2. In his opening address, the Representative of the Director-General of UNESCO, Mr Georges B. Kutukdjian, reminded the adoption by the Executive Board of UNESCO in May 1998 of the Statutes of the IBC, which enabled its mandate to be defined and which established the Intergovernmental Bioethics Committee (IGBC). He went on to clarify the role of the IGBC, which is to examine the opinions and recommendations of the IBC, notably in respect of the implementation of the Universal Declaration on the Human Genome and Human Rights.

3. After electing as its Chairperson H. E. Mr Najib Zerouali Ouariti, Minister of Higher Education, Executive Training and Scientific Research of Morocco, the Intergovernmental Committee adopted its agenda and rules of procedure with an amendment to Rule 10. Its Bureau consists of the representatives of the Dominican Republic, Germany, the Republic of Korea and South Africa as Vice-Chairpersons, together with the representative of Hungary as the Rapporteur.

4. The Chairperson of the IGBC welcomed the fact that this Committee was being set up in his own country whose interest in bioethical matters he underlined. He felt that, although ethical problems arise primarily at the level of researchers, these matters are all the more complex when economic and political factors also come into play. The implementation of the conclusions of the IBC may prove to be a very long process in which the States have a vital role to play, through the Intergovernmental Committee, by taking the necessary measures for their implementation.

II. Presentation of the Work of the Sixth Session of the IBC

5. Before presenting the work of the Sixth Session of the IBC, its Chairperson, Mr Ryuichi Ida, wished to recapitulate achievements to date. He drew attention to the twofold mission which had been entrusted to the IBC on its creation and the main lines of emphasis of the Universal Declaration on the Human Genome and Human Rights. He went on to present a summary of the work of the Fifth Session of the IBC. Finally, he informed the Intergovernmental Committee of the public sessions, which were devoted to consideration of the 'Implementation of the Universal Declaration on the Human Genome and Human Rights', and on the 'Ethics and Confidentiality of Genetic Data', as well as the round table on 'Bioethics and Public Debate: Information, Education, Participation'. He further mentioned the meetings reserved for members of the IBC during which state-of-the-art presentations were made on research on cloning, xenotransplantion and embryonic stem cell research. The Chairperson of the IBC went on to inform the IGBC of the hearing by the IBC of Mr Kari Stefansson, Chief Executive Officer and President of *DeCode genetics* (Iceland) on the project entitled 'The Planned Healthcare Database in Iceland'. Referring to the future programme of the IBC, its Chairperson gave a provisional list of discussion topics and of some projects for action to be pursued. Among the subjects, he made particular mention of research on embryonic stem cells, the economic aspects of the human genome mapping and its applications, together with North-South solidarity and co-operation as priority topics.

6. In conclusion, the Chairperson of the IBC, while stressing the priority role of States in the effective implementation of the principles set out in the Declaration, stressed the importance of establishing harmonious co-operation between the IBC and IGBC based on a constructive dialogue, so as to advance the process of reflection on the ethics of the life sciences.

7. Following this general presentation, some representatives of States referred to the working method of the IBC, with particular reference to the holding of private sessions. Although it was aware of the constraints affecting the IBC and recognized the need for its members to hold private sittings, the IGBC expressed the hope that the works of the IBC, and in particular the state-of-the-art presentations on research, would be wide open to the public, observers and the media, so as to broaden the discussions as far as possible and ensure that they were more transparent.

8. The determination by the IBC of its own work programme was also the subject of some comment. Emphasis had been placed on the important need for the IBC to have sufficient time to define its work programme freely and in complete independence. Moreover, in the definition of this programme, the IGBC felt that the IBC should be guided by the specific nature of the UNESCO mandate (education, science, culture, information and communication) and the relevance of the subjects chosen with reference to the Universal Declaration on the Human Genome and Human Rights. The IBC should give priority to the identification of practices that could be contrary to human dignity, such as germ-line interventions, referred to in Article 24 of the Declaration. Account must also be taken of the activities pursued in the field of the life sciences by other bodies and specialized agencies of the United Nations system. However, referring to the possibility of overlapping competencies between the IBC and other bodies, some participants felt that this did not deprive the IBC of authority to deal with the ethical aspects of the issues.

9. As to the preparation of reports by the IBC on specific topics, the IGBC stressed the need to organize all appropriate consultations with the parties concerned, such as vulnerable groups, notably ethnic minorities and indigenous populations.

10. In parallel, although the IBC had the ultimate discretion to decide the subjects for discussion, the IGBC advanced the idea of having the opportunity to propose topics of reflection to the IBC which might then act as a consultant to the governments by helping them resolve certain bioethical problems.

11. In addition, the members of the IGBC felt that it would be appropriate for its future sessions to be convened by the Director-General of UNESCO alternately with meetings of the IBC and after a sufficient lapse of time to enable the Member States of the Intergovernmental Committee to consider the conclusions and documents of the IBC.

12. Following these general remarks on the organization of the IBC's work, the IGBC took cognizance of the reports drawn up by the two Working Groups of the IBC.

A. Report of the IBC on 'Confidentiality and Genetic Data'

13. Mrs Michèle Jean, Chairperson of the Working Group on 'Confidentiality and Genetic Data', presented to the IGBC the report drawn up by the group with the remarks of the IBC on this matter (see Report of the Sixth Session of the IBC on this point).

14. During the discussion, some representatives of the IGBC Member States suggested that confidentiality might be considered from the angle of different groups, i.e. ethnic minorities and indigenous populations and in particular groups with specific genetic characteristics. The work involving these populations or population groups raised some concern over the exploitation of their intellectual property rights.

15. Attention was also called to the fact that ethical considerations relating to confidentiality might differ from one country to another and the question as to whether, from the ethical angle, harmonization was necessary in this area.

16. Some representatives referred to the concept of law mentioned in Article 7 of the Universal Declaration on the Human Genome and Human Rights, and felt that it not only covered acts of Parliament, as had been pointed out during the Sixth Session of the IBC, but also the aspect of custom and practice. This specific mention should be contained in the report to enable allowance to be made for the situation of the 'common law' countries.

17. The suggestion was made that an explanatory document could be drawn up on the confidentiality of genetic data, by analogy with the explanatory report on the Council of Europe's Convention on Human Rights and Biomedicine.

18. Mention was also made to the reference contained in the Universal Declaration on the Human Genome and Human Rights to public international law and international law of human rights. This reference meant that Article 9 and the other provisions of this Declaration shall be interpreted in compliance with the criteria set out in the Vienna Convention on the interpretation of the treaties and in accordance with the principles for the interpretation of international law on human rights.

19. In its second part on the identification of the different types of genetic data, the report made reference to the notion of race. Some participants stressed the fact that there was no scientific or genetic foundation for a distinction between races.

20. The importance of training health and social science professionals and, in particular, genetic experts was stressed; they must be properly qualified to inform the persons who undergo genetic tests or take part in genetic research of the present and possible future use of available data concerning them. Some speakers also felt that the matters of computerized data and genetic samples should be dealt with in more detail.

B. Report of the IBC on the Implementation of the Universal Declaration on the Human Genome and Human Rights

21. Mr Héctor Gros Espiell presented to the IGBC the report of the meeting of the Working Group on the Implementation of the Universal Declaration on the Human Genome and Human Rights and the 'Proposals in view of the Application of Article 24 of the Universal Declaration on the Human Genome and Human Rights', together with the 'Draft Guidelines for the Implementation of the Declaration', as approved with amendments by the IBC at its Sixth Session (see the report of the Sixth Session of the IBC on this point).

22. The IGBC noted with satisfaction the Draft Guidelines laid before it and commented on various points. It felt that point 2.2 on consciousness-raising education and training regarding the principles of the Declaration represented a very heavy task for the IBC and, more generally, for UNESCO, and that its purpose was very broad, indeed too broad. Concerning the creation of a dynamic relationship between the different actors involved referred to in point 2.4 of the draft guidelines, some representatives, referring to Article 24 of the Universal Declaration on the Human Genome and Human Rights, felt that it would be appropriate to include vulnerable groups among these actors. Explanations of the concept of 'vulnerable persons', which was referred to in section 3.4.1, had also been requested. In this regard, the need for further thought to be given to the interpretation of Article 24 of the Declaration was mentioned. In addition, one representative envisaged the definition of vulnerability in the broad sense to include persons who were illiterate or lacking in basic education.

23. Exchanges between the independent ethical committees and their networking, referred to in Article 23 of the Declaration and dealt with in section 3.3.2 of the Draft Guidelines, were also considered by the IGBC which laid emphasis on the need for the States to pursue this action in a co-ordinated manner, notably through UNESCO, which had already put in place a database on these bodies. Some members of the IGBC felt that the proposal for organization of the third summit of the ethics committees could also permit this co-ordination.

24. Moreover, in regard to point 5 on evaluation, the IGBC hoped that this would be pursued in compliance with the procedures laid down by the Executive Board and the General Conference of UNESCO, notably because of its budgetary implications.

25. Having regard to the 'Proposals for the Implementation of Article 24 of the Universal Declaration on the Human Genome and Human Rights by the International Bioethics Committee of UNESCO (IBC)', the IGBC felt that, in the context of the first part concerning the dissemination of the principles set out in the Declaration, special procedures should be envisaged in the light of the levels of education of the public concerned and the interested non-governmental organizations and higher education institutions on the same basis as the national committees, as privileged relays for the dissemination of the principles of the Declaration.

26. Referring to the further examination of issues raised by the application of the principles set out in the Declaration, the IGBC suggested that the possible publication of the world report on bioethics should also be made by electronic means, even though some members of the Committee had expressed their reservations as to the desirability of drafting such a report.

27. The discussions enabled the respective competencies of the two committees to be clarified; they are both placed on an equal footing and their work, although parallel, is different. The statutory provisions setting up the IGBC were mentioned, with particular reference to those concerning the decision-making process. Mention was also made of the fact that the formulation of opinion and recommendations referring to the implementation of the Declaration and covered by chapter IV of the Proposals should be understood in the context of Article 11(2) of the Statutes of the IBC and that, pursuant to Article 7 of the Statutes, the opinion and recommendations of the IBC must be made public immediately and disseminated widely. Reference was likewise made to the fact that it was not the IGBC's role to formally approve the work of the IBC. On the other hand, it was entitled to put forward such commentaries

or opinions as it felt appropriate to the Director-General who in turn forwards them, with the opinions and recommendations of the IBC, to Member States, the Executive Board and the General Conference.

28. Last but not least, the IGBC felt that consideration must be given to all practices even if, in some cases, the IBC concluded that these practices had no scientific foundation.

29. At the end of the discussions, some participants laid emphasis on the complementarity of the two committees which would have to co-operate in the fullest possible mutual respect. Moreover, the importance for the IBC of delivering independent ethical opinions and of safeguarding and strengthening the transparency of its work was stressed. With that end in view, a representative suggested that the prominent figures nominated by the Director-General as members of the IBC should declare their interests in any profit-making businesses or any positions of responsibility held by them in such companies.

III. Conclusions

30. At the end of the discussion, the IGBC adopted a text setting out the following conclusions reached by it in its work.

> The Intergovernmental Bioethics Committee (IGBC), in the presence of the International Bioethics Committee, in a climate of mutual respect, aware of the magnitude of the scientific, ethical, political and educational work to be performed and recognizing the shared principles of openness which guide work in this area, held its first session in Rabat on 11 and 12 October 1999 and pursued its discussions in a spirit of constructive co-operation and mutual support.
>
> 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. The following observations were made, however, in the course of the discussions:
>
> (i) with a view to the creation of a dynamic relationship between the different actors referred to in point 2.4, it would be appropriate to include vulnerable groups among these actors;
>
> (ii) the evaluation, which is envisaged in Section 5, should be performed in compliance with the procedures laid down by the Executive Board and the General Conference, notably because of its budgetary implications.

