Human Rights Teaching

Bioethics and human rights

UNESCO
Bioethics and Human Rights

Final report and recommendations of the International Meeting on Bioethics and the Social Consequences of Biomedical Research

Moscow, USSR, 13-15 May 1991

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This publication has been prepared before the recent changes which have occurred in the countries formerly constituting the Soviet Union. We have therefore kept in this publication the denominations of USSR, SSR of Bielorussia and SSR of Ukraine.

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This issue of Human Rights Teaching was prepared by Georges B. Kutukdjian, assisted by Sheila Bennett and Rosemary Castelino.

Correspondence concerning this periodical should be addressed to:
Human Rights Teaching
Division of Human Rights and Peace
UNESCO, 7, Place de Fontenoy, 75700 Paris, France.

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Introduction

1. The International Meeting on Bioethics and the Social Consequences of Biomedical Research was convened, on the initiative of UNESCO, in Moscow (USSR) from 13 to 15 May 1991 and organized in co-operation with the Centre for Human Sciences and the Institute of Philosophy of the USSR Academy of Sciences and the National Research Centre of Surgery of the USSR Academy of Medical Sciences. Medicon, Medigrant and Sapex made financial contributions for the material organization of this meeting.

2. The experts were invited in their personal capacity to discuss four substantial topics (see Annex 1 — Agenda). They came from 15 countries from different regions of the world (see Annex 2 — Final List of Participants).

3. On the proposal of the Organizing Committee of the International Meeting, Academician Bayev (USSR) chaired the Opening Session, Academician Petrovsky (USSR) the First Session, Professor Kimura (Japan) the Second Session, Dr Morales (Argentina) the Third Session and Professor Milani-Comparetti (Italy) the Fourth Session. Dr Boyle (USA) who was the Rapporteur of this meeting, conducted the discussions on and adoption of the Final Report and Recommendations and chaired the Closing Session.
4. Academician Bayev (USSR) welcomed the group and provided an overview of the historical foundations of ethics in the USSR. The Soviet society has traditionally judged bioethical problems consequentially, using the standard of what was "good for society". He noted that judging actions based only on "the good of society" or the common good, can have severe consequences. He called for a reconsideration of an ethics based solely on this historical norm.

5. Mrs Fournier, Assistant Director-General for Social and Human Sciences of UNESCO, welcomed the group and indicated UNESCO's specific interest in bioethics. She gave the examples of surrogacy and transplantation, among other practices that have created new and different choices for individuals, families, and society. These choices stand to transform the life of society, but they also present certain dangers, especially to human rights. Education and international co-operation is necessary to address bioethical questions and UNESCO is ideally situated to foster education and international co-operation while avoiding duplications of other international efforts on this issue (see Annex 3).

6. Academician Petrovsky (USSR) welcomed the participants on behalf of the Academy of Medical Sciences. After outlining the history of bioethics in the USSR, he proceeded to expose bioethical concerns such as experimentation, commercialization of organs, transplantation, and the like. He was pleased to announce the establishment of the Institute of Man, which will study bioethical issues as they affect the human person.
Session 1

Problem of transplantation of organs

(President: Academician Petrovsky)

7. Academician Konstantinov (USSR) provided a clinical description of transplantology in the USSR and an excellent overview of the ethical questions this new technology poses for clinicians and society. Transplantation creates inherent problems — economic, political, cultural, legal, and ethical — which cannot be overlooked.

8. He noted there are two broad sets of questions about decision-making in transplantation. One concerns the medical problems of organ transplants and involves decision-making by physicians. Among the medical decisions to be made are the following: Are there any alternatives to transplantation for this patient? What are the medical indications or counter-indications for this patient?

9. The other set of questions concerning decision-making is beyond the competence of the medical profession and depends on social indications which must be discussed by ethicists, theologians and lawyers, for example. The broad question that must be considered is: Who is empowered to decide the questions surrounding transplantation? This question has two aspects: the issue of procuring organs from living and dead donors, and the issue of the distribution of organs.

10. Within the question of procuring organs we must resolve the issue of the definition of death. Should whole-brain death be considered an alternative to cessation of heart and lungs as a means of determining death? What instrumentation and criteria should be used to determine whole-brain death? Related to the topic of procurement of organs, society must resolve the issues of donation of organs on the one hand and commercialization or sale of human organs on the other.

11. The distribution of organs poses unique social and legal problems. Presently, there is an inadequate supply in many countries, among them the USSR, because physicians are unwilling to register patients and because laymen and even many clinicians do not acknowledge, nor are they educated about, whole-brain death definitions. Another problem is the availability of services and the licensing institutions to provide transplantation. Also noted was the problem of limiting services to groups of people because of their lack of adequate insurance.

12. Professor Gerin (Italy) approached the host of issues surrounding the definitions of death and noted there is not universal consensus on this definition. Among the issues considered are: the medical determination of death, so that the jurists can rely on a clear definition of death; certification of neurological death in children under a specific age; the subjective wishes of patients expressed in consent; presumed consent; donor cards; and the remuneration of organ donors. In concluding, Professor Gerin expressed a hope that each country would create ethics committees at national and local levels so as to contribute to the decision-making process of medical and research institutions.

13. At the end of the first session, Soviet physicians and others interested in transplantology in the USSR presented an address for the consideration of the participants (see Appendix).

Questions, answers and commentary

Definition of death

14. Many commentators noted the factor of cultural diversity and the determination of death. Sometimes problems arise because of the unavailability of instrumentation within different institutions. At other times problems occur because the medical staff or community has not been educated about brain death. At still other times, problems arise because there are deep philosophical differences concerning the boundaries between life and death (coma, etc.).

7
Supply of Organs

15. Many speakers noted the inequality in the supply of organs between rich and poor countries. Many fundamental and inexpensive health needs are not provided in developing countries, while high technology transplantation benefiting relatively few is available in developed countries. Selection of recipients is also a problem and revolves around the following considerations: age, geographic origin, medical knowledge, ethical position of the team. Pediatric transplantation, which is equally important, imposes special issues that warrant further debate.

Presumed Consent

16. A number of opinions were expressed over the issue of presumed consent for organ donations. Opinions varied widely, from those concerned that presumed consent will be abused if it is too easy for people to have access to the newly dead, to those concerned that the present organ shortage can be overcome by considering organs not as being the property of the individual, but of society. People have strong moral obligations to assist others when it is of little risk to themselves and great benefit to others.

Recommendations

17. The following recommendations to UNESCO are based on some general underlying assumptions about transplantation expressed by participants. First, tension was noted between the different points of view: autonomy vs. solidarity. Depending on the view on which a nation bases its approach to bioethics, the choice surrounding transplantation will have practical normative consequences for human rights. For example, a strong cultural bias towards autonomy will entail a rejection of presumed consent, and a strong cultural proclivity towards solidarity will foster presumed consent for organ donation.

18. An international forum affords the opportunity to discuss such assumptions, advancing both human rights and the development of bioethics as a scholarly endeavour.

19. Another assumption concerns the integrity of the human person. While each society has different cultural conceptions, some agreement exists about fundamental attitudes towards the human person such as: human persons are not merely a collection of organs to serve as spare parts; no individual is the sole master of his or her own body, nor does society have ultimate control over the human body; essential to treatment of the person is a recognition that decisions about transplantation must be made in an atmosphere of freedom and with appropriate informed consent.

