Meeting of Government Experts
Responsible for Finalizing the Draft
International Declaration on Human Genetic Data

UNESCO Headquarters, 25 to 27, 28 or 29 June 2003
(Room XI, Fontenoy building)

Summary of the International Consultation on the
Revised Outline of the International Declaration
on Human Genetic Data (22 January 2003)

Annex: List of replies to the questionnaire as at 4 June 2003
I. INTRODUCTION

At its 165th session (Paris, 7-17 October 2002), shortly before the ninth session of the International Bioethics Committee (IBC) (Montreal, Canada, 26-28 November 2002), the Executive Board invited the Director-General to “continue the preparation of an international declaration on human genetic data, in consultation with the Member States and other relevant international organizations (…), with a view to its adoption by the General Conference at its 32nd session” (165 EX/Decision 3.4.2, para. 9).

UNESCO therefore launched an international consultation. Ms Nicole Questiaux and Mr Patrick Robinson, co-chairpersons of the IBC Drafting Group for the elaboration of an international instrument on genetic data, and Mr Pierre Sané, Assistant Director-General for Social and Human Sciences, sent documentation on 31 January to: Permanent Delegations of the Member States and Permanent Observer Missions of non-Member States; the United Nations and specialized agencies of the United Nations system and other international and regional intergovernmental organizations (IGOs); international non-governmental organizations (NGOs) maintaining relations with UNESCO; bioethics committees, commissions, centres and institutes; national agencies for the protection of personal data; private-sector businesses using human genetic data; former members of IBC and some one hundred eminent personalities and experts worldwide specializing in the field of bioethics. The documentation included the Revised Outline of the International Declaration on Human Genetic Data of 17 January. It also included a brief presentation of the Revised Outline, including a glossary of technical terms used therein, and a questionnaire concerning the outline to assist in the formulation of replies. Since very few responses had been received by the deadline of 28 February set for IGOs, NGOs, bioethics committees, personalities and so forth or by the deadline of 15 March set for the Member States, the deadline was accordingly extended to the end of April 2003.

The list of replies to the questionnaire received between 15 March and 4 June 2003 is presented in the Annex.

This summary presents an analysis of the replies received. It follows the format of the questionnaire and refers to the articles as set out in the Revised Outline. First and foremost, the summary:

- highlights the convergences and divergences between the viewpoints expressed;
- lists the strengths and weaknesses of the Revised Outline, as revealed by the replies;
- presents the concrete proposals which have been made.

A preliminary draft has already been distributed in conjunction with the forthcoming meeting of government experts responsible for finalizing the international declaration on human genetic data. The Revised Outline of 17 January was modified by the IBC Drafting Group in the light of the Public Hearings Day (Monte Carlo, Monaco, 28 February 2003) on issues involving human genetic data of concern to the various social and economic stakeholders in the public and private sectors. The Revised Outline was further refined by observations made at the 166th session of the UNESCO Executive Board (UNESCO Headquarters, 11 April 2003), replies to the questionnaire and proposals made by IBC on 11 and 12 May 2003, at its tenth session.

The summary indicates, usually in a footnote, how the replies were taken into consideration and reflected in the preliminary draft.
I. AIMS AND SCOPE OF THE INTERNATIONAL DECLARATION ON HUMAN GENETIC DATA

I.1. In your opinion, what should be the aims of a declaration on human genetic data at the level of international law? Do such aims correspond to those put forward in the Revised Outline?

On the whole, the respondents highlighted the consistency of the Revised Outline, which they saw as a timely, comprehensive and balanced document, and congratulated UNESCO for that initiative. Only one State considered the adoption of such a declaration to be inappropriate.

The essential aims of the declaration are respect for human dignity and the protection of human rights and fundamental freedoms and they emerge clearly from the document. Many respondents considered nevertheless that the international declaration should make explicit mention of those aims. Many respondents indicated that one of the aims of the declaration was to establish “good practice” in the field of human genetic data. One State believed that the declaration should cover only non-medical purposes for which human genetic data are collected, processed, used and stored while another State would limit the scope to medical and scientific purposes.