Having regard to 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)', the IGBC made the following observations:

(i) in the context of the dissemination of the principles set out in the Universal Declaration on the Human Genome and Human Rights (I.6), special procedures shall be envisaged depending on the levels of education of the target public. Moreover, the international non-governmental organizations concerned and higher education institutions must be regarded, on the same footing as the national ethical committees, as privileged relays;

(ii) as to the further examination of issues raised by the application of the principles set out in the Declaration (II.2), the world report on bioethics would be circulated by electronic means. However, some members of the IGBC expressed reservations as to the desirability of writing such a report;

(iii) the formulation of opinions and recommendations concerning the implementation of the Declaration (IV.1) shall be considered in the context of Articles 7 and 11(2) of the IBC Statutes. The opinions and recommendations of the IBC are announced immediately and circulated widely. For its part, the IGBC examines the results of the work of the IBC and formulates its remarks on it. The reports of both committees are submitted in parallel to the Director-General. Finally, the Director-General is responsible for forwarding the opinions and recommendations of the IBC, with those of the IGBC, to Member States, the Executive Board and the General Conference;

(iv) the IGBC felt that consideration must be given to all the practices even if, in some cases, the IBC concluded that these had no scientific foundation.

The Intergovernmental Committee hopes that, in defining its work programme, the IBC will be guided by the following criteria:

(i) priority given to the identification of practices that could be contrary to human dignity, such as germ-line interventions, referred to in Article 24 of the Universal Declaration on the Human Genome and Human Rights;

(ii) the specific nature of UNESCO's mandate (education, science, culture, information and communication);

(iii) the relevance of the subjects chosen with reference to the Universal Declaration on the Human Genome and Human Rights;

(iv) setting up of co-operation and consideration of activities undertaken in the field of life sciences by other bodies and specialized agencies of the United Nations system and other independent bodies and, where appropriate, seeking co-operation with these institutions.

Referring to the working methods which the IBC envisaged using to establish its reports on specific themes, the IGBC welcomed the intention by the IBC to organize appropriate consultations with parties concerned, notably with vulnerable groups such as ethnic minorities and indigenous populations.

The members of the IGBC felt that it would be appropriate for its next session to be convened by the Director-General alternately with the session of the IBC and after a sufficient lapse of time to enable its members to examine the conclusions reached by the IBC.

31. In conclusion, the Chairperson of the Intergovernmental Committee expressed his warm thanks to members of the Committee and to the other participants and observers.

IV. Closing Session

32. H. E. Mr Najib Zerouali Ouariti, Minister of Higher Education, Executive Training and Scientific Research of Morocco and Chairperson of the Intergovernmental Committee, pointed out that the definition of the procedures and working methods of the IBC and IGBC would enable them to pursue their work in a spirit of close understanding and complementarity. Such exchanges between these two committees would be bound to consolidate the defence of human beings, their rights and uniqueness.

33. The Representative of the Director General, Mr Georges B. Kutukdjian, reiterated his message of thanks to His Majesty King Mohammed VI for his High Patronage, to His Royal Highness Prince Moulay Rachid for his Effective Presidency, and to the Government of the Kingdom of Morocco, and in particular H. E. Mr Najib Zerouali Ouariti, Minister of Higher Education, Executive Training and Scientific Research.

He went on to refer to the fruitful outcome of this first session whose conclusions would be brought to the attention of the Director-General for presentation by him to the 30th session of the General Conference of UNESCO. Finally, he thanked the representatives of the Member States of the IGBC and the observers for attending the meeting.

Chapter 3

REPORT ON CONFIDENTIALITY AND GENETIC DATA

(by the Working Group of the IBC on Confidentiality and Genetic Data)*

I. Introduction

1. The Universal Declaration on the Human Genome and Human Rights (hereinafter called the Declaration), adopted by the General Conference of UNESCO on 11 November 1997, states in Article 7: 'Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions set by law'.

2. This provision has arisen out of an imperative need. Indeed, the development of science is now such that it is the cause of some concern. The international community can not allow human beings to undergo operations and be subjected to research without raising barriers to safeguard their dignity.

3. The Declaration seeks to ensure the development of human genetics in a way that fully respects the dignity and rights of the human person and is beneficial to humanity as a whole. Respect for the dignity and fundamental rights of the human person is a major ethical imperative and is affirmed in Article 2 of the Declaration:

> a) Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics.
>
> b) That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.

4. In a field as specific as human genetics, the Declaration states in Article 1 that the human genome is 'in a symbolic sense, ... the heritage of humanity'.

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* See the composition of the Working Group, page 19.

5. The totality of an individual's genetic data constitutes his genome. It belongs to him personally and, at the same time, forms part of the 'fundamental unity of all members of the human family' (Art. 1).

6. Although this second aspect of the genome is an important point of the Declaration, it must be stressed that the essential aim of this Declaration is to safeguard the dignity of the human person.

7. In the context of genetic research and its applications, the principle of respect for dignity implies that human beings must be recognized as such and not be considered by science as objects.

8. Respect for human dignity must consider not just one of the constituent parts of an individual but his 'entire being' in its fullness.

9. The basis for the principle of confidentiality of genetic data is the human right to privacy, which has been recognized in the major human rights instruments adopted after the Second World War, starting with the Universal Declaration of Human Rights.

10. Article 12 of the Universal Declaration of Human Rights of 1948 provides: 'No one shall be subjected to arbitrary interference with his privacy family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks'.

11. Article V of the American Declaration of the Rights and Duties of Man of 1948 (in point of time, actually this Declaration was adopted before the Universal Declaration of Human Rights) provides: 'Every person has the right to the protection of the law against abusive attacks upon his honour, his reputation, and his private and family life'.

12. Article II of the American Convention on Human Rights of 1969 provides: '(1) Everyone has the right to have his honour respected and his dignity recognized. (2) No one may be the object of arbitrary or abusive interference with his private life, his family, his home, or his correspondence, or of unlawful attacks on his honour or reputation. (3) Everyone has the right to the protection of the law against such interference and attacks'.

13. Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms of 1950 provides: '(1) Everyone has the right to respect for his private and family life, his home and his correspondence. (2) There shall be no interference by a public authority with the exercise of this right except such as in accordance with the law and is necessary in a democratic society in the interests of national

security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health and morals, or for the protection of the rights and freedoms of others'.

14. Article 17 of the International Covenant on Civil Political Rights (ICCPR) of 1966 provides: '(1) No one should be subjected to arbitrary or unlawful interference with his privacy, family, honour or correspondence, nor to unlawful attacks on his honour and reputation. (2) Everyone has the right to the protection of the law against such interference or attacks'.

15. Finally, in dealing with the issue of confidentiality, Article 10 of the European Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention of Human Rights and Biomedicine of 1997 provides: '(1) Everyone has the right to respect for private life in relation to information about his health. (2) Everyone is entitled to know any information collected about his health. However, the wishes of individuals not to be so informed shall be observed. (3) In exceptional circumstances, restriction may be placed by law on the exercise of the rights, contained in paragraph 2 in the interest of the patient'.

16. In order to ensure respect for the dignity of the human person, the Universal Declaration on the Human Genome and Human Rights solemnly proclaims the confidentiality of genetic data. This confidentiality, thus affirmed, seeks to protect the individual against the disclosure of the data that belongs to him.

17. However, while the principle of confidentiality is recognised, its protection must necessarily be regulated. The implementation of the protection of the human genome, which is so closely linked to the human person, must be supported by the executive, legislative and judicial powers. Indeed, the intervention of the legislative branch, which expresses the opinion of the majority in a democracy, is an additional guarantee for the protection of human rights. Furthermore, in order to support the need for protection by law, the provisions of Article 7 are accompanied by those of Article 9 which sets forth the objectives that the law must bear in mind in the event of limitations on the principle of confidentiality.

18. What would be the effectiveness of a protection whose object is unknown to its beneficiaries? This is why, over and above the principle of confidentiality as proclaimed, and in order that this principle may not remain a pious wish, Articles 17, 18 and 19 of the Declaration invite States to solidarity with respect to individuals and amongst them.

II. Identification of the Different Kinds of Genetic Data

19. The human genome is composed of about 100,000 or more genes and 3 billion basepairs of DNA. Although the overall organization of DNA and great majority of genes are common to all human beings, there occur a large number of structural differences between individuals. Some of these differences, alone or combined, are unique to each individual, which can be considered as 'private information' for a given individual or family. Some other changes are shared by all individuals belonging to a lineage or an ethnic group.

20. The genetic data which can be considered as subject to confidentiality are any genetic data which enters into one of these categories (data specific for an individual or a group of individuals). Genetic information about people comes in many forms. For example, a person's blood type (A, B, AB, O), the colour of a person's hair and many features of appearance. At another level, there is information in the form of karyotype, i.e. chromosome composition: the sex chromosomes X and Y, and various unusual compositions such as the number of X and/or Y chromosomes, or the number of copies of chromosome number 21 are some examples.

21. In recent years, there has been an explosion in the sophistication of genetic information that can be gleaned about an individual, and from samples of that individual: tissue, blood, urine or even sweat. These derive from examination of the individual's DNA and can be obtained by a number of strategies. For example, they could come in the form of the size specific restriction fragments (the piece of DNA that encodes a particular sequence residing between two adjacent sites that are cut by a particular DNA cutting enzyme that recognised a particular DNA sequence as a cut site). Probes that recognise specific DNA sequences are then used in the analysis of sizes of the DNA produced by various DNA cutting enzymes (restriction enzymes). More recently, in vitro enzymatically synthesized DNA, using short specific DNA primers to direct which sequences are synthesized, have been introduced for some kinds of analysis of both DNA and RNA. For even greater specificity, specific DNA sequences can be sequenced and the arrangement of basepairs determined.

22. Genetic information in these various categories is obtained for different reasons. For example, karyotyping is often carried out for purposes of prenatal diagnosis for the identification of an extra copy of chromosome 21, indicating a prenatal genetic disorder and often resulting in termination of pregnancy. This procedure also reveals the gender of the

foetus, sometimes revealed to the parents, sometimes not. In addition, the procedure also detects abnormalities in the number of X or Y chromosomes, an anomaly not frequently revealed to the parents.

23. The DNA 'fingerprints' are being widely used for identifying individuals and the relatedness of individuals. Both military and police organizations are accumulating banks of DNA from individuals for forensic and other identification purposes. Immigration services and courts are using such identification to characterize the relatedness of individuals and paternity.

24. Information derived in the form of DNA sequence has been derived from the international sequencing efforts of the Human Genome Project where the full sequencing of the human genome is expected to be completed in the near future.

25. Specific portions of the sequencing effort have been delineated for the identification of diseases that are the consequence of DNA sequence alterations transmitted in the human germ line.

26. Much of the currently generated individual genetic data are derived from medical studies whose purpose is to identify a specific DNA sequence for genetically determined diseases. Some other genetic data (DNA fingerprints) are generated for forensic studies aiming to identify a suspected person or to identify a biological relationship between individuals or between parents and children. A third category of data are generated for population genetics studies to establish, for example, genetic relations between different ethnic groups. Genetic data generated for medical reasons are often used to confirm a clinical diagnosis of a disease. However, with the introduction of tests for 'genetic risks', some medical data can serve to predict the likelihood of an individual to develop a disease, even if the clinical signs of the disease are not apparent at the time of data collection.

27. The misuse of this type of genetic data generated for medical reasons may lead to individual discrimination based on genetic background. Genetic data generated for non-medical reasons is not usually used to determine information related to a disease or a genetic risk for a disease. However, such data also should be carefully examined against possible misuse for discrimination of individuals for familial or ethnic reasons.