20. With these considerations in mind, the participants of this meeting recommended that UNESCO cooperate with the United Nations, its Specialized Agencies, and the competent international intergovernmental and non-governmental organizations so as to achieve the recommendations below.

a) UNESCO should promote research and education which are needed concerning the problem of access to and supply of organs. The discussion of the just distribution of organs has been generally limited, with no full consideration given at an international level. In the interests of justice, the problems associated with the scarcity of organs, the availability of services, and the basis for distribution — in particular where children are concerned — needs a forum for discussion and development of research in bioethics and education programmes. UNESCO stands as an education body capable of providing such a forum for these critical issues.

b) Definitions of death may still vary greatly among cultures. Even so, UNESCO is well suited to raise the level of awareness of the public and medical professions concerning the various views of the definition of death. UNESCO can promote educational training efforts at all levels, most especially in medical colleges where this information is crucial for future health care workers.

c) The commercialization of organs looms as a fundamental problem both in the appropriate procurement and fair distribution of human organs and tissues. The possibilities of a more or less covert commercial market is a real threat. Therefore international forum discussion about the issues of reciprocity, solidarity, and mutual aid must be encouraged, as well as international agreements concerning the non-commercial procurement of human organs and tissues.
Session 2

Information of the patient and informed consent

(President: Professor Kimura)

21. Professor Kimura (Japan) in speaking of informing the patient and informed consent, addressed three broad areas: the cultural aspects of patient information in medical services; the human rights aspects of patient information and privacy; and, the educational aspects of patients’ rights in the community. After a thorough analysis of the situation in Japan which traditionally fosters a paternalistic view toward informed consent, he offered five conclusions. First, physicians should directly convey information to the patient but this process must be sensitive to cultural values. Second, the patient should be told the truth as early as possible so that she or he can make appropriate life choices. Third, the care of the terminally ill, especially in hospice programmes, requires that information be given so that the patient can decide whether to opt for life-sustaining treatment. Fourth, genuine human relationships require honest disclosure, especially in the doctor-patient relationship. Finally, bioethical education for the public and professionals is necessary (as manifest in grass-roots movements), and this can be supported by the efforts of UNESCO.

22. Professor Sass (Germany) provided past, present, and future views of the shifting notion of informed consent. This paternalism in medicine can be explained by hierarchical social structures and it still manifests itself in culturally conservative societies.

23. Today there has been a shift in biomedical ethics because of the recognition of two principles: informed consent and telling the truth. These principles arose in part because of the change in human rights consciousness and a new view of the doctor-patient relationship as a partnership. The requirement for informed consent differs for therapy and research. In research there can be vulnerable subjects and an understanding of the costs and risks is often highly uncertain, therefore requirements for informed consent are greater. In therapy, informed consent must nevertheless be required because different options for healing exist and because patients’ choices are idiosyncratic and based on their culture.

24. In the future, health care will advance from cure to prevention. Informed consent will require education for prevention. There needs to be a transformation from paternalism to personal health competence. Health education should become a transverse theme in future education programmes and all curricula must take this into account. The integration of bioethics and health literacy in education programmes will have the same effect as the fight against illiteracy. In general, UNESCO can contribute by: (a) defining health education as a transverse theme in future programmes; and, (b) by taking immediate action to introduce topics of health into as many programmes as possible.

Questions, answers, and commentary

The Tactics of Informed Consent

25. The “who, what, and when” of informed consent must be explored at greater depth. For example, what volume of information should be provided to patients and what risks disclosed? How extensive should the information be for oncology patients or the dying? Who should provide the information — the physicians, the family, or nobody? Are there any circumstances when informed consent should not be given? Can the information be provided in a balanced manner providing adequate information, yet also being judicious about the uncertainty of medical diagnosis? Must the consent be written?

Informed Consent and Cultural Diversity

26. Participants voiced concern regarding whether cultural divergences on informed consent should be encouraged. Views ranged from the suggestion that human rights require informed consent be given, to the
suggestion that culture has not been acknowledged in bioethics and that there needs to be consideration of cultural values which would limit informed consent. No one disagreed in principle that each culture must foster informed consent, but disagreement remains over the justification of exceptions to this general rule.

**Informed Consent and Psychology**

27. Most participants agreed that informed consent is more than the mere presentation of facts. Clinicians must present tragic information only when they are sure of their diagnosis and they should be attentive to the psychological aspects of this information for the patient. Clinical evidence indicates that while providing information can be therapeutic, information given without full respect for psychological needs can result in precipitous action on the part of the patient.

**Telling the Truth and Confidentiality**

28. Various participants noted that informed consent is caught in an intricate web of values including telling the truth and confidentiality. Informed consent is intimately linked to telling the truth to the patient. In cases where information is retained from the patient, such exceptions must be culturally sensitive and respectful of human rights.

**Informed Consent and Children**

29. There needs to be a tripartite relationship between the child, the family, and the physician. Informed consent in relation to children does not merely involve giving information to miniature adults. Consideration must be given to the age of the children and to their ability to participate in medical decision-making. It was also cautioned that others should not give consent on behalf of children under certain circumstances in research and transplantation.

**30. Recommendations**

a) UNESCO must foster health literacy programmes within the context of human rights teaching and should educate people about their own rights as human beings, especially medical rights within the context of human rights. This means that it should define health education as a Transverse Theme in future programmes, and it should introduce topics of health into as many programmes as possible. Also, UNESCO should function as an educational network or clearing-house for all health literacy programmes, including the variety of grass-roots movements which are being formed in many nations.

b) UNESCO could provide a forum for discussion of the possible interpretations of free and informed consent in addressing the underlying assumptions — for example the cultural ones — when raising issues such as autonomy and solidarity.

c) UNESCO could encourage the development of forums to promote free and informed consent in research and therapy.
Session 3

Bioethics and the law

(President: Professor Morales)

31. Professor Kokkonen (Finland) gave an overview of the advantages and inconveniences of the existence of laws in the areas of bioethics. Referring to the Council of Europe’s Ad Hoc Committee of Experts on Bioethics (CAHBI), she pointed out that laws governing bioethics presently exist and that the political will to legislate remains. The main objective of CAHBI is to fill the political and legal gaps that result from rapid developments in biomedical sciences. In recent years CAHBI has recommended laws or offered official reports on transplantation, mental disorders, recombinant DNA, artificial procreation, and genetic screening. Through its deliberations it has proved helpful in protecting the freedom of researchers.

32. Professor Morales (Argentina) addressed the issues of bioethics and human rights in developing countries. She noted that bioethics offers an opportunity to improve the quality of life and the records on human rights throughout the world. To realize this, a global perspective is imperative; bioethics must not be restricted to developed countries, but must benefit developing countries as well. Bioethics can appear as a mirror of the disparity in standards of the quality of life, as the examples of trade in organs, illegal experimentation, and unregulated drug testing so vividly illustrate. Bioethics must address the reality that access to basic care is denied to many, while a few receive much. Fundamental problems of life and health require serious ethical consideration of the problems within less developed countries, namely adequate food, preventive medicine, overpopulation, etc.

33. Professor De Waechter (Netherlands) provided a thorough overview of Research Ethics Committees (RECs) and Institutional Review Boards (IRB) by considering two questions. First, do we need laws to establish and implement ethical practice in research? In speaking of the situation in the Netherlands, he noted that laws have been proposed to protect human subjects and to safeguard the scientific process. However, existent health laws may be broad enough to cover these concerns.

34. Second, should REC/IRBs be advisory or regulatory? He noted that in the United States of America IRBs are mandatory and have sanctioning power. In the Netherlands, on the other hand, RECs are advisory, with no power to enforce their judgments. The weakness of this alternative is that restricted advice is given and possible research grants are limited. He proposed that countries develop a new compromise system, i.e. “a moderately regulatory research ethics committee.”

Questions, answers and commentary

Scope of Bioethics

35. Many comments highlighted that little agreement exists over the definition and scope of bioethics. Some participants suggested that bioethics be limited to the concerns of the medical profession around which bioethics developed. Others went further and maintained that bioethics must include biomedical research, biotechnology, and environmental concerns. As a science, bioethics cannot be self-selective and limited to the issues and agenda set by Western developed countries.