The format selected (General Provisions, Collection, Processing, Use, Storage, Promotion and Implementation) covers the crucial areas and makes it easier to read and understand the document. Many respondents pointed out that the Revised Outline did not directly address the question of the commercialization of human genetic data, often assembled in databases. Several of them therefore regretted that sufficient emphasis had not been laid on international cooperation with regard to human genetic data issues. Some States would have preferred an explicit reference to Article 4 of the Universal Declaration on the Human Genome and Human Rights.

I.2. Are the fields of application of the international declaration explicit in the Revised Outline? If not, should mention be made, for example, that the declaration also covers proteomic data that are generated by genetic data?

Most States took the view that the document should mention proteomic data that are generated by human genetic data. Nonetheless, many eminent personalities argued that any specific reference might limit the scope of the declaration.

I.3. Should the declaration be accompanied by an explanatory memorandum with an article-by-article commentary?

The majority of respondents were in favour of an explanatory memorandum which would inform the reader, and would be a pedagogic tool rather than a source for interpretation of the articles. In their replies some States expressed a preference for an explanatory memorandum which described step-by-step the procedures to be followed in the collection, processing, use and storage of human genetic data and biological samples. A few respondents suggested that reference to an explanatory memorandum should be made in the declaration. Some respondents suggested that the explanatory memorandum should be regularly updated by IBC in the light of new information. Some States were, however, of the opinion that a memorandum is unnecessary.

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1. See Article 2(a) of the preliminary draft of the international declaration on human genetic data.
2. See Articles 19 and 23(b) of the preliminary draft.
3. Article 4: “The human genome in its natural state shall not give rise to financial gains”.
II. PREAMBLE

II.1. In your opinion, does the Preamble define the specificity of human genetic data?

On the whole, the responses were positive. At the same time, numerous observations were made with regard to Article 3 under “General Provisions” which defines the special status of human genetic data. First, with regard to paragraph (a), there was general agreement that the description of human genetic data as “sensitive” should be eliminated. Some suggested using the expression “special data” while others preferred the expression “special category of data”. Secondly, some respondents stressed the special status of genetic data in view of the importance of their impact. Thirdly, with reference to paragraph (b), some respondents suggested that in addition to the “cultural significance” of human genetic data, mention should also be made of their economic, social and political significance.

II.2. Should there be other elements of assessment to highlight the importance of human genetic data?

Some thought that the Preamble should include a reference to the relevant international instruments adopted by the United Nations system, in particular those protecting the rights of the child. In addition, some States felt that the etiological, epidemiological and ethical significance of the collection of human genetic data had not been adequately emphasized while others thought that more explicit mention should be made of the importance of human genetic data for research on and development of new drugs and treatments and, more generally speaking, for the improvement of health and the quality of life.

III. GENERAL PROVISIONS (Articles 1 to 6)

III.1. Is the definition of “human genetic data” satisfactory to you?

In general, the definition was considered to be satisfactory. However, the authors of some replies considered that it would be preferable to state that human genetic data are information about genetic characteristics of individuals, rather than heritable characteristics. In particular, one State pointed out that somatic cell gene therapy could modify genetic characteristics without affecting heritable characteristics. Some eminent scientists considered that the definition is restrictive, given, for instance, that genetic data may also be obtained by analysis of ribonucleic acid (RNA). Furthermore, a few States considered too vague the statement that, in addition to the analysis of deoxyribonucleic acid (DNA) sequences, the data in question may be obtained “by other means”. Proposals were made to replace that phrase by “clinical means” or “scientific means”. In the replies concerning this issue, the view was expressed that definitions should be included in the document. Whilst considering the definitions to be important, some replies considered that they should rather be presented in a Glossary, annexed to the declaration or to the explanatory memorandum.