Genetic data generated for medical purposes

28. Some human diseases are known to be caused by an inherited germ-line mutation. It has now become possible to identify disease causing germ-line mutations for a large number of diseases both prenatally and

postnatally. In some countries, molecular diagnosis has become common in the medical community. Mutation analysis has also been used to analyse healthy relatives of persons affected with a genetic disease.

Genetic data generated for non-medical reasons

29. This type of genetic data is generated mostly for forensic studies to identify a person through DNA fingerprints. Judiciary systems in most countries are equipped with material for DNA fingerprinting which is used to compare, for example, the DNA fingerprints of a suspected individual with that biological material (blood, semen,...) collected at the scene of a crime. DNA fingerprinting is also used for identification of the biological father of a child, most often to resolve disputes over an inheritance.

30. Genetic data is also collected for DNA fingerprinting in the army, as well as for some immigration requests to establish, for example, a genetic relationship between different members of a kindred.

31. Although there are no examples for the time being, DNA fingerprints may serve to identify the origin of an individual, or a group of individuals. The history of humanity has tragic examples of religious or ethnic discriminations based on, for example, skin colour or skull dimensions. There is a risk of using the DNA profiles of individuals for similar kinds of discrimination(1).

III. The Principle of Confidentiality and Genetic Data

32. The confidentiality of data stemming from scientific research has been emphasised in a number of international documents such as the Nuremberg Code, the Helsinki Declaration (the World Medical Association, WMA) and the International Ethical Guidelines for Biomedical Research Involving Human Subjects (Council for International Organizations of Medical Sciences, CIOMS). Furthermore, legal instruments have been adopted in order to protect the confidentiality of personal or sensitive data(2), not to mention national legislations protecting the right to privacy(3).

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1. See the Report of the IBC on Bioethics and Human Population Genetic Research (*Proceedings of the Third Session of the IBC*, Vol. I, 1995).

2. By the United Nations Commission on Human Rights, the Council of Europe, the Organization for Economic Development and Cooperation (OEDC) and the European Commission.

3. See Michael, J. *Privacy and Human Rights.* Paris: UNESCO & Dartmouth, 1994.

33. Although genetic data may be characterized as medical and personal data, and, therefore, subject to the legal regime that would ordinarily apply to such data, a special regime for genetic data is warranted because it provides sensitive information not only about an individual, but also about his family (relatives and descendants). Hence this information is of a transgenerational nature. Genetic data, therefore, has characteristics that are at the same time individual and shared; for both reasons, the regime of confidentiality and access to information needs to be carefully elaborated to guard against misuse of the data that can be damaging to an individual and his family.

Features of the Principle

34. As set out in Article 7 of the Declaration, there are two conditions for the application of the principle of the confidentiality of genetic data.

35. First, the data must be 'associated with an identifiable person'. If the data is anonymized, that is, is not related to an identifiable person, the requirement for confidentiality does not apply. This is reasonable and logical, since the principle of confidentiality attaches to a person: if there is no identifiable person with whom the data can be associated, there is no need for confidentiality. It is not enough that the data can be associated with any human being: for the principle of confidentiality to apply, the data must be associated with an identifiable person, i.e. a person whose identity can be established. This limitation on the principle of confidentiality is essential to allow certain legitimate uses of genetic data, for example for research or epidemiological purposes. In these cases, the coding of genetic data should ensure anonymity of information and the coding system should be strictly confidential.

36. The phrase 'and stored or processed for the purpose of research or any other purpose' describes genetic data which requires confidentiality; that is, data is stored or processed for research or any other purpose, including diagnosis and treatment. Indeed, the storing and computerised processing of genetic data in general, as well as collections of DNA samples over many years, raise specific issues as to the confidentiality of the data concerned. For example, the issues concerning the repository of this data, the authority holding the coding system of its anonymity and the authority responsible for its possible uses, will have to be addressed in each country within its legal framework. Furthermore, attention should be paid to the constitution, exchange and transfer, and use by the private sector of genetic data banks without breach of confidentiality.

37. The second condition for the application of the principle is that data which satisfies the test of association with an identifiable individual 'must be held confidential in the conditions set by law'. This condition anticipates the regime for disclosure.

Disclosure

38. Disclosure of genetic data implies free, informed and explicit consent. This consent can only be given to a medical unit which is bound by medical secrecy.

39. Disclosure of genetic data - justifiable only in exceptional situations foreseen by law - must always be preceded by a case-by-case analysis of harms and benefits with the idea of minimising harms and maximising benefits.

40. Several considerations could permit disclosure of genetic data, for example, to the person concerned, family members, third parties and for research purposes(4).

A. Person Concerned

41. Article 5(c) of the Declaration provides that 'the right of an individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected'. This is a special provision, particularly relevant to predictive genetic tests, that entitles the person tested to be informed of the results of genetic examination(5). In a normal situation it would not be reasonable to withhold such results from the person concerned.

42. Are there situations in which the results of genetic examination may be withheld from the person tested against that person's wishes? Where the information is sensitive and could be psychologically damaging to the person tested, the question may arise whether it should be withheld or whether its transmission should be delayed (the latter is so called 'therapeutic privilege' of delayed disclosure). In the absence of a provision allowing for derogation from Article 5(c), for example, in the interest of the patient, it would seem that the person tested could insist on the information being given to him/her.

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4. For an analysis of this issue, see study entitled *'Privacy, Confidentiality and Genetic Information'* by Bartha Maria Knoppers, prepared for the IBC. This study is available, in English and French, at the Division of the Ethics of Science and Technology of UNESCO.

5. See the Report of the IBC on Genetic Counselling (*Proceedings of the Third Session of the IBC*, Vol. I. UNESCO, 1995), which has emphasized the need for non-directive genetic counselling.

43. Note that the European Convention on Human Rights and Biomedicine provides in Article 10(3) for a special exception to the right (in its second paragraph) whether to be informed or not of information about one's health: 'in exceptional cases, restrictions may be placed on the exercise of the rights contained in paragraph 2 in the interest of the patient'(6). There is thus in this Convention, unlike the Declaration, a particular provision that would allow for the withholding of information where it is felt that such information would be psychologically damaging to the person tested(7).

44. Article 5(c) of the Declaration also gives the person tested the right not to be informed of the results of genetic examination. There might be a situation in which is felt that the person tested should, against his wishes, be informed - perhaps a rarer situation than the one in which it is felt that the person tested should not, against his wishes, be informed. In the case of a person having expressed a wish not to be informed of the results of genetic research, how can this right be reconciled with the necessity of informing him of danger, if such research should reveal a deleterious mutation or a genetic susceptibility to an illness that could be prevented for the person concerned or members of his/her family?

45. In the absence of a provision allowing for derogation from Article 5(c), for example, in the interest of family members or the general public, the person tested could insist on the information not being given to him/her.

46. This right not to know applies above all in the identification of a genetic predisposition to genetic disorders for which no treatment or prevention is available. The question is whether a doctor ought to inform a patient about a genetic condition that will not reveal itself for many years and for which there is no treatment. Given the present state of our knowledge of human genetics, a number of doctors and geneticists agree that this is inappropriate.

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6. For a consideration of this issue, see Knoppers, *supra* note 4, at page 3, and the *1995 WHO Guidelines on Ethical Issues in Medical Genetics and the Provision of Genetic Services* – par. 7.2.1, pp. 38-39.

7. That Convention also has a general exception provision in Article 26. But that would not apply to the right whether to be informed in Article 10(2). However, it would apply to the broader right of a person in Article 10(1) to 'respect for private life in relation to information about his or her health'.

B. Family Members

47. There could be imperative reasons that genetic information, while of an individual character, be shared among family members. The explicit, informed consent to disclosure of the person tested is required. The compelling social considerations that could justify disclosure to family members include public health and the protection of the rights and freedoms of others. Family members whose health and general welfare could be affected by the genetic data of an individual, could be informed of as much of that data as is relevant to them. Such information should exclude aspects of the data that are specific to the individual and have no implications for family members.

48. Ethical obligations to vulnerable persons of limited competence and/or decision-making capacity may require a special approach to protect their interests. For example, in exceptional cases when an individual (a patient) is functionally unable to understand a genetic risk, only those legally responsible for that individual may be involved and genetic counselling may be offered. Assignment of the (voluntary) decision to a team of experts may be accepted as a last resort because of limited means of understanding and assimilating information by a counsellee.

49. In the particular case of monozygotic twins (where genetic testing of one individual reveals the status of the other), if one twin wishes to be tested and the other does not, a physician may decide (after counselling) to test the twin who requests it.

50. Disclosure of information (of genetic risk, positive results of a presymptomatic test) to a spouse or partner could only be envisaged in cases where the genetic condition of one spouse/partner may affect the other spouse's/partner's future even when children are not intended. That disclosure should be via the patient him/herself and with his/her explicit consent.

51. The special aspects of certain types of genetic diagnosis proposed during prenatal life and infancy must also be taken into consideration. Parents have the right to know about the state of a child's health, whether the illness be curable or not. The family of the child, whether unborn or born, has the special responsibility of ensuring that genetic data remains confidential: parents remain the guardians, on behalf of their children, of information about them. It is their duty, if necessary in agreement with genetic counsellors and pediatricians, to decide to what extent, when and in what form the child be informed about his/her genetic data. However, they should be particularly vigilant, considering the vulnerability of children and the lifetime consequences of disclosure of their genetic data.

C. Third Parties (Insurers/Employers/Schools/Adoption Agencies)

52. The question of disclosure of genetic data to third parties such as insurers and employers raises serious ethical objections. It is argued that the human right to work(8) and the human right to social insurance(9) (at least, health insurance as distinct from life insurance) warrant prohibiting the disclosure of genetic data to employers and insurers, even if the concerned individual has consented(10). The Working Group believes that consent given out of fear of not being employed or insured has not been freely given.

53. Moreover, it should be kept in mind that a genetic test may be performed for preventive diagnostic purposes. Hence, the data derived from that test does not necessarily imply that the individual is at a particular risk provided that preventives measures are taken. Moreover, such disclosure may expose kin of an individual, since genetic material is shared by biological relatives. Hence, identifying a genetic causative agent in one person has implications that go beyond that person and insurers and employers may, beyond a given individual, hold information about that individual's relatives.

54. Employers and insurers who deny employment and insurance on the ground of an individual's genotype are at variance with Article 6 of the Declaration which stipulates that 'no one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity'.

55. An alternative approach is to allow access to the information but to prevent it from being used for discriminatory purposes(11). It is difficult to identify the compelling social interest that is served by disclosure of genetic data to employers and insurers.

56. The fundamental issue raised by these two approaches, particularly in relation to insurance, is the relationship between an individual's freedom to contract, on the one hand, and Articles 7 and 9 on the other. Does the principle of confidentiality of genetic data override an individual's

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8. See Article 23 of the Universal Declaration of Human Rights and Article 6 of the International Covenant on Economic, Social and Cultural Rights.

9. See Article 22 of the Universal Declaration of Human Rights and Article 9 of the International Covenant on Economic, Social and Cultural Rights.

10. *1995 WHO Guidelines*, *supra* note, par. 7.2.6, p. 45.

11. *Ibid.*

freedom to contract with an insurer on the basis of data that he/she wishes to disclose to that insurer? That question is not fully answered by the Declaration.

57. Nevertheless, genetic data could be disclosed if a job involves responsibility for another's life or safety, when a worker's genetic disorder (particularly some late onset neurological conditions) may seriously endanger another individual. In certain instances, an applicant's genetic condition might make him/her especially vulnerable to specific environmental/occupational substances and therefore an employer might want to have access to the results of a specific genetic test(12). An employer may request testing as a condition of continued employment in cases where an employee has a family history which indicates a significantly elevated risk for a disorder which may involve a risk to other persons.