Scope of Research Ethics Committees

36. One participant and several speakers described the rich variety of existing research ethics committees. The scope of RECs’ power varies from country to country (for example, concerning the issues they commonly address and the way they sanction). Sharing of information on an international level about the functioning of these committees needs to be supported.
Scope of Laws

37. Almost every commentator implicitly or explicitly presented a view of the relationship between bioethics and law. One position is that questions of bioethics cannot be solved in legal terms. Morality is difficult to legislate, and this is especially true with the rapidly changing biotechnology. Such a view might foster the adoption of professional codes of conduct.

38. A second view is that existing legislation sufficiently accommodates problems of bioethics. The reason for developing specific laws on bioethical matters must be clearly and forcefully presented before existing regulations covering bioethics are set aside.

39. A third view is that a general framework of legislation should be developed. Some participants went further and suggested that biomedical science has created new ethical problems, e.g. genetic screening/therapy, in vitro fertilization, so that we need new laws to cover new situations. Doubt remains whether these are in fact new situations but, equally, doubt remains as to whether there should be specific legislation for bioethics, even though we are presently enacting laws.

40. Recommendations

a) UNESCO ought to promote further research into identifying bioethical issues where recourse to legislation would be helpful.

b) UNESCO should promote international co-operation and track efforts to legislate bioethical concerns and other legal efforts at both national and international levels.

c) UNESCO should support the national development of independent professional or academic institutions which are able to provide guidelines and to help their professionals to apply these guidelines in their clinical practice.

d) UNESCO should offer support for the legal protection of research subjects and encourage the development of bioethical institutions, particularly in developing countries.
Session 4

Social institutionalization of bioethical activity

(President: Professor Milani-Comparetti)

41. The presentation by Professor Michaud (France) on social institutionalization of bioethics activities was based on his experience in France. He offered two examples of the tremendous progress achieved in the areas of in vitro fertilization and genetic testing. Nevertheless, he also indicated the uncertainties and possible abuses to which these techniques could lead.

42. He described three alternatives for addressing bioethical issues. The first one would be of complete abstention in proposing solutions; the second of adopting appropriate legislation; the third, selected by France, would be the creation of ethics committees which are both interdisciplinary and pluralistic, to the extent possible. The French National Consultative Committee of Ethics has concentrated on the areas of research, information and sensitization. It has aimed, on the one hand, to convince the scientific community that it should not be viewed as a shackle to research but that its role is to strike notes of caution against possible abuses. On the other hand, it has aimed at educating the society at large as to what is at stake in these matters. In some cases the French committee has recommended the adoption of specific legislation on certain subjects. Hence it has moved towards a dualistic institutionalization involving formulation of consultative opinion and the recommendation of specific legislation. He concluded with the hope that some major principles will be identified and stated at the international level, which will be governed by the overriding value of the dignity of the human person.

43. Dr Yudin (USSR) considered the question of the institutionalization of bioethics in sociological terms. He noted that the topic presupposes that bioethics is an emerging social institution in the modern world and the forms of its development vary. Bioethics emerges as a way of regulating source-normative conflicts and strains which are specific to modern development. In particular, the scientific and technological progress in biomedicine raises ever new moral and legal problems. Also, the human rights movement throughout the world and the many issues on its agenda - for example, the right to health care - is the main object of bioethical concern. Development of bioethics is very important for the USSR and, possibly, it can look to the powerful ecological movement as a movement to emulate.

44. Dr Boyle (USA) considered the advantages and disadvantages of the national, state, and local responses to bioethical concerns in the United States. At the national level, response has been of an advisory nature, with the President's Commission identifying a consensus and promoting a body of literature. This commission drew a moral consensus but other national bodies have not been as successful. State interventions have more readily helped develop grass-roots consensus and enact laws. Locally, hospital ethics committees are the most prevalent response to bioethics, providing education, consultation and policy development. However, there is no agreement on procedural matters: whom should the committees serve? who should be on the committees? what topics should they cover? What is the extent of their authority? These procedural issues must be identified early and agreement reached; otherwise these committees will fail. Likewise committees must consider their moral methodology because it has an enormous effect on civil rights.

45. An ethics committee can only be transferred from one institution to another when it has been tailored to meet the needs of the institution. Local committees can only start after national groups have developed a consensus and a broad literature exists to help the committee. UNESCO can foster international exchange and co-operation in developing committees.
Questions, answers and commentary

Social Institutionalization of Bioethics

46. There was wide consensus that bioethics should be institutionalized because existent institutions are not currently meeting such a need. Again questions arose over the issue of whether bioethics has brought new questions and demands new institutional responses. It was noted that legal institutions may not fully answer the problems posed by bioethics. Flexible structures need to be tailored to meet cultural needs. UNESCO could foster the introduction of EC and REC/IRB in countries that have not yet developed such structures, especially by offering guidance to qualifying members.

47. Recommendations

a) UNESCO should welcome and encourage the establishment of institutional responses to bioethics, such as ethics committees, as instruments of justice, for the protection of human dignity and for the enhancement of humanistic values.
b) UNESCO should foster an international forum on the formation of institutional responses to bioethical problems.
c) UNESCO could assist in co-ordinating the transfer of literature in bioethics for all countries.
d) UNESCO could provide leadership to expand the topics that need to be addressed in bioethics.
48. The Moscow International Meeting on Bioethics and Social Consequences of Biomedical Research highlighted the growing importance of bioethical problems, as well as the growth of public interest in such problems. This growth is due to two main factors:

- Technological progress and the emergence of new questions
- The human rights movement throughout the world.

Many biological problems are of international character and require international guidance and co-ordination to prevent attacks against the fundamental rights of the human being, as specified in the United Nations Universal Declaration of Human Rights.

"Article 1
All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

"Article 22
Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international cooperation in accordance with the organization and resources of each State of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

"Article 25
1. Everyone has the right to a standard of living adequate for health and well-being of himself and his family, including food, clothing, housing, and medical care and necessary social services...

"Article 26
1. Everyone has the right to education...
2. Education shall be directed to the full development of the human personality..."

To promote these human rights constructively in the field of bioethics, UNESCO can offer the following practical responses:

1. To encourage the exchange of information and of experience of education on the ethical and legal problems relating to research, application, and resource allocation in the fields of biology, medicine and health care.
2. To foster an international system of exchange of experts concerning the critical questions of bioethics. This would include the exchange of experts *inter alia* from medicine and other health care professions, law, philosophy and theology, and representatives from ethics committees and commissions.
3. To promote international conferences and other efforts concerning bioethical issues aimed at sensitizing the public on health literacy. These conferences could work out recommendations for bioethics to be included in educational curricula.
4. To encourage high-quality teaching on the problems raised by bioethics in all countries and in particular developing countries, taking into account their different cultural context and their specific needs.
5. To promote, in co-operation with interested international intergovernmental and non-governmental organizations the creation of an international bioethics association of institutions.
Closing session

49. In his concluding remarks on behalf of the Organizing Committee, Dr Yudin (USSR) stressed the importance of this meeting for international co-operation in the field of bioethics. He extended his thanks to the Director-General of UNESCO, to Mrs Fournier, Assistant Director-General for Social and Human Sciences, and to Mr Kutukdjian, Division of Human Rights and Peace. He warmly congratulated the Presidents of the meeting and especially Dr Boyle for having accepted the task of Rapporteur.