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4. Note the elimination of the words “sensitive data” from the fourth preambular paragraph of the Preamble to the preliminary draft and the elimination of the words “sensitive components” from paragraph (a) of Article 4 of the preliminary draft.
5. See Article 4, paragraph (a)(ii) of the preliminary draft.
6. See the first preambular paragraph and Article 8(c) of the preliminary draft.
7. See the explanatory memorandum concerning the sixth preambular paragraph of the preliminary draft.
8. See in Article 1 of the preliminary draft the definition of human genetic data which uses the terms “nucleic acids” and “by other scientific analysis”.
9. See Article 1 of the preliminary draft.
III.2 **Should the international declaration also deal with human biological samples that serve to produce human genetic data?**

In many replies, the point was made that biological material or biological samples from which human genetic data are generated must be taken into account in the document. However, some States indicated that biological samples could be collected for purposes other than to produce genetic data. Nevertheless, the reference to “biological samples” must be clearly defined.

III.3 **Does the international declaration sufficiently highlight the complexity of a person’s identity which should not be reduced to his or her genetic characteristics?**

On the whole, the authors of the replies were satisfied with Article 2. One State considered that it should be stated clearly that genetic characteristics are an aspect of personality. On the other hand, several others regretted the fact that a more central role had not been accorded to personal and ethical factors in the formation of a person’s identity. Some States considered that the spiritual dimension should also be mentioned.

III.4 **Are the purposes for the collection, processing, use and storage of human genetic data sufficiently explained?**

A significant majority of the States, institutions and eminent individuals consulted stated that the purposes are explicit. Several observations were made about Article 4 of the Revised Outline. First, the reference to “medical and other scientific research” seemed vague. The authors of certain replies wondered whether research for the purpose of preventive health care was covered by the terms “scientific research”. Secondly, a few replies suggested specifying that all the purposes should be authorized by national legislation. Lastly, instead of stating that human genetic data may be collected, processed, used and stored for “any other purpose consistent with the Universal Declaration on the Human Genome and Human Rights and international human rights law”, a few responses proposed that negative wording should be used to indicate that such data may not be collected, processed, used or stored for any other purpose that is not consistent with the Universal Declaration on the Human Genome and Human Rights and international human rights law. Such wording seems to be preferred insofar as, if another purpose not specified in this article is developed to collect, process, use or store genetic data, those using it will not have to prove that it is consistent with the Universal Declaration on the Human Genome and Human Rights and international human rights law. On the contrary, it would be those who consider that the other purpose is not consistent with the Universal Declaration on the Human Genome and Human Rights and international human rights law who would have to provide evidence to that effect (see also below Article 12 on access).

III.5 **Article 5 of the Revised Outline entitled “Procedures”**

The replies concerning this article stressed the need for transparent procedures. However, with regard to subparagraph (a), a few replies suggested that it should not be specified that the said procedures should involve “informed participation by society as a whole”. With respect to the same subparagraph, some considered that stating that the debate on these issues should be “open to international participation” lacked clarity. Concerning subparagraph (b), several replies said that

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10 See in particular Article 2 of the preliminary draft, et seq.
11 See Article 3 of the preliminary draft.
12 See Article 5 of the preliminary draft.
13 See Article 6(a) of the preliminary draft.
not all States had a national ethics committee. The authors considered that the phrase “where they exist”\textsuperscript{14} should be added.

\textbf{III.6 Article 6 of the Revised Outline entitled “Non-discrimination and non-stigmatization”}

Concerning subparagraph (a), a few remarks were made to the effect that it should specify that unacceptable discrimination is illegal discrimination, as opposed to what is known as positive discrimination, which is legitimate. Regarding subparagraph (b), it was sometimes noted that the ethical implications of behavioural genetic studies are not sufficiently highlighted.

\textbf{IV. COLLECTION (Articles 7 to 11)}

\textit{IV.1.1 In this section, emphasis is placed on consent. Do you feel that this issue is adequately dealt with?}

Many observations and proposals were made concerning Article 7 of the Revised Outline on consent, namely about the content, form and subject of consent.