58. As far as access to education is concerned, disclosure of genetic data to schools may only be justified for compelling reasons in the interests of a child. This disclosure should be made to the medical unit; the explicit, informed consent (to disclosure) of the parents of the child, or those legally responsible for him/her, is required, as well as commitment by the unit that the data will not be used for discriminatory purposes.

59. Similarly, although adoption agencies may have a legitimate interest in an individual's genetic data, any provision to allow access to such data should seek to ensure that the data is not used for discriminatory purposes.

60. Disclosure of a child's genetic background to adoptive parents is justified when the child is at risk for a serious disorder that generally manifests itself in childhood or adolescence (there is no need for disclosing increased risk of late onset disorders) or a family history indicates significantly elevated risk of a psychiatric disorder with which the adoptive parents may be unable to cope.

61. Disclosure of genetic data about biological parents to the adoptive parents (without person identification) is justified when genetic information is relevant to the child's genetic condition. Genetic data about biological parents may be disclosed to the adopted individual when he/she reaches adulthood (without person identification of biological parents).

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12. See the Report of the IBC on Genetic Screening and Testing (*Proceedings of the Second Session of the IBC*, Vol. I. UNESCO, 1995).

D. Research and Epidemiology

62. In its Article 10, the Declaration provides that research on the human genome should not 'prevail over respect for the human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people'.

63. For research purposes, disclosure should be with consent, or anonymized data only should be used.

64. Disclosure of genetic data for research can be warranted for scientific and public interest and public health purposes. Obviously, any provision for derogation from the principle of confidentiality for research must take account of the need not to identify individuals; that can de done by, *inter alia*, anonymizing genetic data.

65. In particular, the results of genetic population surveys should not be used in a way that might stigmatise the groups of populations concerned, let alone lead to situations of discrimination of individuals belonging to these groups. This implies that individual researchers and research institutions should be particularly alert to this risk and exercise responsibility in disclosing such results.

66. If biological samples used for research are identifiable as belonging to particular individuals, disclosure may be justified when a researcher comes across a person with a monogenic genetic disorder which can be effectively treated (effective therapy available) or finds a genetic feature – such as familial chromosomal structural rearrangement – which involves increased risk of having affected children. Preventive measures in such cases are available and may be offered. Informed consent given prior to research must include the conditions under which the data might, if need be, be disclosed.

IV. Limitations on the Principle of Confidentiality

67. Derived as it is from the right to privacy enshrined in a number of international instruments, the principle of confidentiality has the kind of limitations, explicit or implied, that are attached to that right in those instruments(13). The limitations are set out in Article 9 of the Declaration as follows:

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13. Broadly speaking, these may be described as public interest exceptions or derogations. Article 8(2) of the European Convention for the Protection of Human Rights and Fundamental Freedoms provides: 'There should be no interference by a public authority with the exercise of this right except such as is in accordance with

> In order to protect human rights and fundamental freedoms, limitations to the principle of consent and confidentiality may only be prescribed by law, for compelling reasons within the bounds of public international law and the international law of human rights.

68. Any law should be drafted in accordance with the international law of human rights. The limitations set out in this Article relate not only to the principle of confidentiality (Art. 7), but also to the principle of consent by an individual as a requirement for research, treatment or diagnosis affecting that individual's genome (Art. 5). Although the two principles are not unrelated, the Working Group's focus is on the principle of confidentiality.

Conditions for the Application of Article 9 of the Declaration

69. Article 9 identifies three sets of circumstances in which limitations may be placed on the principle of confidentiality.

70. First, since the basic norm is the primacy of the principle of confidentiality, the article stresses the exceptional nature of limitations on that principle, which are given a very narrow and confining scope 'in order to protect human rights and fundamental freedoms'. The principle of confidentiality is an offshoot of the human right to privacy; as such, derogations from that principle must be strictly confined to certain defined areas.

71. Second, the intentionally narrow ambit of the limitations is emphasized by the requirement that limitations 'may only be prescribed by law'. This is consistent with the approach in the ICCPR(14). The

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the law and is necessary in a democratic society in the interest of national security, public safety or the economic well being of the country, for the protection of health or morale, or for the protection of the rights and freedoms of others'.

The European Convention on Human Rights and Biomedicine, in its Article 10(3), provides: 'In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraph 2 in the interest of the patient'; Article 26 provides: '(1) No restrictions shall be placed on the exercise of the rights and protective provisions contained in this Convention other than such as are prescribed by law and are necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others'.

14. For example, Article 18(3), indicates that limitations on freedom of thought, conscience and religion must be 'prescribed by law and are necessary to protect public safety, order, health, or morals or the fundamental rights and freedoms of others'.

requirement ensures that any limitations placed on the principle of confidentiality are foreseeable and have a foundation in law as distinct from mere administrative action.

72. Third, the limitations must be 'for compelling reasons within the bounds of public international laws and the international law of human rights'. There are two aspects to this requirement. The first is the exceptional nature of limitations on the principle of confidentiality: the considerations that would justify limitations must be strong, of an imperative nature. The second is that those considerations must be warranted under international law.

73. The question is: what compelling reasons under the law of international human rights would justify a limitation on the principle of confidentiality of genetic data? Broadly speaking, these are pressing public interest or social considerations, that is, reasons that would be sanctioned by international law in the public interest(15). A reading of the relevant international instruments mentioned in the introduction would suggest that these considerations relate in particular to the administration of justice (criminal and civil), and the protection of the rights and freedoms of others, such as threat to the integrity or to the life of a person.

74. Derogation from the principle of confidentiality of genetic data are warranted in the administration of justice in the interest of public order to prevent crime and for the protection of the rights and freedoms of others. But, even in this area where there are obvious compelling social considerations, provision for disclosure should be carefully circumscribed. One uses the term 'administration of justice' in its widest sense to include civil cases, where it might be necessary for a court to order disclosure, for example, in cases of identification of parenthood.

75. Available samples of biological material may be used or made available for identification of parenthood - if such is a verdict of a court. Incidental finding of non-paternity by a medical geneticist may be disclosed, only to the mother and always keeping in mind that the well being of the family and its members overrides any other consideration.

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15. See Knoppers, *supra* note 4. At page 11, speaking of privacy in the European Convention for the Protection of Human rights, she says: 'States may restrict the right to privacy only where they can demonstrate some pressing social need'.

V. Awareness-Raising and Education

76. Whatever the legal safeguards and limitations that will be developed to define the boundaries of the confidentiality of genetic data, its collection, dissemination and use will continue to raise hopes for a possible cure or relief as well as fears of a possible infringement on one's free will and private life.

77. Researchers, legislators, employers and insurance companies will certainly continue to take a very great interest in all developments in this sector and do not at all need to be reminded of the importance of doing so. Whether this will be the case for the general public is a matter of doubt. This is why the Working Group considers it to be extremely important to look closely into the question of awareness and education. In its opinion, it is up to all the institutions concerned to attach the greatest possible importance to the transparent, clear and precise communication of their intentions.

78. It happens far too often, wherever there is a relationship between institutions and the citizen, that the latter is ill-informed and confronted with documents and sheets that are a closed book to him/her. Often, the person directly concerned will not dare ask for explanations for fear of revealing his/her ignorance, and will give his/her consent without really being informed of the primary or secondary uses to which the information furnished will be put. 'Freedom of consent is the freedom that brings clarity to whosoever grants it; it is also the freedom of the subject who does not suffer external constraint.'(16)

79. In a field as important as that of the use of genetic data, the extent to which information, education and counselling are needed at every step of the process cannot be over-emphasized. It is here that Articles 5, 7 and 9, and especially 21 of the Universal Declaration on the Human Genome and Human Rights take on their full meaning. In particular, Article 21 which says that States should '... take appropriate measures to encourage other forms of research, training and information dissemination conducive to raising the awareness of society and all of its members of their responsibilities regarding the fundamental issues relating to the defence of human dignity which may be raised by research in biology, in genetics and in medicine, and its applications. They should also undertake to facilitate on this subject an open international discussion, ensuring the free expression of various socio-cultural, religious and philosophical opinions'.

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16. Comité consultatif national d'éthique pour les sciences de la vie et de la santé (CCNE), *Ethique et connaissance*. Paris: La Documentation française, 1999, page 80.

Achieving Awareness

80. To achieve greater awareness in society, States should be encouraged to support the ethics councils and committees which organize information days open to the public. For example, the French National Consultative Ethics Committee for Life Sciences and Health (CCNE or *Comité consultatif national français d'éthique pour les sciences de la vie et de la santé*) organizes 'National Ethics Days' for the special benefit of the general public, and more particularly for young people. For its part, the Belgian Bioethics Consultative Committee organized a public conference on 5 May 1999 on 'Heredity: Genetic Tests and Society' which drew a large audience. Belgian schools carefully prepared their students to attend this event and participate in its two debates, one on 'Genetic Tests and Lineage' and the other on 'Genetic Tests and Law'. Similarly, the European Association of Medical Ethical Centres held a conference on 'Human Genetics and Laws of Bioethics' in October 1999, and one of the sessions was open to the public.

81. Indeed, it can be seen that it is very important that these questions be widely discussed so as to ward off both morbid distrust and blind confidence.

82. Raising public awareness can also prevent excessive deviations. As stressed recently by Professor A. Kahn '... people themselves, independently of the reality of the possible prevention of an illness whose probability would have been determined by genetic tests, will likely seek to become "consumers of genetic testing"...'(17).

Education

83. The need for education at all levels must be underscored. States should also encourage health sciences faculties to include classes in ethics, and especially bioethics, and communication skills courses in their curricula. This should make it possible for health care providers, particularly family doctors, as well as professional workers in the health and social sciences, who are likely to use this data, to acquire the knowledge, know-how and skills needed to provide accurate information and sufficient support to people who need to be informed about their genetic profile or about the use that will be made of the available data which concerns them. These professionals must have a clear knowledge of all questions related to the confidentiality and transmission of an

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17. *Ibid.*

individual's or a family's 'genetic past', as means of transmission presently available (such as electronic mail, facsimile equipment, etc.) cannot guarantee complete security. The contents and duration of these training programmes should vary according to the specialty of the professionals concerned. Furthermore, the medical ethics committees and professional licensing bodies should pay careful attention to all complaints submitted concerning the conduct of health professionals with respect to the information and support provided to patients in the field of genetics. The same approach applies to professionals in other social sciences in which such data is used. States are thus invited to adopt appropriated mechanisms to meet these needs.

Genetic Counselling

84. The decisions to be taken in genetics relate to the heredity of families and have very important social, psychological and ethical implications. 'We have achieved greater control over certain phenomena which hitherto were beyond our scope, and are therefore now able to make choices in this field. This is why it is necessary to take unprecedented decisions for which we are ill-prepared .... There is an imperative need to propose a form of psychosocial supervision that will help in the psychological management of genetic risk.'(18)

85. Individuals and families, therefore, before undergoing genetic tests, should be informed of the issues of confidentiality that might arise. 'This approach minimizes psychological shock and hasty decisions. Pre-test counselling should include the information that in some cases test results may be ambiguous or conflicting. ... Counsellees should also be informed before testing about any employers, insurers, other institutional third parties, government agencies, or others who in many countries may lawfully seek access to or be able to require access to their test results. Counsellees should be informed in advance of the clinic's policy on disclosure to relatives at genetic risk and relevant laws and regulations.'(19)

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18. *Gènes, générations et société : l'hérédité humaine*. Leuven: Human Genetic Centre, Catholic University of Leuven, 1999, page 25.