50. Mrs Fournier, on behalf of the Director-General of UNESCO, thanked all the members of the Organizing Committee. She indicated that, within the limits of its resources, UNESCO would spare no efforts to follow up this most fruitful meeting. She thanked all the participants and in particular the Presidents of the different sessions and the Rapporteur.
Annex 1

Agenda

1. Official opening of the meeting by Mr Federico Mayor, Director-General of Unesco;
2. Election of a President, two Vice-Presidents and a Rapporteur;
3. Problem of transplantation of organs;
4. Information of the patient: problem of informed consent;
5. Bioethics and law;
6. Social institutionalization of bioethical activities;
7. Discussion and adoption of main conclusions of the meeting;
8. Closing session.
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<thead>
<tr>
<th>Name</th>
<th>Position and Affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pr Daniel Alagille</td>
<td>Secrétaire général, Association «Le don d'organe pour l'enfant», 75, avenue Denfert-Rochereau, 75014 Paris, France</td>
</tr>
<tr>
<td>Prof. Carlos Alonso Bedate</td>
<td>Centro de Biología Molecular, Facultad de Ciencias, Universidad Autónoma de Madrid, Cantoblanco, 28049 Madrid, Spain</td>
</tr>
<tr>
<td>Ms Joanne R. Bauer</td>
<td>Health and Environment, Carnegie Council on Ethics and International Affairs, Merrill House, 170 East 64th Street, New York, NY 10021-7478, United States of America</td>
</tr>
<tr>
<td>Professor Béla Blassauer</td>
<td>Medical University of Pécs, Institute of Social Sciences, Szegetia, Pécs 127624, Hungary</td>
</tr>
<tr>
<td>Dr Marie-Julien Boukambou</td>
<td>Directeur de recherche, ICPA, 14, boulevard de La Villette, 75019 Paris, France</td>
</tr>
<tr>
<td>Dr Philip J. Boyle</td>
<td>The Hastings Center, 255 Elm Road, Briarcliff Manor, New York, NY 20510, United States of America</td>
</tr>
<tr>
<td>M. Christian Byk</td>
<td>Magistrat, Ministère de la Justice, 13, place Vendôme, 75001 Paris, France</td>
</tr>
<tr>
<td>Pr Guido Gerin</td>
<td>Président, Institut international d'études des droits de l'homme, Via Cantù, 10, 34123 Trieste, Italy</td>
</tr>
<tr>
<td>Mr Jorgen Kelstrup</td>
<td>Président, Danish Medical Research Ethics Committee, 62 Oesterbrogade, DK - 2100 Copenhagen, Denmark</td>
</tr>
<tr>
<td>Mr Rihito Kimura</td>
<td>Bioethics and Law Department, Health Sciences School of Human Sciences, Waseda University, Tokorosawa 357, Japan</td>
</tr>
<tr>
<td>Mrs Paula Kokkonen</td>
<td>Director, Department of Administration Finnish National Board of Health, P.L. 223, 00531 Helsinki, Finland</td>
</tr>
<tr>
<td>Mme Marie-Hélène Lhuguenot</td>
<td>Secrétaire général, Comité consultatif national d'éthique pour les sciences de la vie et de la santé, 101, rue de Tolbiac, 75654 Paris Cedex 13, France</td>
</tr>
</tbody>
</table>
P Maurice Marois
(France) Institut de la vie
3, rue de l'Arrivée, 75015 Paris, France

M. Jean Michaud
(France) Cour de Cassation
Palais de Justice
5, quai de l'Horloge, 75001 Paris, France

Professor Marco Milani-
Comparetti
(Italy) Scientific Director
International Institute for Ethical-Juridical Studies on New Biology
(ISENB)
Villa Eolian, Via Cappuccini, 98057 Milazzo (ME), Italy

Sra. Patricia Morales
(Argentina) Filosofía Ética
P.A. - AMS
Mendoza 2517 90 «A», 1428 Buenos Aires, Argentina

Mr Qiu Ren-Zong
(China) Chinese Academy of Social Sciences
Jianguomenei Dajie 5 Hao, Beijing, China

Mr Pinit Ratanakul
(Thailand) Director
Research Centre of SEA Culture
Lad-Prao
P.O. Box 10-167, Bangkok 10310, Thailand

Professor Hans-Martin Sass
(Germany) Faculty of Philosophy, Education and Public Communication
Ruhr-Universität Bochum
Universitätsstr. 150, 4630 Bochum, Germany

Dr M. A. de Waechter
(Netherlands) Director
Institute for Bioethics
Postbus 778, 6200 Maastricht, Netherlands

Organizing Committee and Participants of the Host Country

A. Organizing Committee

Professor I. Frolov
(Président) Academy of Sciences
President of the Center for Human Sciences of the Academy of Sciences
Volhonka, 14, 119842 Moskva, Russian Federation

Professor V. Zinchenko
(Vice-Président) Vice-President of the Center for Human Sciences
Volhonka, 14, 119842 Moskva, Russian Federation

Professor V. Styopin
(Vice-Président) Director of the Institute of Philosophy of the Academy of Sciences
Volhonka, 14, 119842 Moskva, Russian Federation

Professor B. Yudin
(Vice-Président) Editor of Chelovek Magazine
Volhonka, 14, 119842 Moskva, Russian Federation

Dr E. Filippova
(Secrétaire scientifique) Center for Human Sciences
Volhonka, 14, 119842 Moskva, Russian Federation

Professor B. Petrovsky
(Vice-Président) Academy of Sciences
All-Union Scientific Center for Surgery of the Academy of Medical Sciences
Abricossovskij pereulok, 2, 119874 Moskva, Russian Federation

Dr Bogorad
All-Union Scientific Center for Surgery
Abricossovskij pereulok, 2, 119874 Moskva, Russian Federation
Professor S. Dzemeshkevich
All-Union Scientific Center for Surgery
Abricossovskij pereulok, 2, 119874 Moskva, Russian Federation

Professor A. Grebeniov
Moscow Sechenov Medical Academy
Solianka, 14, 119801 Moskva, Russian Federation

Professor B. Konstantinov
Director of the All-Union Scientific Center for Surgery
Abricossovskij pereulok, 2, 119874 Moskva, Russian Federation

Professor V. Pokrovsky
President of the Academy of Medical Sciences
Solianka, 14, 119801 Moskva, Russian Federation

Professor V. Shumakov
Academy of Medical Sciences
Director of the Institute of Transplantology and Artificial Organs
Ministry of Health
Solianka, 14, 119801 Moskva, Russian Federation

Professor A. Bayev
Academy of Sciences
Leninskij prospect, 14, 117901 Moskva, Russian Federation

Professor V. Kudriavtsev
Vice-President of the Academy of Sciences
Leninskij prospect, 14, 117901 Moskva, Russian Federation

Professor R. Petrov
Vice-President of the Academy of Sciences
Leninskij prospect, 14, 117901 Moskva, Russian Federation

Dr A. Pokrovsky
Director of the UNESCO Office in Moscow
Kalininskiy prospect, 9, Moskva G-19, Russian Federation

Professor P. Simonov
Director of the Institute of Neurophysiology and High Nervous
Academy of Sciences
Boutlerova, 5a, 117865 Moskva, Russian Federation

Professor N. Smirnov
Department of International Humanitarian Co-operation and Human
Rights
Ministry of Foreign Affairs
Kalininskiy prospect, 9, Moskva G-19, Russian Federation

Dr A. Tiukov
Deputy Minister
Ministry of National Education
Tchistoproudnij boulevard, 6, 101856 Moskva, Russian Federation

B. Participants of the Host Country

Professor R. Apressian
Institute of Philosophy
Volhonka, 14, 119842 Moskva, Russian Federation

Dr S. Arab-Ogly
Center for Human Sciences
Volhonka, 14, 119842 Moskva, Russian Federation

Dr N. Avdeeva
Center for Human Sciences
Volhonka, 14, 119842 Moskva, Russian Federation

Professor A. Guseinov
Institute of Philosophy
Volhonka, 14, 119842 Moskva, Russian Federation

Dr V. Ignatiev
Institute of Philosophy
Volhonka, 14, 119842 Moskva, Russian Federation

Professor R. Karpinskaja
Institute of Philosophy
Volhonka, 14, 119842 Moskva, Russian Federation