In the first place, regarding the content of consent (subparagraph (a)), the authors of several replies considered that the nature of the information to be provided should be spelt out in order to obtain consent. The replies came with various proposals to describe the information as “full”, “appropriate”, “understandable”, and so on. Several NGOs considered that the information provided should also specify the risks run by the persons concerned and the benefits they could expect.\textsuperscript{15}

In the second place, with regard to the form of consent (subparagraph (a)), some authors of replies preferred the word “voluntary” to the word “free”. Few of them considered that “express” consent should be defined. Some hoped that the declaration would state that consent must be given in writing, with oral consent being accepted for illiterate people.\textsuperscript{16} Some States considered that the declaration should specify that national legislation or regulation should provide for waivers to consent on an exceptional basis.\textsuperscript{17}

In the third place, with respect to the subject of consent (subparagraph (b)), certain replies proposed that in the case of a person not in a position to consent, legal authorization should be replaced by the authorization of his or her legal representative. The authors of a few replies considered that in certain cases, in addition to the consent of the person concerned, the consent of the couple or family should be envisaged. Others considered that in the case of the collection of biological samples in order to produce data for population-based genetic studies, in addition to the consent of the person concerned, a consultation of the population groups studied should be envisaged, and even the consent of representatives designated by the groups in question.

\textit{IV.1.2 Article 8 of the Revised Outline entitled “Withdrawal of consent”}

Although in general the wording of this article was considered satisfactory, the terminology used was criticized. The terms “anonymous”, “reversible” and “irreversible” were considered to be inappropriate, especially in the comments of NGOs and eminent personalities. In particular, the word “anonymous” implied that individuals would be deprived of the genetic data concerning them.\textsuperscript{18} In addition, some replies, in particular those from personal data protection agencies, wanted

\textsuperscript{14}See Article 6(b) of the preliminary draft.
\textsuperscript{15}See Article 6(c) of the preliminary draft and the explanatory memorandum on this article.
\textsuperscript{16}See Article 8(a) of the preliminary draft and the explanatory memorandum on this subject.
\textsuperscript{17}See the second phrase of Article 8(a) of the preliminary draft and the explanatory memorandum on this subject.
\textsuperscript{18}See throughout the preliminary draft the references to genetic data that are “linked” or “unlinked” to an identifiable person.
the provisions of this article reinforced by removing any reference to time limits beyond which it would no longer be possible to exercise the right to withdraw consent. Some replies also stated that withdrawal of consent should not only not entail a disadvantage or penalty, but also not lead to any discrimination, in particular regarding access to medical care.

Article 9 of the Revised Outline entitled “The right to decide whether or not to be informed”

This article aroused concern since it provides for cases where scientific research does not have the purpose of making discoveries that could be of interest individually to the persons who took part.20

IV.2 Do you feel that genetic counselling is adequately taken into account in the Revised Outline?

Article 10 of the Revised Outline also gave rise to many comments regarding its content and form.

First, the content of genetic counselling. Many replies stressed the need for genetic counsellors to be independent and the non-directive nature of genetic counselling. A few said that stress should be placed on the quality of genetic counselling and the skills genetic counsellors should acquire. Some considered that the article should refer to the right of a patient to information concerning him or her.

Second, the form of genetic counselling. Although many replies on the subject underscored the importance of genetic counselling before, during and after testing – or collection in the framework of medical or scientific research – some hoped that it would be mandatory and not optional, while others wanted clarification as to whether it was free of charge. Furthermore, a few considered that the stress should be more on genetic counselling when the results of testing or research might concern an entire family.22

IV.3 Article 11 of the Revised Outline entitled “Collection of samples in vivo or post-mortem”

The comments on this article concerned above all its title, which seemed incomplete and not to reflect the content of the article in question. Moreover, a few replies proposed that administrative procedures should be mentioned in addition to civil and criminal proceedings. Some said that the article did not refer to national legislation or regulation. Some considered that, with regard to parentage testing, both the interest of the person requesting such identification and the interest of the child should be taken into consideration.