19. Wertz D.C.; Fletcher J.C. and Berg K. in: *1995 WHO Guidelines, supra*, pp. 37-38.

86. It is clear that genetic counselling will have an influence on the decisions which will be taken. It is here that transparency and honesty, as well as the training of the professionals, will play a role. For example, a professional who seeks recognition for research work or is drawn by the lure of gain might provide partial and biased information to a client who could then take a decision that he might regret.

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87. In conclusion, it must be repeated that the march of progress is not going to come to a halt and that it is to the extent that States prepare and support the political strategies and programmes needed to properly educate and transparently inform professional workers and society that we will be able to avoid the worst and benefit from the best. In the words of Madame Noëlle Lenoir: 'Now it seems to me, as Benjamin Constant said, that "publicity is the best guarantee against arbitrariness". Indeed, it is important that citizens be capable of understanding scientific progress and that science in a way should nourish society. This is a question of democracy, since it is for citizens and their representatives to make the choices dictated by these developments. As Jean-Pierre Changeux pointed out, 'this indispensable work of informing the public is achieved through education to which ethics committees contribute at their level and in their way'. It is therefore necessary to do everything to prevent a gap between society and the world of research from becoming wider'(20).

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20. Conclusion of the Symposium *'Bioéthique et droits de l'homme'* organized by the Interministerial Mission on Human Rights (Caen, France, 23-24 October 1998), page 13.

Chapter 4

IMPLEMENTATION OF THE UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS

- **Resolution 30 C/23**
- **Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights**

RESOLUTION 30 C/23(*)

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',

Noting resolution 1999/63 entitled 'Human Rights and Bioethics', adopted by the United Nations Commission on Human Rights at its fifty-fifth session,

Also noting the Director-General's report on the implementation of the Declaration (30 C/26 and Add.),

1. *Endorses* the Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights annexed to this resolution;
2. *Invites* the Director-General to transmit them to the Secretary-General of the United Nations, with a view to the fifty-fourth 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 governmental and non-governmental organizations and to disseminate them as widely as possible;
4. *Invites* Member States, international governmental and non-governmental organizations and all identified partners to take all the necessary steps to implement the Guidelines.

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* Resolution adopted by the General Conference of UNESCO at its 30th session, on 16 November 1999.

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 the application of its results. In order to guarantee the application 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 both giving humankind 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?	3. How?	4. For whom are these guidelines intended?
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.	3.1.1 The translation of the Declaration into the largest possible number of national languages. 3.1.2 The organization of seminars, symposia and conferences at the international, regional, subregional and national levels (in Benin, Croatia, Monaco, United Republic of Tanzania, Uruguay, etc.).	Experience shows that to implement an international instrument, synergy needs to be created between all actors at the different levels. Today, inter-national action is characterized by partnership in which each actor, while retaining his identity and specific nature, complements the role played by the others. These guidelines are intended for:
2.2 Consciousness-raising, education, and training regarding the principles contained in the Declaration are especially important goals if each and every member of society is to 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 and for the various professional groups concerned (for example scientists, philosophers, jurists, judges and journalists).	• States and National Commissions for UNESCO; • UNESCO (Headquarters and field offices); • the International Bioethics Committee (IBC); • the Intergovernmental Bioethics Committee (IGBC);

	3.2.3 The preparation of programmes of education and training in bioethics designed for the secondary and university levels. 3.2.4 The preparation of training programmes in bioethics designed for teachers and trainers. 3.2.5 The preparation of information kits on specific subjects and their dissemination among public and private decision-makers and the media. 3.2.6 The production of audiovisual materials on bioethics for the general public. 3.2.7 Multimedia exhibitions designed especially for young people.	• bodies and specialized institutions of the United Nations system; • competent governmental and non-governmental organizations at the international, regional and national levels; • public and private decision-makers, especially in science 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.
2.3 Exchanges of studies and analyses pertaining to questions of bioethics, and 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.	3.3.1 The creation of bodies such as independent, pluralist and multidisciplinary ethics committees which would be special partners for decision-makers, the scientific community and civil society. 3.3.2 The networking of these institutions so as to facilitate communication and exchanges of experience among them, especially for carrying out joint activities.	

2. What to do?	3. How?	
2.4 The establishment of a dynamic relationship between the different actors is desirable in order to promote dialogue among industrialists, members of civil society, vulnerable groups, scientists and political leaders.	3.4.1 The involvement of the economic actors, especially from industry, and of social organizations such as associations of vulnerable persons and their families and friends. 3.4.2 The organization of public debates on issues covered by the Declaration and the exploration of various approaches (conferences for consensus-building, public consultation, etc.).	
2.5 Freedom of research, especially in genetics and biology, should be respected and scientific and cultural co-operation encouraged and broadened, especially between the countries of the North and the South.	3.5.1 In-depth analysis of the conditions which encourage freedom of research and those which hamper it. 3.5.2 The periodic examination by the IBC of co-operation between the countries of the North and the South and an examination of any obstacles, in order to overcome them.	
2.6 Examples of legislation and regulations that embody the principles set out in the Declaration should be prepared as a source of inspiration for States.	3.6.1 Examples of legislation and regulations that embody the principles set out in the Declaration should be prepared as a source of inspiration for States.	

	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 co-operation 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 inter-governmental organizations and responsible for the co-ordination 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 Fifty-fifth Session.

5. Evaluation

Five years after the adoption of the Declaration, in 2002, UNESCO should evaluate both the results obtained through the guidelines defined 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 in accordance with 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 submitted by the Director-General in 2003 to the statutory bodies of the Organization along with any relevant recommendations.

Chapter 5

Speeches at the Sixth Session of the IBC and the First Session of the IGBC

- **Mr Najib Zerouali Ouariti,**
  Minister of Higher Education, Executive Training
  and Scientific Research of Morocco
  (opening speech)
- **Mr Georges B. Kutukdjian,**
  Representative of the Director-General of UNESCO
  (opening speech)
- **Mr Ryuichi Ida,**
  Chairperson of the IBC
  (opening speech at the Sixth Session of the IBC)
- **Mr Ryuichi Ida,**
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- **Mr Najib Zerouali Ouariti,**
  Minister of Higher Education, Executive Training
  and Scientific Research of Morocco
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- **Mr Ryuichi Ida,**
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- **Mr Georges B. Kutukdjian,**
  Representative of the Director-General of UNESCO
  (closing speech)
- **Mr Najib Zerouali Ouariti,**
  Minister of Higher Education, Executive Training
  and Scientific Research of Morocco
  (closing speech)

I. Mr Najib Zerouali Ouariti,

Minister of Higher Education, Executive Training
and Scientific Research of Morocco
(opening speech)

In the Name of Allah, The Merciful, The Compassionate

Your Royal Highness,
Mr Prime Minister,
Distinguished Ministers,
Excellencies,
Ladies and Gentlemen,

It is indeed a great honour for us today that Morocco hosts, under the High Patronage of His Majesty King Mohammed VI, these meetings on bioethics, which constitutes one of today's burning and sensitive area putting to the test the values of our society and its foundations. Indeed, it is a source of great pleasure, honour and pride that this manifestation enjoys the patronage of His Excellency The King. This support not only reflects the good favour and affection of His Majesty, but is also a source of encouragement and an incitement for the entire scientific research community to participate in the debate on bioethics.

Adding distinction to this manifestation and elevating its status is the fact that His Royal Highness Prince Moulay Rachid is gracing the opening today by presiding it.

The attendance of such a large number of members of His Majesty's Government, led by the Prime Minister, is yet another indication of the importance that His Majesty's Government ascribes to bioethics.

I should like to take this opportunity to express our deep gratitude to UNESCO and to its Director-General, Mr Federico Mayor, for selecting Morocco to host the Sixth Session of the International Bioethics Committee and the First Session of the Intergovernmental Bioethics Committee, as well as the joint session of the two committees.

It is also an opportunity for me to say how happy I am to welcome the participants in these meetings. I should like to thank them for travelling from all parts of the world to attend these meetings and I wish them a pleasant stay in the Kingdom of Morocco.

Your Royal Highness,
Ladies and Gentlemen,

The awareness of the human and social implications of progress in the field of biology and health is one of the most significant developments of the twentieth century. Thanks to discoveries in the fields of genetics, neurobiology and embryology, the human being has access, for the first time, to the knowledge about his/her own biological mechanisms. Beyond such knowledge, he/she has given himself/herself the power to transform the development processes of all living species, including the human species.

Decision-makers, whether in the public or the private sector, have increasingly come to appreciate the potential impact of this new power. All over the world, they feel the need for ethical thinking to accompany scientific research and anticipate its applications. Moreover, the world of scientific research today has become aware that ethical reflection is an integral part of such research.

Your Royal Highness,
Ladies and Gentlemen,

Morocco has contributed to the international debate surrounding bioethics, which began over a decade ago. His Majesty the late King Hassan II had suggested to the Academy of the Kingdom of Morocco, as long ago as 1986, that it dedicate its second session for the year to the discussion of the ethical problems presented by artificial reproductive technologies. That was due to his awareness of the sensitive nature of this problematic issue, and of its vital importance for the entire human community.

Furthermore, the Academy of the Kingdom of Morocco, at its second session in 1997, discussed the subject of 'Human Rights and Gene Therapy', several days after the adoption of the Universal Declaration on the Human Genome and Human Rights.

Bioethics takes on increasing importance in our country, where the status of human rights is increasingly confirmed. It expresses the desire of

Morocco to embark upon a period of consolidating, with determination and steadfastness, the rule of law and respect for the human being, affirmed by Our King, His Majesty King Mohammed VI, in the first speech he delivered after acceding to the throne. This issue remains one of the major concerns of His Majesty. Perhaps the best evidence of this is the eminent care that His Majesty has given to these meetings through his High Patronage and the graciousness of His Royal Highness Moulay Rachid in chairing their inauguration.

Your Royal Highness,
Ladies and Gentlemen,

UNESCO has established, through its Director-General, the International Bioethics Committee to encourage reflection and enrich debate, at the international level, about the ethical, social and human consequences of advances in the biological sciences. Amongst the tasks delegated to this Committee is that of presenting proposals for the establishment of international principles for the protection of the human genome. The Universal Declaration on the Human Genome and Human Rights, adopted by the General Conference of UNESCO at its 29th session, is the result of its work.

This Declaration seeks to ensure that the progress of genetic research respects the dignity of the human being and his/her rights, and safeguards the interest of humanity in its entirety.

The progress made in genetics, which augurs for a better life and better health for human beings, can also be used for destructive purposes contrary to human dignity and to rights of the individual, and which are incompatible with the unity of the human species. Therefore, it had become the responsibility of the international community to protect humanity from these dangers through a declaration of principles, whose respect at the international level will allow us to avoid the pitfalls.

Since its establishment, the International Bioethics Committee has devoted itself to monitoring the implementation of the Universal Declaration on the Human Genome and Human Rights at the international level and has dedicated a number of its sessions to evaluating this implementation. It has also devoted many round-table discussions to subjects related to bioethics. Moreover, an Intergovernmental Committee has been established within UNESCO to examine and appraise the advice and recommendations of the International Bioethics Committee.

On this occasion, it is my pleasure to commend the members of the International Bioethics Committee who, through their valuable work, have given life to the Universal Declaration on the Human Genome and Human Rights, and to express the hopes we place in the Intergovernmental Committee, which we expect to actively participate in enriching the debate and working towards advancing bioethical reflection.

I am convinced that this enrichment will inaugurate a new stage in the process, and I take pride in the fact that the starting point of this new phase is taking place in our country, Morocco. Undoubtedly, the efforts made at the international level can not but contribute to making States and populations more aware of the ethical issues of science and of bioethics in particular. But the efforts at the national level have an extremely important role as a link between global and local action. In this respect, allow me recall the role that National Commissions for UNESCO should play in disseminating the ideals of the Organization, in particular the values and the principles set out in the Universal Declaration on the Human Genome and Human Rights, which the Moroccan National Commission strives towards by taking all means necessary.