Professor V. Munipov
Center for Human Sciences
Volhonka, 14, 119842 Moskva, Russian Federation
<table>
<thead>
<tr>
<th>Name</th>
<th>Institution and Address</th>
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<tr>
<td>Dr P. Nezhnov</td>
<td>Center for Human Sciences</td>
<td>Volhonka, 14, 119842 Moskva, Russian Federation</td>
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<tr>
<td>Dr N. Nossov</td>
<td>Center for Human Sciences</td>
<td>Volhonka, 14, 119842 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor A. Ogurtsoy</td>
<td>Institute of Philosophy</td>
<td>Volhonka, 14, 119842 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Dr P. Tishenko</td>
<td>Institute of Philosophy</td>
<td>Volhonka, 14, 119842 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor O. Byelorussoy</td>
<td>All-Union Scientific Center for Surgery</td>
<td>Abricossovskij perelok, 2, 119874 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor A. Bunyatyan</td>
<td>All-Union Scientific Center for Surgery</td>
<td>Abricossovskij perelok, 2, 119874 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor I. Dementieva</td>
<td>All-Union Scientific Center for Surgery</td>
<td>Abricossovskij perelok, 2, 119874 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Dr T. Egerov</td>
<td>All-Union Scientific Center for Surgery</td>
<td>Abricossovskij perelok, 2, 119874 Moskva, Russian Federation</td>
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<tr>
<td>Professor R. Lebedeva</td>
<td>All-Union Scientific Center for Surgery</td>
<td>Abricossovskij perelok, 2, 119874 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor N. Milanov</td>
<td>All-Union Scientific Center for Surgery</td>
<td>Abricossovskij perelok, 2, 119874 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor M. Perelman</td>
<td>Academy of Medical Science</td>
<td>Abricossovskij perelok, 2, 119874 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor A. Yorish</td>
<td>Institute of State and Law</td>
<td>ul. Frunze, 10, 119841 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor G. Litvinova</td>
<td>Institute of State and Law</td>
<td>ul. Frunze, 10, 119841 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor E. Lukasheva</td>
<td>Institute of State and Law</td>
<td>ul. Frunze, 10, 119841 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor U. Isakov</td>
<td>Academy of Medical Sciences</td>
<td>Solianka, 14, 109801 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor A. Ivanushkin</td>
<td>Academy of Medical Sciences</td>
<td>Solianka, 14, 109801 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor F. Komarov</td>
<td>Vice-President of the Academy of Medical Sciences</td>
<td>Solianka, 14, 109801 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor V. Kovanov</td>
<td>Academy of Medical Sciences</td>
<td>Solianka, 14, 109801 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor M. Kuzin</td>
<td>Academy of Medical Sciences</td>
<td>Solianka, 14, 109801 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor U. Lisitsya</td>
<td>Correspondent Member of the Academy of Medical Sciences</td>
<td>Solianka, 14, 109801 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor N. Malinovsky</td>
<td>Academy of Medical Sciences</td>
<td>Solianka, 14, 109801 Moskva, Russian Federation</td>
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<tr>
<td>Professor G. Riabov</td>
<td>Academy of Medical Sciences</td>
<td>Solianka, 14, 109801 Moskva, Russian Federation</td>
</tr>
<tr>
<td>Professor V. Saveliev</td>
<td>Academy of Medical Sciences</td>
<td>Solianka, 14, 109801 Moskva, Russian Federation</td>
</tr>
</tbody>
</table>
Professor G. Shingarov  Institute of Philosophy
Solianka, 14, 109801 Moskva, Russian Federation

Professor G. Tsaregorodtsev  Department of Philosophy
Academy of Medical Sciences
Solianka, 14, 109801 Moskva, Russian Federation

Professor V. Yadov  Director of the Institute of Sociology of the Academy of Sciences
Krgijanovskogo Street 24/25, k.5 117259 Moskva, Russian Federation

Professor L. Tsiganov  Chief Expert
Ministry of Health
Rahmonovskij pereulok, 3, 101431 Moskva, Russian Federation

Professor R. Korotkikhh  Institute of Public Health Management
Obuha, 12, 107120 Moskva, Russian Federation

Professor M. Mirsky  Institute of Public Health Management
Obuha, 12, 107120 Moskva, Russian Federation

Professor O. Schepin  Director of the Institute of Public Health Management
Obuha, 12, 107120 Moskva, Russian Federation

Dr B. Leonov  Director of the All-Union Scientific and Experimental Institute of Medical Equipment
Kassatkina, 3, 129301 Moskva, Russian Federation

Professor S. Doletsky  2nd Medical Institute
Department of Surgery
Ostrovitianova, 1, 117437 Moskva, Russian Federation

Professor N. Zharikov  2nd Medical Institute
Department of Psychiatry
Ostrovitianova, 1, 117437 Moskva, Russian Federation

Professor N. Bekhtereva  Institute of Brain
Academy of Sciences
Ac. Pavlova, 12, 197022 St. Petersbourg, Russian Federation

Professor L. Spivak  Institute of Brain
Ac. Pavlova, 12, 197022 St. Petersbourg, Russian Federation

Professor N. Bochkov  Center for Medical Genetics of the Academy of Medical Sciences
Moskovoretchie, 1, 115478 Moskva, Russian Federation

Professor B. Bratus  President of the Association of Humanistic Psychology
Psychology Department
Moscow State University
Avenue Marx, 18, Moskva, Russian Federation

Professor A. Brouchinskij  Director of the Institute of Psychology
Academy of Sciences
Jaroslavskaja 13, 129366 Moskva, Russian Federation

Professor V. Fedorov  Vishnevsky Institute of Surgery
Academy of Medical Sciences
B. Serpuhovskaja, 27, 113093 Moskva, Russian Federation

Professor A. J. Gourvich  Vice-Director of the Institute of Reanimatology
Nicolskaja, 9, 103012 Moskva, Russian Federation

Professor A. P. Gromov  Director of the Institute of Juridical Medicine
Sadovaja-Kudrinskaja, 3, k.2, 123242 Moskva, Russian Federation

Professor V. Kaznacheev  Institute of Clinical and Experimental Medicine
Jadrintzwevskaia, 14, 630091 Novosibirsk, Russian Federation

22
Professor I. Kirpatovski  Topographic Anatomy and Operational Surgery Department  Medical Department, Lumumba Friendship University, Micluho-Maklaja, Moskva, Russian Federation

Dr A. Kiselev  Institute of Medical Information  Moskovoretskaja naberajknaja, 2a, 109240 Moskva, Russian Federation

Professor L. Kitaev-Smik  Institute of Psychology  Academy of Sciences  Jaroslavskaja, 13, 129366 Moskva, Russian Federation

Professor G. Kryzhanovsky  Director of the Institute of Normal Physiology  Academy of Medical Sciences  Guertcena, 6, 103009 Moskva, Russian Federation

Professor V. Lektorsky  The Problems of Philosophy Magazine  Smolenskij Boulevard, 20, 129301 Moskva, Russian Federation

Professor U. Rytchkov  Institute of General Genetics  Academy of Sciences  Gubkina, 3, 117809 Moskva, Russian Federation

Professor D. Sarkissov  Chief Scientific Secretary  Presidium of the Academy of Sciences  Leninskiy prospect, 14, 117901 Moskva, Russian Federation

Dr E. Serovski  Institute of Neurosurgery  Fadeeva, 5, 125047 Moskva, Russian Federation

Professor U. Shaposhnikov  Priorov Central Institute of Traumatology and Orthopedics  Priorova, 10, 125299 Moskva, Russian Federation

Professor V. Teriaev  Sklifosovski Institute of Ambulance  B. Kolhoznaja Place, 3, 129010 Moskva, Russian Federation

UNESCO

Mme Francine Fournier  Sous-Directeur général pour les sciences sociales et humaines

Mr G. B. Kutukdjian  Spécialiste principal du programme  Division des droits de l'homme et de la paix

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Assistant Director-General
for Social and Human Sciences
UNESCO

Your Excellencies,
Ladies and Gentlemen,

It is with great pleasure that I take the floor to address your distinguished gathering on behalf of the Director-General of UNESCO, Mr Federico Mayor. I know that he would have liked to be with you in person because of his ties of friendship with many of the prominent figures present here today and also because of the topics on the agenda of this "International Meeting on Bioethics and the Social Consequences of Biomedical Research" which is now opening in this magnificent city of Moscow. The four facets of bioethics — scientific, ethical, juridical and cultural — are of great personal interest to the Director-General; he will therefore be paying particular attention to your conclusions and recommendations.