V. STORAGE (Articles 12 to 15)

Article 12 of the Revised Outline entitled “Access”

Some comments pointed out that the access of a person to his or her genetic data was permitted but not the access of a group. Other comments on the same article related to a preference for a negative formulation: “No-one shall be denied access to his or her genetic data” (see question III.4 above).

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19 See Article 9 of the preliminary draft.
20 See Article 10 of the preliminary draft.
21 See Article 11 of the preliminary draft and the explanatory memorandum on the definition of the various terms.
22 See Article 11 of the preliminary draft and explanatory memorandum.
23 See Article 12 of the preliminary draft.
24 See the explanatory memorandum on the sixth consideration of the Preamble.
V.1 In this section, emphasis is placed on the confidentiality of human genetic data with respect to third parties. Do you feel that the Revised Outline provides for adequate protection?

Article 13 of the Revised Outline also gave rise to many comments and proposed additions. In general, some of those who replied to the questionnaire wondered why the article did not deal with human genetic data which was unlinked to an identifiable person.25

With regard to subparagraph (a), the wording used to guarantee confidentiality of “human genetic data linked to an identifiable person, a family or a group” appeared to some to be too peremptory. They would prefer wording to the effect that “Every effort will be made to guarantee the confidentiality of genetic data linked to an identifiable person, a family or a group”.

V.2 Should it be specified that confidentiality with respect to third parties concerns, in particular, employers, insurance companies and educational institutions? If so, do you feel that other bodies should be specified?

With regard to subparagraph (b), many replies argued that the term “third parties” should be defined where it states that “human genetic data linked to an identifiable person shall not be disclosed or accessible to third parties”. What about the doctor who has prescribed a genetic test for a patient? Should the family be considered as a third party? On this last point, many scientists considered that the declaration should provide for the possibility of disclosing genetic data to family members, subject to the consent of the person concerned.

Many of those who replied considered that it was not enough to mention employers and insurance companies. In their view, it was necessary to add: the army, the police, the security services, penal institutions, intelligence services, immigration services, governmental and non-governmental organizations, religious institutions, etc.

Some comments concerned national legislation or regulation which should, in no circumstances, infringe the principle of confidentiality of genetic data with regard to third parties or envisage exceptions. The replies, in particular those of national ethics committees, stated that genetic data should, on no account, be disclosed or transmitted to employers or insurance companies, even with the consent of the person concerned.

A few replies proposed the deletion of subparagraph (b).

V.3 Article 14 of the Revised Outline entitled “Unlinking of human genetic data”

A few replies stressed that this article should not constitute an obstacle to research which must sometimes be conducted on genetic data linked to identifiable persons, families or groups.26

V.3 Article 15 of the Revised Outline entitled “Accuracy, reliability, quality and security”

The wording “the accuracy, reliability, quality and security of human genetic data shall be ensured” appeared to some to be too peremptory. They would prefer wording to the effect that “Every effort will be made to ensure the accuracy, reliability, quality and security of human genetic data”.

25 See Article 14(d) of the preliminary draft.
26 Article 14 of the Revised Outline has been deleted and its content inserted in Article 14(c) of the preliminary draft which responds to this concern.
VI. USE (Articles 16 to 20)

Article 16 of the Revised Outline entitled “Change of purpose”

Several replies stated that provision must be made for a change of purpose to be decided by national regulation and not only national legislation when genetic data come to be used. Some considered that it was not sufficient for changes of purpose to be decided by legislation: the decision should also be in conformity with international human rights law. Moreover, they considered that the consent of the person concerned should be obtained each time that the objective of scientific research changed and not only the purpose. Others, however, took the view that the article should be qualified since a change of purpose sometimes represented no more than a minimal risk of misuse of genetic data.

VI.1 In this section the Revised Outline sets forth the principles that should guide free circulation of human genetic data under conditions guaranteeing the respect of human dignity and protection of human rights and freedoms. Do you feel that this balance has been achieved?