Your Royal Highness,
Ladies and Gentlemen,

The programme of the session of the International Bioethics Committee is substantive and distinctive. There are new subjects to be studied, and a round table devoted to 'Bioethics and Public Debate' will examine the most useful methods for the promotion of education, training and information in the field of bioethics and, also, the effect on experts and on the public at large. Public awareness through broad public discussion, with the participation of scientists, will help promote individual responsibility. This awareness which is essential for the fully informed participation of all social actors in societal choices.

The second session, which will be dealing with the topic of ethics and confidentiality of genetic data, will contribute to the protection and respect of the dignity, the inviolability, identity and uniqueness of the human being in all biomedical research. The Universal Declaration on the Human Genome and Human Rights strives for the protection of individuals from discrimination based on genetic characteristics. Its implementation should not ignore this basic element of respect for the human being.

Ladies and Gentlemen,

Your work will be followed with much enthusiasm and interest by specialists world-wide and the public at large. Once again, we congratulate you for your work and the services you have rendered, which deserve praise and admiration. May Allah crown the work of your session with success and good fortune.

Peace and the Mercy and Blessings of Allah be upon You!

II. Mr Georges B. Kutukdjian,

Representative of the Director-General of UNESCO
(opening speech)

Your Highness,
Mr Prime Minister,
Right Honourable Ministers,
Your Excellencies,
Ladies and Gentlemen,

On behalf of Mr Federico Mayor, Director-General of UNESCO, I wish first of all to thank His Majesty King Mohammed VI for kindly conferring his High Patronage on the Sixth Session of the International Bioethics Committee of UNESCO, the First Session of the Intergovernmental Committee and the joint session of these two bodies, and to thank also His Royal Highness Prince Moulay Rachid for his Effective Presidency. The kind proposal of the Kingdom of Morocco to host these three meetings here in Rabat bears testimony to the importance the country attaches to bioethics, since the Moroccan Royal Academy organized debates on the subject in December 1997 on the occasion of the adoption of the Universal Declaration on the Human Genome and Human Rights.

The Director-General has also asked me to express his gratitude to the Bureau of the IBC, and particularly to its Chairperson, as well as to the members, who accomplish their difficult task with a keen sense of the responsibilities incumbent on them. And finally, I wish to express the thanks of the Director-General to the experts and specialists and to the representatives of Member States and of the international intergovernmental and non-governmental organizations present here today.

Humanity is entering the third millennium with Faustian powers and is more than ever the 'master and possessor of nature', as Descartes put it. Yet, paradoxically, it is not its own master. Humanity's development is still uncertain due to the various scientific undertakings in fields such as biology and genetics, which are profoundly calling in question the foundations of its traditional morality. Where the 20th century was the century of the mastery of matter, the 21st century will most certainly be that of the mastery of life. For in a few decades there have been major upheavals in the field of biology and genetics, with the result that we are now in a position to transform the human species.

Cloning well illustrates the staggering power which humanity is gradually acquiring of intervening in the processes of the development of living matter. This transition from reproduction to replication is paving the way to a universe of identical beings born of a gigantic undertaking of imitation. The reflection to which it is giving rise and the establishment of ethical principles presupposes on the one hand that all the various sectors of civil society as a whole participate more and more actively in a genuine, wide-open public debate with a view to identifying the real problems, establishing points of reference, and proposing innovative solutions that are geared to the future. An essential preliminary to achieving this objective is that the public be informed and educated - a question on which the round-table debate will in fact be focusing in the course of the present session.

In the other hand, reflection of this nature presupposes that disciplines be decompartmentalized and that there be dialogue amongst cultures. The fact that the present session is being held on the African continent is particularly significant and bears testimony, should such testimony be necessary, to the need to promote such dialogue. It must be underlined in this context that more and more developing countries are demonstrating their will to take part in the ethics debate at the international, regional and/or national level.

Your Highness,
Ladies and Gentlemen,

The previous session of the IBC, which was held in the Netherlands in December 1998, marked a turning point in the existence of that body, since, by adopting the Committee's Statutes on 7 May 1998, the Executive Board of UNESCO made it possible to institutionalize the IBC and define its duties. It is thus the task of the IBC to promote reflection on the ethical and legal issues raised by research in the life sciences and their applications, to encourage the exchange of ideas and information, and to co-operate with the governmental and non-governmental organizations concerned by bioethics. Furthermore, the Statutes also assign the Committee the task of disseminating the principles set out in the Declaration and further examining issues raised by their applications and by the evolution of the technologies concerned. The IBC thus decided to put forward proposals which are based on Article 24 of the Declaration and on which you will be called upon to state your views.

The implementation of this Declaration is all the more urgent since progress in biology and genetics is accelerating and is raising both hopes for humanity and dilemmas or indeed serious concern. It is for this reason that draft guidelines have also been drawn up with a view to identifying not only the tasks incumbent on the various actors for promoting the implementation of the Declaration, but also the means of action for carrying out those tasks. The Committee also plans to assess both the results obtained and the impact of the Declaration. In accordance with its terms of reference, the Committee will also examine a report on confidentiality and genetic data, for this question is essential to the protection of the privacy of the individual. In view of the fact that genetic information - which provides information on individuals, their health and predispositions, as well as on their collaterals and descendants - and given the specific risks of abuse and discrimination which might ensue, access to this information must have special protection.

Your Highness, not a week goes past without reports in scientific journals or major newspapers recounting new genetic discoveries. These discoveries and their applications in biomedicine concern all countries, whether industrialized or developing. They concern them all for although they may not change public and private life today, they will certainly transform it tomorrow. The challenge which UNESCO is taking up through the activities of its International Bioethics Committee is that of accompanying this prodigious progress with reflection on the ethical aspects which is equal to the issues at stake.

The Director-General of UNESCO would have very much liked to be with you at these meetings but has had to remain at Headquarters for the 157th session of the Executive Board. He wishes this session every success.

Thank you.

III. Mr Ryuichi Ida,

Chairperson of the IBC
(opening speech at the Sixth Session of the IBC)

Your Excellencies,
Colleagues,
Ladies and Gentlemen,

It is a great pleasure and honour for me to declare open the Sixth Session of the International Bioethics Committee of UNESCO.

On behalf of all of the members of the Committee I wish to thank in particular the Government of the Kingdom of Morocco for inviting the Committee to hold its Sixth Session in this wonderful room in Rabat. The whole atmosphere already holds the promise that the results of our work will be fruitful.

Before opening our work I wish to inform you that the Committee has elected its Chairperson, Vice-Chairpersons and Rapporteur during a private session; it re-elected all of the members of the Bureau, i.e.: myself as Chairperson; His Excellency Mr Héctor Gros Espiell, Dr Mohammed Hamdan, Ms Michèle Jean and Professor Jacek Zaremba as Vice-Chairpersons, and Ms Yolande Tano Bouah as Rapporteur.

Scientific advancement is so rapid that it is difficult for reflection on bioethics to keep pace with it. Yesterday we discussed reproductive human cloning. Today we have to devote attention to totipotent embryonic stem cells. We adopted the Universal Declaration on the Human Genome and Human Rights only recently and already researchers are beginning to talk about post-genome research. The International Bioethics Committee should keep abreast with the speed of this scientific advancement. There are bioethical issues which still remain unresolved or which at least must still be debated. In my country, Japan, for example, we are reopening the discussion on organ transplants. The problems raised by bioethics are far from resolved. It is for this reason that I spoke of continuity and innovation at the Fifth Session, which was held in Noordwijk, The Netherlands, last year. As Chairperson I have always endeavoured, and will continue to endeavour, to lead the International Bioethics Committee in a spirit of harmony.

The Sixth Session of the International Bioethics Committee is particularly important for two reasons. First, the subjects which will be discussed are to a certain extent a combination of continuity and innovation. The round table on 'Bioethics and Public Debate: Information, Education, Participation' is crucial for the promotion of bioethics; it will be chaired by Ms Nicole Questiaux, and six personalities will be taking part. The discussion on the other two subjects - the follow-up of the Declaration and the confidentiality and genetic data – aims at further developing the debate held in the working groups and also approving the proposals and projects put forward in the discussions of those two working groups.

Secondly, this session of the Committee will be followed by the First Session of the Intergovernmental Committee which has been established in order to ensure dialogue between the members of the IBC, an independent body, and the representatives of States. This innovation should be fruitful from both the point of view of the dissemination of our work and the mutual understanding between these two bodies.

After the present session, we shall continue to broaden, insofar as possible, the horizons of the IBC's activities. A number of projects and proposals have already been put forward, such as the organization of regional seminars dealing with questions of bioethics specific to various regions, the support for the third summit of the national bioethics committees, the publication of a document explaining the Declaration, the dissemination of information on national or regional legislation and regulations, etc.

Such are our ambitions for the present session and for the immediate future. I would like to invite all participants to debate these various crucial questions thoroughly and sincerely.

IV. Mr Ryuichi Ida,

Chairperson of the IBC
(closing speech at the Sixth Session of the IBC)

Your Excellencies,
Colleagues,
Ladies and Gentleman,

The International Bioethics Committee has just concluded the work of its Sixth Session here in Rabat. These two and a half days of work have brought intensive and stimulating ideas, which have sometimes also been provocative. We have been honoured by the High Patronage of His Majesty King Mohammed VI and the Effective Presidency of His Royal Highness Prince Moulay Rachid. The profound interest of the Kingdom of Morocco in issues of bioethics was demonstrated by the presence of His Royal Highness and the entire Moroccan Government at the opening ceremony. The ideas put forward by His Excellency Mr Najib Zerouali Ouariti, Minister of Higher Education, Executive Training and Scientific Research and President of the Moroccan National Commission for Education, Culture and Science, once again revealed the tremendous importance of bioethics for the future of humankind as a whole.

The speech of the representative of the Director-General of UNESCO, Mr Georges B. Kutukdjian, our Secretary-General, enlightened us on our duty and our universal responsibility to promote scientific advancement while respecting both human dignity and human rights.

The round table, which was chaired by Mrs Nicole Questiaux, Chairperson of the Permanent European Conference of National Ethics Committees, highlighted the difficulties and the means of promoting public debate in the field of bioethics. Bioethics is not only an area of reflection for decision-makers or scientists, or even intellectuals; it is also, and above all, a subject for the public at large, that is to say, for each and every one of us. The importance of education at various levels, not only in faculties of medicine and other scientific faculties but also at secondary school level, was underlined in particular. Moreover, we are delighted to see that young people are aware of the bioethical issues at stake and of the need for personal commitment in this respect.

I wish to draw your attention to Article 20 of the Universal Declaration on the Human Genome and Human Rights, which stipulates the duty to promote the principles set out in the Declaration through bioethics education at all levels. The Committee is aware of its responsibility to support the organization and setting up of education in bioethics. I wish to inform you that the Committee has its own website, to which everyone may accede.

The follow-up to the Declaration is one of our Committee's most urgent tasks. The working group on the issue, which is chaired by His Excellency Mr Héctor Gros Espiell, has presented proposals in view of the application of Article 24 of the Declaration. These proposals concern various crucial factors, i.e. the means of disseminating the principles set out in the Declaration, the modalities of furthering the subjects in the application of its principles, the consultations with the parties concerned, the recommendations and opinions of the IBC, the identification of practices contrary to human dignity, and proposals on the subjects to be dealt with in the future.

The report of the meeting of the Working Group on the follow-up and the Group's proposals have been approved by the Committee. The most important result of this working session, however, is the Committee's approval of the Draft Guidelines for the Implementation of the Declaration. Under the headings 'What to do?', 'How?' and 'For whom are these guidelines intended?', this draft sets out a whole range of measures for implementing the Declaration.