I should like to take this opportunity to express my gratitude to the Academy of Sciences of the USSR, and in particular to its Centre for Human Sciences and the Institute of Philosophy, to the Academy of Medical Sciences and the National Research Centre for Surgery, together with the Ministry of Foreign Affairs and the USSR Commission for UNESCO, for their co-operation at every stage in the preparation of this meeting. My thanks are also due to MEDICON, MEDIGRANT and SAPEX for their financial assistance towards the material organization of this meeting.

UNESCO's interest in the complex of issues which are known today under the term "bioethics" is not recent. In the early 1970s, this subject area made its appearance as an important focal point for reflection on the social and cultural changes brought about by scientific and technological progress. A symposium on the "Problems and positive results of scientific research in molecular genetics" was organized at that time by UNESCO in Madrid in co-operation with the Spanish High Council for Scientific Research. This symposium examined the potential scope for genetic manipulation applied to the solution of problems of vital concern to mankind. It drew attention to the acceleration of genetic erosion and suggested the creation of an international network of "seed banks" to ensure the preservation of genetic resources, notably of plants.

Another symposium was later organized by UNESCO in Varna in 1979; it was attended by eminent biologists and philosophers and led to the appearance, in 1978, of a work entitled "Biology and Ethics" by Bruno Ribes, then Chief Editor of the review "Etudes" in Paris which was published by the Organization in French, English and Spanish.

More recently, UNESCO entrusted the International Council of Social Sciences (ICSS) with the task of organizing an international symposium in collaboration with the International Council of Scientific Unions and the International Council of Philosophy and Human Sciences. That meeting, held in Barcelona in March 1985, discussed human rights against the background of recent advances in science and technology.

On this basis, UNESCO asked the ICSS to prepare a study surveying the branches of the clinical and biomedical sciences whose activities may have an impact on human rights. In addition, UNESCO asked the World Federation for Mental Health (WFMH) to set up a multi-disciplinary, international working party to study the impact of new human reproductive technologies on the rights of women. These two studies were examined during a second international symposium held in Barcelona in November-December 1987.

The recommendations of this second symposium highlighted a number of important points. Firstly, the vulnerability of underprivileged groups in face of recent advances in science and technology. To take two
examples, members of under-privileged groups rarely have access to in vitro fertilization techniques, one major reason for this being a lack of information. Conversely, the practice known as “surrogate motherhood” is liable to further worsen the situation of women belonging to the underprivileged groups.

The symposium then turned its attention to a problem which is causing increasing concern to the public, namely the impact of compulsory or voluntary medical screening on human rights. With reference to screening, it called particular attention to:

(a) the possibility that it may lead to a temptation to adopt certain forms of eugenics;
(b) the potential for destruction of the private life of individuals or of the life of a couple which may, for example, stem from screening to overcome infertility;
(c) the dramatic repercussions of compulsory screening in the case of certain jobs, for example on the right to work and once again on the temptation to resort to eugenics as a means of adapting individuals to the needs of the labour market;
(d) the acceleration of the evolution of an illness or other physical or mental handicap through a process known to medical and psychological research by which a patient may act in a manner which hastens the confirmation of a diagnosis.

Lastly, the symposium stressed the need for a detailed study of the problems created by organ transplantation and the sale of organs and human foetuses.

In conclusion, the following four areas were highlighted as appropriate subjects for future research:

(a) the impact of compulsory or voluntary screening on human rights;
(b) the implications for human rights of transactions involving body parts and human foetuses;
(c) the impact of surrogate motherhood on the rights of women and on the rights of the child, and
(d) the potential impact of the expanding bio-engineering industry on human rights.

In 1988-1989, UNESCO asked the WFMH to set up a working party to study in more detail the implications for human rights of transactions involving body parts and human foetuses. That study is available in English.

The initiative for this gathering came from the Director-General. It was conceived from the outset as an inter-disciplinary meeting in an area which does not coincide with any single traditional academic discipline but requires instead teamwork between scientists, philosophers, legal experts, sociologists, theologians and specialists in communication, to mention but a few. Its main aim is to foster an exchange of ideas and experience between the chairmen or heads of national committees of ethics and specialized institutes. The survey of the problems encountered and the initial conclusions that can be drawn on each of the items on the agenda will no doubt encourage the strengthening or creation of regional and international networks of institutions with a view to the definition of joint programmes.

Why is this meeting being held at this particular juncture and what is the specific nature of UNESCO’s action in this field? First, in strictly practical terms, it must be borne in mind that if the sphere of bioethics seemed to be an area remote from the immediate concerns of most people in the world some twenty years ago, this is no longer true today. Admittedly, the problems are perceived differently from one country to another and in rural or urban environments, etc. However, generally speaking, the problems which arise are understood more clearly and more precisely. Nowadays, in particular, each of us is aware of the need to make choices, especially in the health sector. We are increasingly obliged to make a selection which will be conditioned by the information to which we have access and are able to analyze. Thus, each and every one of us takes a whole series of decisions, both minor and major, for ourselves and for others, especially for our family. These decisions have a direct or indirect influence not only on our future, but also on that of others. Of course, it is not the nature of these decisions that has changed, but our own knowledge — the extent of which varies — of their implications. In brief, the central issue is that of the responsibility which we bear: we are gaining increasing mastery over our own rights and freedoms.

Secondly, this heightened awareness of the repercussions of science and of its applications to society and also its feedback effects — creating what might be defined as a dynamic relationship which is transforming life in society — leads us to approach the field of bioethics as one in which the central interests of society are at stake. On this level, which is universal in that it raises questions touching on the very foundations of our society, the process of reflection in which UNESCO and its co-organizers have invited you to take part today, aims to improve as far as possible our knowledge in this field. It has the further aim of clarifying these challenges facing society for the benefit of the entire international community. Of course, the goal of this encounter is not to recommend choices, but to highlight certain aspects which might guide the decision-makers.

Thirdly, the specific nature of UNESCO’s action in this sphere is not directly of a normative nature but, as prescribed by its Constitution, to encourage “co-operation among the nations in all branches of intellectual activity” and to suggest “educational methods best suited to prepare the children of the world for the responsibilities of freedom” (Article I, paragraph 2, sub-paragraphs (c) and (b)). Today, bioethics is increasingly
emerging as one of the poles which might serve as a basis for reshaping relations within the community, between individuals and national institutions, etc.

Ladies and Gentlemen,

In selecting the items to be included on the agenda of this meeting, the organizing committee naturally took care to avoid all duplication of the activities and work undertaken by other international, inter-governmental or non-governmental organizations. It further considered that the subjects chosen should be not only pertinent and topical, but should also attract — at least potentially — the interest of all the countries of the world. They must also clearly fall within the spheres of competence of UNESCO, that is to say education, science, culture and communication. The latter criterion was of a practical nature: the subjects chosen should be capable of leading to concerted international action based on education and information.

The four central topics that were selected already appear on the agenda of the meeting and I shall not repeat them here. They correspond to the criteria outlined above and have a close bearing on the problems which are attracting the attention of various sections of the intellectual community. The issue of organ transplantation poses numerous questions of a scientific, ethical and juridical nature and others touching on justice, equity and the exercise of human rights.

The availability of information to the medical patient is coming increasingly to appear as an essential corollary of the creation of a sense of responsibility in the exercise of his freedom to subscribe to certain choices rather than to others.