The comments on this issue chiefly emphasize the need to bring together Articles 18 and 19 of the Revised Outline. Some States asked for the term “regulation” to be clarified. Other States proposed to replace the guarantee of “equivalent levels of protection” by “the highest ethical and legal standards, specifically those prescribed in the present Declaration”. Some others considered that the legislation or regulation of the countries of origin of biological samples should take precedence over those of the recipient country.

VI.2 Do you believe that the Revised Outline adequately covers the issue of the sharing of benefits resulting from the use of human genetic data?

Many comments concerned Article 20 of the Revised Outline, essentially emphasizing its importance and, in the case of States, the priority which they accord to that issue. At all events, some replies pointed out the need to specify that human genetic data must be used for the benefit of humanity. Some considered that the examples given lacked clarity while, for others, they were unnecessary. While calling attention to the importance of this provision, some replies expressed a reservation: the examples given might suggest that access to medical care was not a right but was something that must be earned. Moreover, the wording “benefits resulting from the use of human genetic data (...) shall be shared” appeared too peremptory to some respondents. They would prefer wording to the effect that “Every effort will be made to share the benefits resulting from the use of human genetic data (...)”.

VII. STORAGE (Articles 21 to 33)

VII.1 Do you think it is necessary for each country to set up a monitoring and management system of human genetic data?

The replies to this question were almost unanimous in favour of a national monitoring and management system of human genetic data. The replies of those who expressed reservations focused on what they described as the vague concept of a monitoring and management system. The

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27 See the title and content of Article 16(a) of the preliminary draft.
28 See Article 16(a) of the preliminary draft which introduces the idea of the public interest in the use proposed by the change of purpose and the case of genetic data unlinked to an identifiable person envisaged in Article 16(b).
29 See Article 18 of the preliminary draft entitled “Circulation and International Cooperation”.

same applied to the idea that the system should also deal with the “ownership regime of human genetic data”.

VII.2 Do you think that the Revised Outline adequately covers the dangers of inappropriate storage and cross-linking of human genetic data?

With regard to Article 22 in general, there were some questions as to why the reasons for the destruction of human genetic data and the biological samples from which they were generated were not fully covered by the Revised Outline.

In a few replies, reservations were expressed about Article 22(a), in particular since the destruction of human genetic data and biological samples of persons found not guilty following criminal proceedings might be a problem should the need for a new trial arise. It was therefore proposed by some to use a more general form of wording indicating that the inappropriate storage of genetic data and biological samples of a person found not guilty following criminal proceedings should be prohibited, unless that person gives his or her prior, free, informed and express consent. Furthermore, some replies indicated that it would be useful to specify that the biological samples and genetic data in question should be stored in a place under the control of the public authorities and designated as a depository by national legislation or regulation.

With respect to Article 23, concerning possible cross-linking between human genetic data collected for different purposes, the authors of some replies considered that the article should first and foremost ban the cross-linking of genetic data unlinked to an identifiable person with genetic data linked to identifiable persons. Some others considered that cross-linking should be authorized on condition that prior, free, informed and express consent is obtained. A few others considered that in any event, Articles 22 and 23 did not cover all the possibilities for abuse in regard to the storage of human genetic data and biological samples. However, these replies did not state what had been omitted or overlooked.

VIII. PROMOTION AND IMPLEMENTATION (Articles 24 to 27)

VIII.1 Do you feel that provisions other than those foreseen in the Revised Outline could contribute to the promotion and the implementation of the international declaration?

Many replies dealt with the need to strengthen ethics education, training, teaching and information. In particular, several replies stressed the role non-governmental organizations can play in this field. Some also hoped that the mass media would be explicitly named in relation to ethics information.

Lastly, with regard to Article 25, some replies advanced the idea of strengthening the roles conferred upon the International Bioethics Committee (IBC) and the Intergovernmental Bioethics Committee (IGBC). However, the replies gave no precise indication as to how to do so.

IX. OTHER COMMENTS

A few replies considered that the definitions should cover the genotype and phenotype and include mitochondrial information.