The two working sessions reserved for the members of the IBC were devoted to three state-of-the-art presentations on scientific advancements and to a hearing on a concrete case concerning bioethics.

The presentation on xenotransplantion by Professor Fritz Bach of the Harvard Medical School highlighted the confrontation between the right of patients to have access to better treatment and the interests of the human community. This is perhaps a more complex issue than a matter of bioethics.

The presentation on the current state of cloning techniques by our colleague Professor Michel Revel, who won the Israeli Award for Medicine 1999, made us realize that the ethical assessment of the various insemination and reproduction technologies is a difficult task. Professor Revel also gave a precise description of the scope of human cloning for reproductive and non-reproductive purposes.

In his paper on the state-of-the-art on embryonic stem cell research, Professor Nombela Cano, our colleague from the Committee and President of the High Council for Scientific Research in Spain, demonstrated that the embryo is the 'hard core' of the ethical debate in this field.

The hearing of Dr Kari Stefansson, the Chief Executive Officer and President of the Icelandic firm *deCode genetics*, revealed the nature and characteristics of the databank he has created in Iceland under the supervision of the 'Act on a Health Sector Database'.

Several participants requested that these two working sessions be opened to members of the public so that they can be informed as precisely as possible of the current status of scientific advancement. The Committee will take account of this request in the organization of the forthcoming session of the IBC. However, devoting two working sessions to internal discussions which are closed to the public does not mean holding our discussions in secret - far from it. This system has been adopted so that the Committee itself can assume its own responsibility in the bioethics debate and so that its members can examine important and sometimes delicate questions in depth.

The working session which we have just concluded was devoted to ethics and the confidentiality of genetic data. It was chaired by Professor Sylvia Rumball and was based on the very valuable results of the Working Group on the subject. The draft report drawn up by the group is remarkable and certainly constitutes a reference document. The paper presented by Ms Michèle Jean clearly demonstrated that the confidentiality issue arises where various ethical issues overlap.

That was a brief summary of the work of this session. All of the opinions, suggestions, information and criticisms expressed in the course of the session will be taken into account for our future work - and in this context I wish to express my sincere thanks to all of the participants for their contribution to our work.

I shall now present our plan of work for the forthcoming session. We shall continue to have two working groups and to hold two sessions reserved for the members of the IBC, since we consider this system efficient and essential. The programme will be organized more appropriately, of course, to take account of the opinions expressed by several observers.

The subject matter of our future programme will consist of two components. The first is that of discussion. The committee has examined various suggestions and proposals regarding the subjects to be dealt with at the forthcoming session, but since time is short I can only give you a provisional list of the topics suggested for the time being. A number of these subjects were already contained in the final section of the proposals of the Working Group on the follow-up of the Declaration. The research in question concerns research on embryonic stem cells and interspecific hybrids, the 'post-mapping' of the human genome (ethical issues of post-genome research), the protection of the human embryo, the possible use of genetic research results for non-peaceful purposes, North-South international co-operation and solidarity, the trend to secrecy in scientific research which is more marked than in the past, the consequences of changes in priority of public and private funding of research, the free and informed consent, the sequencing of the human genome, bioethics education, the economic aspects of the human genome, requirements for setting up national bioethics committees, the status of genetic data in different countries, the IBC procedure for formulating recommendations and opinions, the genetically modified organisms, the experiments on living subjects, the rights of the human embryo and the risk assessment. All these proposals will be examined within the next few days and we shall decide on the subjects to be debated at the forthcoming session as soon as possible.

The second component concerns action. Several projects are currently under examination; for example, support for the organization of the third summit of the national bioethics committees, the organization of regional seminars on bioethics, the organization of a round table on the economic implications of the human genome, the establishment of an information network on national legislations and regulations. However, these plans of action will be carried out according as our budget and circumstances permit.

Furthermore, a project is currently under way involving the publication of a compendium of commentaries on the Declaration. It will be a sort of commentary set out article by article, and it is due - hopefully - to be published very shortly.

In my opening address I spoke of the speed of scientific progress and the Committee's efforts to keep abreast. The papers presented and discussions held in the course of this session have shown us that a spirit of harmony is absolutely essential in a field such as bioethics. It is not a question of making a hard and fast distinction between black and white, but of finding the best solution for the life of the individual and for the human community as a whole.

Before closing the present session, I should like to express all my thanks to the Director-General of UNESCO, to all the members of the International Bioethics Committee and to all the participants at this session for their most valuable and efficient contribution. My thanks go in particular to Mrs Lamia Salman El-Madini, the UNESCO Representative in Rabat, for her invaluable assistance in the organization of this session in Rabat. I also thank all the staff of the Secretariat, and in particular Mr Georges Kutukdjian, our Secretary-General, for his untiring efforts, which enabled us to reap the benefits we now have in hand. Without their assistance the Committee would have been unable to fulfil its task.

It now remains for me to express my deep gratitude to His Majesty King Mohammed VI - and to His Royal Highness Prince Moulay Rachid - for his generous hospitality.

I also thank most sincerely Mr Zerouali Ouariti, the Minister of Higher Education, and the entire Government, especially the Ministries of Higher Education and Foreign Affairs and Co-operation and all the staff who have assisted us. And last but not least, I thank our interpreters, who are always most efficient.

I said right at the beginning of the session that the atmosphere was promising, and I am glad to say that I was not mistaken. I invite everyone present here to continue to help us in the activities of the Committee, and I hereby declare the Sixth Session of the International Bioethics Committee of UNESCO closed.

V. Mr Najib Zerouali Ouariti,

Minister of Higher Education, Executive Training
and Scientific Research of Morocco
Chairperson of the IGBC
(opening speech at the First Session of the IGBC)

Ladies and Gentlemen,

The Director-General of UNESCO had called for the creation of a committee entrusted to reflect at the international level and to encourage the debate on the ethical and social consequences of progress achieved in biology, and more particularly in genetics and biotechnology. The work of this Committee led to the adoption by the General Conference of UNESCO at its 29th session of the Universal Declaration on the Human Genome and Human Rights.

The role of this body, comprised of scientists, philosophers and intellectuals, is of paramount importance insofar as its members enjoy an independence which allows them to freely examine the issues in-depth, and that the diversity of their fields of competence provides multiple possibilities for comparison, complementarity and generalization. Nevertheless, there are a number of phases between the time the Committee draws its conclusions and their implementation and intermediary relay mechanisms are needed.

This is why the Executive Board of UNESCO at its 154th session decided to create the Intergovernmental Bioethics Committee (IGBC). The recommendations, proposals, or even international declarations or conventions cannot be effective if States do not make decisions and put into place the frameworks necessary for the repercussion at a national level of the efforts made by the international community, if they do not undertake to conciliate the position of international organizations and the expectations of all components of society.

The role of the IGBC is even more important and its mission even more vital as it concerns confronting such opinions and recommendations with the demands of a reality marked by cultural diversity and economic disparity. Considering the reciprocal links between the two committees, this undertaking could even make a substantial contribution to finding a solution to the ethical problems that science in general gives rise to.

Ladies and Gentlemen,

I wish you much success in the accomplishment of this difficult undertaking. Welcome to Morocco whose air and beauty will bring you, I hope, inspiration and courage.

May God protect our Sovereign, His Majesty King Mohammed VI, his brother Prince Moulay Rachid and all members of the Royal Family.

Peace be with you!

VI. Mr Ryuichi Ida,

Chairperson of the IBC

(presentation at the First Session of the IGBC)

Sir,

I would like first of all to congratulate you warmly on your election to office as Chairperson of the Intergovernmental Committee and I also congratulate the members of the Bureau.

It is with great pleasure that we, members of the IBC, are attending the First Session of the Intergovernmental Committee. Dialogue and co-operation will be ensured between us, between the IBC and the IGBC.

Previous Work

When the IBC was set up in June 1993 it was composed of about 50 personalities, who were appointed in a personal capacity. It was – and still is – the only body in the United Nations system whose title contains the term of 'bioethics'.

It has pursued two objectives:

- that of allowing exchange of views on the questions of bioethics with which we are confronted today because of the very rapid progress made in science and technology. Up until 1997 several subjects have been dealt with by the IBC: genetic screening and testing, genetic counselling, gene therapy, population genetics, neuroscience, access to experimental treatment and the development of plant biotechnology;
- that of drawing up an international instrument for the protection of the human genome. It achieved this objective in 1997 with the adoption of the Universal Declaration on the Human Genome and Human Rights.

Features of the Declaration

The fundamental concept of the Declaration is the protection of every individual human being, in his/her dignity and his/her human rights, as far as research on the human genome and its applications is concerned. Consequently it has a dual framework.

The first is the dialectic of freedom of research and the rights of the persons concerned. The Declaration affirms the need to guarantee freedom of research on the one hand, and on the other hand, it foresees the scope of the freedom of human genome research and its applications from the point of view of respect of human rights, fundamental freedoms and human dignity. Practices contrary to human dignity are not allowed. The respect of the rights of the persons concerned is dealt with through free and informed consent, special considerations with regard to vulnerable persons and groups, the right to privacy and the confidentiality of genetic data.

The second framework concerns the protection of human rights from the aspect of genetic characteristics of each human being. The Declaration prohibits any form of discrimination based on genetic characteristics, the confidentiality of the genetic data associated with an identifiable person being the central factor in this respect. This raises a difficult question: who do genetic data belong to?

The Declaration underlines the role of States both in promoting genetic research and in considering the related ethical and social implications. It invites States to set up independent, multidisciplinary and pluralist ethics committees at the national level.

North-South international solidarity and co-operation are also a key principle for equitable development in the field of genetics.

We sum up all these factors in one single expression, that of 'the ideology of humanity'. The Declaration has not been limited to the UNESCO framework since the General Assembly of the United Nations has also endorsed its principles. It has thus become 'universal' in every sense of the term.

The Declaration is a declaration of principle and thus an ethical instrument which is not legally binding. However, the fact that UNESCO has adopted this Declaration and that it has also been endorsed by the United Nations General Assembly constitutes a landmark in the history of humanity. Implementation of the Declaration is thus the key factor for protecting human dignity and human rights in the field of genetics.

Article 24 of the Declaration entrusts the task of the follow-up to the new International Bioethics Committee.

The Proceedings of the Fifth Session of the IBC

The International Bioethics Committee has been reconstituted in accordance with the Resolution of the General Conference on the implementation of the Declaration in November 1997. The present Committee is composed of 36 members, who are appointed in a personal capacity by the Director-General of UNESCO. The present IBC has a dual role of continuity and innovation.

The Committee is in itself an innovation, since it will be operating henceforth on the basis of Statutes and a new composition. What is also new is the creation of the Intergovernmental Committee in parallel, in order to guarantee dialogue with the IBC. This demonstrates the States' evident interest in and awareness of the problems raised by bioethics.

The Committee also represents continuity, since one of our principal tasks is the implementation of the Declaration. It is precisely for that reason that the IBC has been reconstituted.

At the Fifth Session of the IBC, which was in fact the first meeting of the new Committee, we held three working sessions and a round-table debate, as has been the tradition of the IBC. The subjects dealt with were: 'Bioethics and Women's Rights', 'Ethics and Preventive Medicine' and 'The Follow-up to the Declaration'; the round table focused on 'Ethics and Uses of Genetic Engineering in Industry'.

The working session on 'Bioethics and Women's Rights' was chaired by Ms Michèle Jean, Vice-Chairperson and Special Advisor to the Canadian Minister of Foreign Affairs at the European Commission. The working session revealed how necessary it is to improve and even standardize the situation of women in each society. The report of the working group is very extensive and is devoted to the comparative study of the various issues concerned. Opinions differ widely on this issue, which concerns the very core of bioethics. This report is due to be published by UNESCO shortly.