The subject of "bioethics and law" opens up a wide range of questions on matters which are of pressing topicality. The question as to whether legislation should be enacted in the field of bioethics or consultative mechanisms set up instead to define the guiding principles is in fact becoming increasingly urgent. This in turn immediately leads on to the further question of a definition of the limits of legislation or guiding principles, the weight which must attach to individual decisions and that of a local or central authority and so forth. However, internationally acceptable norms or principles may perhaps have to be laid down.

The fourth theme, partly linked to the third, poses the problem of the need to establish institutional structures responsible, within the framework of a specific mandate, for guiding bioethical activities. Your exchange of views and experience on this matter is bound to be enriching in its own right, but it may equally help later on to shape the views of the decision-makers in many countries who have not yet made their choice.

At this stage, I think it is relevant to quote, despite its length, an extract from Article 15 of the International Covenant on Economic, Social and Cultural Rights adopted by the United Nations in 1966 which states that:

"1. The States Parties to the present Covenant recognize the right of everyone:

   (b) to enjoy the benefits of scientific progress and its applications;

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for the conservation, the development and the diffusion of science and culture.

3. The States Parties to the present Covenant undertake to respect the freedom indispensable for scientific research and creative activity.

4. The States Parties to the present Covenant recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields."

Your Excellencies,
Ladies and Gentlemen,

Before concluding, I would like to share with you, in all modesty, some of my own personal thoughts. In the years to come, in addition to the rights and fundamental freedoms that each and every one of us has a duty to defend, it is already becoming clear that two specific aspects must play a pivotal role in the protection of human rights and the respect for democracy. I refer to the human body and identity.

The subject of the body raises a great many questions. How can the body of a human being be defined? To whom does it belong? Who may make use of it? Who can decide its partial or total dispossession? Under what conditions and subject to what limitations? Can a decision to change it be justified in the eyes of future generations? Would it still be the body of the same person? Where does the dividing line lie between a body
which is the same and one which is different? All these questions are at present changing established values relating to the significance of life, death, time etc.

In the same way, the proliferation of data files and their combinations or interfaces facilitated by the use of computers, is fragmenting to some extent the very concept of identity. The right to a private life and the security of the individual are the targets for attacks which are as formidable as they are massive and as insidious as they are anodyne or imperceptible.

By way of conclusion, I should like first of all to draw your attention to the fact that the Orientation Note which was prepared by the Centre for Human Sciences of the USSR Academy of Sciences in co-operation with the UNESCO Secretariat, includes several themes that are not intended to be either binding or exhaustive. They map out certain paths which you may like to explore.

However, when your conclusions and recommendations come to be formulated for the attention of the Director-General, it might perhaps be opportune to bear in mind the four main themes outlined in section D of the Orientation Note which are concerned with:
(a) the role which UNESCO can play in bioethics;
(b) the desirability of creating a representative high level consultative structure to guide UNESCO’s action related to bioethics in areas of crucial importance which are evolving rapidly;
(c) the need to provide a steering framework to encourage international exchanges of experience between bioethics institutes, committees and commissions;
(d) the possibilities and ways and means of introducing education and information on bioethics at appropriate levels.

Your Excellencies,
Ladies and Gentlemen,

It is with keen and attentive interest that my colleagues and I will be following your discussions and taking note of your conclusions and recommendations.

Francine Fournier
Annex 4

Orientation note

A. UNESCO'S Activities

1. In 1984, UNESCO included in its Work Plan of the Approved Programme and Budget for the first time an activity on "human rights and recent advances in science and technology". Thus began a reflection on the necessity for an increased protection of human rights, taking into account new dangers which had already appeared or which were appearing over the horizon. More particularly, it was "to consider the problems raised by recent advances in science and technology in connection with the effective protection of human rights". An international symposium was foreseen mainly to study questions which arise from brain research, biological and neurophysiological experimentation and genetic manipulations.

2. To this end, UNESCO entrusted to the International Council of Social Sciences (ICSS) the responsibility of organizing the international symposium in question, in Barcelona (Spain) in March 1985. This meeting, which was held thanks to the cooperation between ICSS, the International Council of Scientific Unions (ICSU) and the International Council of Philosophy and Human Sciences (ICPHS), adopted "Conclusions and Recommendations" which were widely disseminated among concerned institutions and researchers.

3. The Recommendations emphasized the importance of:

Recommendations of highest priority
   I. Promote human rights by seeking the broadest possible applications, on a world-wide basis, of scientific advances already tested in the fields discussed at this meeting;
   II. Promote contributions of all disciplines represented at this symposium and of interdisciplinary teams to enhancement of human rights.
   III. Encourage awareness, responsibility and action for human rights on the part of scientists and clinicians in the disciplines considered at this symposium;
   IV. Consider the impact of new reproductive technologies on the human rights of women;
   V. Promote consideration of the human rights of patients and in particular promote standards for the use of neuroleptic drugs.

Recommendations of major importance
   I. Promote research on topics and in areas of the world where improvement is clearly needed;
   II. In the formulation of policies and the administration of programmes in education and health, consult panels of experts in neuroscience and behaviour and related disciplines;
   III. Consider critically any calls to limit research particularly when it is claimed that the research would directly contravene human rights;
   IV. Promote basic research in order to ensure continued possibilities for benefiting human rights beyond what can now be envisaged;
   V. Consider and assess the impact on human rights of current research on genetic manipulation and artificial procreation.

4. On the basis of the recommendations of this international symposium, UNESCO requested the ICSS to prepare a study mapping the branches of clinical and biomedical sciences whose activities can have an impact on human rights. In addition, UNESCO asked the World Federation for Mental Health (WFMH) to create a multidisciplinary and international working group to study the impact of new reproductive tech-
nologies on the rights of women. These two studies were examined during a second international symposium held in Barcelona in November-December 1987.

5. The recommendations of the second symposium highlighted some important points. Firstly, the vulnerability of underprivileged groups vis-à-vis recent advances in science and technology. Thus, for example, members of underprivileged groups rarely have access to in vitro fertilization techniques, even if it is only through lack of information, although couples from these groups could wish to benefit from this technique to overcome infertility. In this same area, but seen from another angle, surrogate motherhood can worsen the situation of unemployed women belonging to underprivileged groups.

6. The symposium then outlined a problem of increasing public concern, namely the impact of compulsory or voluntary screening on human rights. Lastly, the symposium emphasized the necessity for a close study of the problems of organ transplantation and those related to the trade of body parts as well as of fetuses.

7. In conclusion, the four following areas were indicated as subjects for future research:
   (a) the impact of compulsory or voluntary screening on human rights;
   (b) the implications for human rights of transactions concerning body parts and human fetuses;
   (c) the impact of surrogate motherhood on the rights of women and on the rights of the child; and
   (d) the potential impact on human rights of the expanding biotechnological industry.

8. In 1988-1989, UNESCO asked the WFMH to create a working group to study in greater detail the implications for human rights of transactions concerning body parts and human fetuses. This study is available in English.

B. Aims of the present meeting

9. The present international meeting, held on the initiative of UNESCO, is organized by the Centre of Human Sciences of the USSR Academy of Sciences, in collaboration with the Institute of Philosophy of the USSR Academy of Sciences and the National Scientific Centre for Surgery and with the support of “Medigrant” and “Medicon”. It aims at fostering exchange of ideas and experience between presidents or heads of national committees of ethics or specialized institutes. An overview of the problems encountered and the first conclusions that can be drawn will no doubt encourage the creation of a network of institutions and to establish joint programmes.

10. In selecting the items to be included in the Agenda of the present meeting, the organizing committee was careful to take the following criteria into account:
   (a) avoid all duplication of activities and work undertaken by other international intergovernmental or non-governmental organizations;
   (b) gain the interest of, at least potentially, all the countries of the world whether developed or developing;
   (c) fall clearly within the fields of competence of UNESCO;
   (d) lead to concerted action on the international level based on education and information.