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30 On this last point, see Article 20 of the preliminary draft.
31 See Article 21(a) of the preliminary draft.
32 See Article 24 of the preliminary draft.
33 See Article 25 of the preliminary draft.
Some replies suggested that the declaration should introduce the notion of the non-instrumentalization of the human individual, along the lines of the provisions on non-discrimination and non-stigmatization.

Some hoped that the consent of the couple would be required for genetic diagnoses of embryos and foetuses.

Several replies expressed the hope that a UNESCO Internet site would be devoted to human genetic data.

A few States wanted UNESCO to develop model legislation on human genetic data which they could use as a reference.

One State noted that the international declaration repeatedly refers to ethics committees, established at various levels. It considered that the Intergovernmental Bioethics Committee (IGBC) could produce guidelines concerning the establishment, composition and functioning of such committees.

Many States stressed the importance of education and information about all aspects of human genetic data and considered that the role played by UNESCO in the matter should be highlighted.34

34 See Articles 24 and 26 of the preliminary draft.
ANNEX

INTERNATIONAL CONSULTATION ON THE REVISED OUTLINE
OF THE INTERNATIONAL DECLARATION ON HUMAN GENETIC DATA

List of Replies to the Questionnaire as at 4 June 2003

I. MEMBER STATES OF UNESCO

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II. NON-MEMBER STATES WHICH HAVE SET UP A PERMANENT OBSERVER MISSION TO UNESCO

United States of America  
Holy See

III. FORMER MEMBERS OF THE INTERNATIONAL BIOETHICS COMMITTEE (IBC) AND EMINENT PERSONALITIES

<table>
<thead>
<tr>
<th>Name</th>
<th>Position and Affiliation</th>
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<tbody>
<tr>
<td>Mr Sidney Altman</td>
<td>Nobel Prize for Chemistry, Yale University, United States of America</td>
</tr>
<tr>
<td>Mr Vladimir I. Ivanov</td>
<td>Director, Medical Genetics Research Centre, Academy of Medical Sciences of Russia, Russia</td>
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<tr>
<td>Ms Irma Arnoux</td>
<td>Professor of Law, University of Bordeaux, France</td>
</tr>
<tr>
<td>Mr François Jacob</td>
<td>Nobel Prize for Medicine and Physiology, President, Committee to Defend Scientists, France</td>
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<tr>
<td>Ms Laurence Azoux-Bacrie</td>
<td>President, Bioethics Sub-Commission, Paris Bar Association, France</td>
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<tr>
<td>Mr Rubén Y. Lisker</td>
<td>Professor of Human Biology, Director of Research, Salvador Zubiran National Nutrition Institute, Mexico</td>
</tr>
<tr>
<td>Ms Patricia Baird</td>
<td>Professor, Department of Medical Genetics, University of British Columbia, Canada</td>
</tr>
<tr>
<td>Mr Darryl Macer</td>
<td>Professor, Eubios Ethics Institute, Japan</td>
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<tr>
<td>Mr Adriano Bompiani</td>
<td>Former President, Italian Bioethics Committee, Professor of Medicine, Italy</td>
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<td>Mr Bertrand Mathieu</td>
<td>Professor of Law, University of Paris I, France</td>
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<tr>
<td>Mr Jean-Jacques Cassiman</td>
<td>Professor, Human Genetics Centre, University of Louvain, Belgium</td>
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<td>Mr André Mégarbané</td>
<td>Professor, Faculty of Medicine, Saint Joseph University, Lebanon</td>
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<tr>
<td>Mr Ricardo Cruz-Coke</td>
<td>Director, Genetics Unit, J.J. Aguirre Hospital, University of Chile, Chile</td>
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<tr>
<td>Ms Jaroslava Moserová</td>
<td>Senator, President of the General Conference at its 30th session, Czech Republic</td>
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Mr Jean Dausset  
Nobel Prize for Medicine and Physiology  
President, Centre for the Study of Human Polymorphism  
President, Universal Movement for Scientific Responsibility (MURS)  
France