The working session on 'Ethics and Preventive Medicine', which was chaired by Professor Michel Revel, who won the Israeli Award for Medicine 1999, revealed the areas of light and the shadow-land of preventive medicine. It is essential that we investigate the usefulness and effectiveness of biotechnology and of advanced genetic engineering and that we devote thought to the physician-patient relationship, etc..

The follow-up to the Declaration was presented by His Excellency Mr Héctor Gros Espiell, Chairperson of the Legal Commission of the former IBC and Vice-Chairperson of the present Committee. The adoption of the Declaration is not an end in itself, it is the point of departure for reflection on the conduct of researchers, patients, persons concerned and all of us as individuals. The report which Mr Gros Espiell will present in the course of this session is the result of the discussion we held on the subject at the Sixth Session.

The round-table debate on ethics with regard to the uses of genetic engineering in industry revealed how difficult it is to resolve the confrontation between bioethics and human rights, on the one hand, and the logic of the market economy, on the other.

At its Fifth Session, the Committee decided to set up two working groups – on the follow-up of the Declaration and on the issue of confidentiality and genetic data. The IBC also decided to reform its working methods and to divide the session into two parts, i.e. two working sessions plus a round table, all of which are open to the public, and two working sessions reserved for the members of the IBC. The purpose of this reform is to assume our responsibility through in-depth discussions amongst the members of the IBC.

The Sixth Session of the IBC

The Sixth Session here in Rabat was composed of four working sessions and a round-table debate. In working groups we also examined two particularly important topics directly connected with the Declaration.

The round table, which was chaired by Ms Nicole Questiaux, Chairperson of the Permanent European Conference of National Ethics Committees, highlighted the difficulties and the means of promoting public debate in the field of bioethics. Bioethics is not only an area of reflection for decision-makers or scientists, or even intellectuals; it is also, and above all, a subject for the public at large. The importance of education at various levels, not only in faculties of medicine and other scientific faculties but also at secondary school level, was underlined in particular. We are also delighted to see that young people are aware of the bioethical issues at stake.

I wish to draw your attention to Article 20 of the Universal Declaration on the Human Genome and Human Rights, which stipulates the duty of States to promote the principles set out in the Declaration through bioethics education at all levels. The Committee is aware that it has to take the initiative in this area with a view to facilitating the setting up and shaping of education in bioethics. I wish to inform you that the Committee has its own website, to which everyone may accede.

The follow-up to the Declaration is one of our Committee's most urgent tasks. The Working Group on the issue, which is chaired by His Excellency Mr Héctor Gros Espiell, has presented proposals in view of the application of Article 24 of the Declaration. These proposals concern various crucial factors, i.e. the means of disseminating the principles set out in the Declaration, consultations with the parties concerned, the recommendations and opinions of the IBC, the identification of practices contrary to human dignity and the proposals on the subjects to be dealt with in the future.

The report of the meeting of the Working Group on the follow-up and the Group's proposals have been approved by the Committee. The most important result of this working session, however, is the Committee's approval of the Draft Guidelines for the Implementation of the Declaration. Under the headings 'What to do?', 'How?' and 'For whom are these guidelines intended?', this draft sets out a whole range of measures for implementing the Declaration.

The two working sessions reserved for the members of the IBC were devoted to three state-of-the-art presentations on scientific progress and to a hearing on a concrete case concerning bioethics.

The presentation on xenotransplantion by Professor Fritz Bach of Harvard Medical School highlighted the confrontation between the right of patients to have access to better treatment and the interests of the human community. This is perhaps a more complex issue than a matter of bioethics.

Professor Bach developed four ethical considerations: the risk for society, the elaborate form of free and informed consent, the possible mutations after transplantion, and the transgenerational risks. He also underlined the economic aspects of xenotransplantion.

The presentation of the current state of cloning techniques by our colleague Professor Michel Revel, who won the Israeli Award for Medicine in 1999, made us realize that the ethical assessment of the various insemination and reproduction technologies is a difficult task. Professor Revel also gave a precise description of the scope of human cloning for reproductive and non-reproductive purposes, mentioning not only human cloning techniques but also the various therapeutic possibilities, the use of human cloning for non-reproductive purposes and the question of genetic identity.

In his paper on the state-of-the-art on embryonic stem cell research, Professor Nombela Cano, our colleague from the Committee and President of the High Council for Scientific Research in Spain, demonstrated that the embryo is the 'hard core' of the ethical debate in this field. The totipotency of embryonic stem cells raises the important and delicate question of defining the human embryo as well as the question of the quality of human life.

The hearing of Dr Kari Stefansson, the Chief Executive Officer and President of the Icelandic firm *deCode genetics*, revealed the nature and characteristics of the databank he has created in Iceland under the supervision of the 'Act on a Health Sector Database'.

The last working session was devoted to ethics and the confidentiality of genetic data. This session was chaired by Professor Sylvia Rumball and was based on the results of the Working Group on the subject. The draft report drawn up by the Group is remarkable and certainly constitutes a reference document. Ms Michèle Jean's presentation clearly revealed that the confidentiality issue arises where various ethical issues overlap.

That was a brief summary of the work we carried out at the Sixth Session of our Committee. All of the opinions, suggestions, information and criticisms expressed in the course of this session will be taken into account for our future work.

I shall now present our plan of work for the forthcoming session. We shall continue to have two working groups and to hold two working sessions reserved for the members of the IBC, since we consider this system efficient and essential.

The subject matter of our future programme will consist of two components. The first is that of discussion. The Committee has examined various suggestions and proposals regarding the subjects to be dealt with at the forthcoming session, but since time is short I can only give you a provisional list of the topics suggested for the time being. A number of these subjects were already contained in the proposals of the Working Group on the follow-up to the Declaration:

1. research on embryonic stem cells and interspecific hybrids;
2. the 'post-mapping' of the human genome (ethical issues of post-genome research);
3. the protection of the human embryo;

4. the possible use of genetic research results for non-peaceful purposes;
5. North-South international co-operation and solidarity;
6. the tendency towards secrecy in scientific research which is more marked than in the past ;
7. the consequences of changes in priority of public and private funding of research.

I must add other subjects to this list which were proposed by the members of the Committee in the course of the session devoted to the issue: the free and informed consent, the sequencing of the human genome, bioethics education, the economic aspects of the human genome, requirements for setting up national bioethics committees, the status of genetic data in different countries, the IBC procedure for formulating recommendations and opinions, the genetically modified organisms, the experiments on living subjects, the rights of the human embryo and the risk assessment.

As regards the 'action' component, we are planning several projects, which are still under consideration; for example, support for the organization of the third summit of the national bioethics committees, the organization of regional seminars on bioethics, the organization of a round table on the economic aspects of the human genome, the establishment of an information network on national legislations and regulations. Furthermore, a project is currently under way involving the publication of a compendium of commentaries on the Declaration, set out article by article; this compendium is due to be published very shortly.

In my opening address at the Sixth Session of the IBC I spoke of the speed of scientific progress and the Committee's efforts to keep abreast. The papers presented and discussions held in the course of this session have shown us that a spirit of harmony is absolutely essential in a field such as bioethics. We are not seeking to make a clear, hard and fast distinction between two opposing positions; rather, we are endeavouring to find the best solution for the life of the individual and for the human community as a whole.

However, the co-operation of the Member States of UNESCO is essential if this goal is to be achieved and if the principles set out in the Declaration are to be put into actual practice. The International Bioethics Committee will be glad to continue the dialogue on the ethical issues which fall within its field of responsibility.

We shall be delighted to hear your opinions and any proposals you may wish to make regarding the work of the IBC. Let us have your ideas! As the Chairperson of the IBC, I can assure you that all opinions and suggestions – and also any criticisms – will be duly taken into account by the IBC. The coexistence of our two committees can only further the debate on universal bioethics; it will do so significantly and effectively for the benefit and value of humanity as a whole.

VII. Mr Georges B. Kutukdjian,

Representative of the Director-General of UNESCO
(closing speech)

Sir,
Your Excellencies,
Ladies and Gentlemen,

At the conclusion of the meetings of the UNESCO bioethics committees, I should like first of all, on behalf of the Director-General of UNESCO, to reiterate our thanks to His Majesty King Mohammed VI for his High Patronage and to Prince Moulay Rachid for his Effective Presidency. The Director-General also thanks the Government of the Kingdom of Morocco and more particularly you yourself, Sir, for your welcome and support and for that of all of your staff, especially Ms Naïma Tabet, Secretary-General of the Moroccan National Commission for UNESCO.

The Director-General has asked me to express his gratitude to Professor Ryuichi Ida, the Chairperson of the IBC, to the Vice-Chairpersons and the Rapporteur and to all the members of the IBC. He is also grateful to you for chairing the Intergovernmental Bioethics Committee, and he thanks the Bureau and members of that Committee.

The meetings which have just been held have been fruitful in several respects. First of all, it is on the basis of the recommendations addressed to the Director-General by the joint session of the two committees that in several weeks' time the Director-General will present the Draft Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights to the General Conference for adoption.

Secondly, the IBC has been able to open a debate on current research in biology and genetics, some of which, such as research on embryonic stem cells, raises unprecedented questions.

Thirdly, the joint meetings of the two committees here in Rabat have been very beneficial and have formed the foundation for an open dialogue that is geared to the future. The Director-General will thus also be glad to bring the results of the work held in Rabat, which have been crowned with success, to the attention of the General Conference.

Before closing, I should like to bid farewell to all participants who are returning to their various countries a good journey and to say to you all, whether you are leaving or staying, that I hope to see you again very soon.

Thank you.

VIII. Mr Najib Zerouali Ouariti,

Minister of Higher Education, Executive Training
and Scientific Research of Morocco
(closing speech)

Mr Chairperson of the International Bioethics Committee,
Mr Representative of the Director-General,
Mrs Representative of UNESCO in Morocco,
Representatives of the Member States of the Intergovernmental Bioethics Committee,
Ladies and Gentlemen,

We have now come to the closing session of the meetings of the International Bioethics Committee, the Intergovernmental Bioethics Committee and the joint meeting of those two bodies. These sessions have been very hard work but they have been very rich in discussions and exchange of views, which have led to the establishment of working methods between the International Bioethics Committee and the newly created Intergovernmental Committee.

I consider that the conclusions reached yesterday afternoon, and which were reported to me very briefly, will enable these two committees to work together in harmony and above all to complement each other. I think that this is one of the main objectives formulated by the UNESCO Directorate on the basis of recommendations made both by the Executive Board and the General Conference, and I think that you have succeeded in defining these working methods in a spirit of complementarity. I believe that the role of the International Bioethics Committee remains that of freedom of thought, reflection and work and that of the Intergovernmental Committee will be essentially to apply and implement any recommendations which may emerge from either the Universal Declaration on the Human Genome and Human Rights or from any other analytical efforts, by adapting these applications to the various sociocultural and religious characteristics specific to the various member countries of this Intergovernmental Committee. Furthermore, the Intergovernmental Committee will be responsible for bringing topical issues to the attention of the International Bioethics Committee - issues which can give rise to difficulties at the national, regional or international level.

I believe that this exchange between the International Bioethics Committee and the Intergovernmental Committee can only strengthen human rights, respect for human dignity and for human uniqueness, and above all reduce the number of conflicts which may arise, whether racist in origin or having genetic or genetically racial causes. The objective which we have set ourselves is to defend humanity and its rights, to defend its equality and its uniqueness, and I am convinced that in all of your discussions this has been the principal objective. I believe that beyond the level of these committees the major objective which we have all set ourselves is humanity, humanity alone, humanity in its entirety and in all its grandeur.

Thank you.

Chapter 6

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