Mr Renzo Pegoraro  
Executive Director, Lanza Foundation  
Italy

Ms Silvia Piccinini  
Professor of Private Law  
Italy

Mr Kjell Fuxe  
Professor of Histology, Neuroscience Department  
Karolinska Institute  
Sweden

Mr Ludwig Schmidt  
Professor of Bioethics  
Central University of Venezuela  
Venezuela

Mr Guido Gerin  
President, International Institute for the Study of Human Rights  
President, International Bioethics Centre, Trieste  
Italy

Mr Huanming Yang  
Head, Human Genome Project  
Chinese Academy of Science  
China

IV. AGENCIES OF THE UNITED NATIONS SYSTEM

Office of the United Nations High Commissioner for Human Rights

V. INTERNATIONAL AND REGIONAL NON-GOVERNMENTAL ORGANIZATIONS (NGOS)

Council for International Organizations of Medical Sciences (CIOMS)  
Disabled Peoples’ International  
European Academy of Arts, Sciences and Humanities  
European Forum for Good Clinical Practice, Ethics Working Party  
Fédération de la voix de l’enfant  
Genetic Interest Group (GIG)  
Human Genome Organization (HUGO)  
International Association of Law, Ethics and Science  
International Council for Global Health Progress  
International Federation of University Women  
Ligue internationale pour l’éthique médicale  
Joint Programme Commission on Science and Ethics, of which the following organizations are members:

Association of Arab Universities  
B’nai B’rith International  
Catholic International Education Office  
Caritas Internationalis  
Education International  
Inclusion International  
International Association of Charities  
International Association of Educators for World Peace  
International Association of Lions Clubs  
International Association of Literary Critics
International Catholic Society for Girls
International Christian Union of Business Executives
International Council for Science (ICSU)
International Council of Jewish Women
International Council of Women
International Federation for Home Economics
International Federation for Housing and Planning
International Federation for Parent Education
International Federation of Human Rights
Pax Christi International
Pax Romana International Catholic Movement for Intellectual and Cultural Affairs
Soroptimist International
Women’s International League for Peace and Freedom
World Association of Girl Guides and Girl Scouts
World Association for Small and Medium Enterprises
World Confederation of Teachers
World Council of Comparative Education Societies
World Federation of Scientific Workers
World Federation of United Nations Associations
World Organization for Early Childhood Education
World Peace Council
World Union of Catholic Women’s Organizations

VI. ETHICS COMMITTEES, COMMISSIONS AND CENTRES

Australian Law Reform Commission, Australia
Bioethics Advisory Committee, Belgium
Korean Bioethics Association, Republic of Korea
National Bioethics Advisory Committee, Côte d’Ivoire
National Bioethics Committee, Croatia
Egyptian National Bioethics Committee, Egypt
National Bioethics Committee, Russian Federation
Hellenic National Bioethics Committee, Greece
Centre for Bioethics and Medical Humanities, Indonesia
Iranian Science and Technology Research Organization, Iran
Central Medical Ethics Committee, Latvia
New Zealand Catholic Bioethics Centre, New Zealand
Committee of Deans of Faculties of Science, New Zealand
Environmental Risk Management Authority, New Zealand
Health Research Council, New Zealand
National Bioethics Committee of the Republic of Uzbekistan, Uzbekistan
Latin American and Caribbean Federation of Bioethics Institutions, Panama
Southeast Asian Centre for Bioethics, Philippines
Human Genetics Commission, United Kingdom
National Science Foundation, Sri Lanka
Central Ethics Commission of the Swiss Academy of Medical Sciences, Switzerland
National Medical Ethics Committee, Tunisia
VII. NATIONAL PERSONAL DATA PROTECTION AGENCIES

Hellenic Data Protection Authority, Greece
Privacy Commissioner for Personal Data in Hong Kong
Privacy and Data Protection Authority, Iceland
State Data Protection Inspectorate, Lithuania
Privacy Commissioner of Norway, the Data Inspectorate, Norway
Office for the Protection of Personal Data, Slovakia