11. In this perspective, the Agenda for the meeting includes the following four main themes:
   (a) Problem of transplantation of organs;
   (b) Information of the patient: problem of informed consent;
   (c) Bioethics and law;
   (d) Social institutionalization of bioethical activities.

C. Problem areas

12. What definition(s) should be provided to “bioethics”? Can this (these) definition(s) have a universal character or is it (are they) culturally linked, in the wider sense?

(a) Problem of transplantation of organs

13. One of the first questions in this field is on the unequal development of the possibilities for organ transplantations, on the one hand because of scientific and technical limitations and, on the other, from one country to another. The difficulty of access to the services in this domain presents the first problem which is combined with the one of access to available organs.

14. If it is true that this question has been put for a long time, we can still legitimately ask ourselves if the prac-
tice should not be controlled both at the national and international levels at the present time. Can one speak of norms which would be common to and compulsory in all countries? Should principles and criteria be established so as to guide this practice? Is it possible to overcome the double opposition:

poor countries = organ suppliers//rich countries = organ consumers?

15. Does the transplantation of organs come up against questions of religious or spiritual convictions? Are there mechanisms in place to overcome them in practice, notably in cases of emergency?

16. To what can the donor consent and in what conditions (therapeutic finality, lawful or unlawful transactions, etc.)? Is his consent always indispensable? Should people be protected against themselves? In other words, to what can one consent, in what conditions and according to what methods.

(b) Information of the patient: problem of informed consent

17. Information of the patient is a necessity, if not a right, but in certain cases or circumstances it can be found that limits are being imposed on it. Reciprocally, patients may wish that information is not transmitted to their families. Inversely, in certain circumstances it can be considered that it is not opportune to inform patients about their state of health or about the probable evolution of their illness, although the next of kin should be. These different cases bring up the question that touches on “the right to privacy”.

18. For several decades, it has been obvious that the information of patients with a view to their consent to a therapy can become an indispensable factor in the success of the treatment. It has become no less obvious that the information of the patient in certain circumstances can accelerate the state of deterioration or, again, lead someone to act in such a way as to hasten the realisation of a diagnosis foretelling the evolution of an ailment or of an infirmity (self-fulfilling prophecy).

19. In addition, it is not appropriate to speak of “consent” unless it is based on comprehensive (not omitting any essential aspect), balanced (giving the arguments for and against in one sense as in another) and authorized information (based on scientific authority). It is true that in practice this problem can come up against difficulties in the case, for example, of an emergency, of an adult who is unable to give his consent (accident, coma, etc.) or of a minor.

20. Also, in practice it can lead someone to indecision, even if counselling is provided at the same time as information. Therefore, in scientific circles the idea of the responsibility of each citizen appears more and more as preparing the citizen to give or to refuse his/her consent in a given situation.

21. It has to be recognized that at the present time, institutions, both educational and informational, hardly prepare — or do not prepare completely — for the exercise of this responsibility with regard to our body, especially as often it must be exercised in dramatic conditions, of psychological stress or on vital aspects.

22. Here again, perhaps should be mentioned the particular principles and/or criteria to guide the practice of the personnel and communities who are involved in the information of the patient (medical and nursing staff, hospital and para-hospital staff, medical and biological analyses personnel, etc.).

(c) Bioethics and law

23. In a modern democratic state based on the rule of law, the institutions often consider that they must legislate when faced with problems which reach, or which can virtually concern, a large number of individuals or groups. Must it legislate in the area of bioethics? What would be the advantages and the inconveniences of the existence of legislation (primary and secondary effects, in particular on scientific research and experimentation) or of the absence of such legislation (protection of the individual against possible abuse)? How to reconcile the right to privacy and the requirements of a civil society (which belongs to the public realm) in this field? Is it even worthwhile to legislate in a field where scientific discoveries can render complex juridical structures obsolete? Rather than racing with scientific discoveries in the biomedical field — to set up legal norms to the application or to their repercussions on the social level — is it not necessary to enunciate the guiding principles to orient action and practice?

24. There already exist international instruments, mainly European, thanks to the work of the Council of Europe, on precise questions calling for specific protection of the rights of individuals and of their fundamental freedoms (computerized card indexes, use of “genetic finger prints” or “genetic markers”, etc.). In the present case, these instruments concern countries which aim at a juridical harmonization commonly agreed upon. Is it possible to encourage similar undertakings at a universal level which go further than the regional framework? How to ensure that the highest requirements for protecting human rights will be applied throughout the world and that what is impossible to carry out in developed countries without breaking the law will be equally so in developing countries?
(d) Social institutionalization of bioethical activities

25. For several decades, in particular since the beginning of the 1970s, institutes, committees or commissions of bioethics have been created in certain countries. They have of course varied objectives due to their different mandates but, nevertheless, they have contributed to the social institutionalization of bioethical activities.

26. In particular, they have demonstrated that in fact basic societal choices are at stake in bioethics. They have undertaken and encouraged the reflection which has made scientists as well as decision-makers and the public aware of these basic societal choices.

27. What are the first lessons to be drawn from this experience? Would such an institutionalization be suitable at the world level today? If yes, in what conditions should such an institutionalization take place to yield results both for reflection and for action in this field? How were bioethics institutionalized in different societies taking into account their socio-cultural and economic characteristics? Can the advantages and inconveniences of these different formulas be assessed at present?

D. Conclusions

28. The international meeting in Moscow from 13 to 15 May 1991, which provides an opportunity for addressing recommendations to the Director-General of UNESCO as well as to the scientific community, will wish perhaps to bear in mind the following questions:

(a) Taking into account the diversity of approach in the field of bioethics, as well as the specificity of approach of the different international organizations, both intergovernmental and non-governmental, what role can UNESCO play in a field which appears to be increasingly vital for all individuals in their daily life in tomorrow’s world?

(b) Should UNESCO create a representative council structure of high level to guide its action in domains of crucial importance and rapid evolution?

(c) Further, should UNESCO not supply a framework conducive to encouraging exchanges of experiences, at the international level, between bioethics institutes, committees and commissions?

(d) Finally — true to its vocation in the field of education and because of its mandate to develop the knowledge of human rights through teaching and information — should UNESCO foresee the possibilities and the ways and means to introduce, at the appropriate levels, education and information in bioethics, so as to prepare future generations to face up to the concrete and ethical implications of the changes in the medical, hygiene and sanitary landscape?
Appendix

Address

By the participants of the Host Country in the
“UNESCO International Meeting on Bioethics and Social Consequences
of Biomedical Research” in View of the Development of Clinical Transplantology

“The development of organ and tissue transplantation considerably increases the possibilities for guaranteeing the sovereign human right to health and life.

The Soviet Union belongs to a group of countries which have realistic professional opportunities for rendering medical assistance to terminally ill people by transplanting vitally important human organs.

At the same time the Soviet Union lacks a legislation that would regulate organ and tissue transplantation. There are no mechanisms for financing these costly operations. The Soviet public has very little knowledge of the possibilities, results, and problems of clinical transplantology.

The low level of organ and tissue transplantation in the clinical practice in the Soviet Union is becoming catastrophic and is acquiring not only social, but moral importance too. Soviet doctors find themselves very often in a situation when they have to deny Soviet people the treatment which has become routine in developed countries.

The legal norms, regulating medical practice in the Soviet Union, lag behind the achievements of medical science and health care, which makes the relations between doctors and patients and their relatives more difficult. This, in its turn, limits the progress of medicine, as the application of new methods of diagnosis and treatment requires legal permission.

Realizing our responsibility for the future of Soviet transplantology and health care, we call upon:

The Supreme Soviet and Governments of the Republics of the Soviet Union to form, without delay, commissions coordinating the activities of the interested organizations in working out a legislation providing for unimpeded development of clinical transplantology in the Soviet Union. Considering the different levels of development and application of medical law in different countries and realizing that the social, legal and ethical problems of transplantology have an international character, we ask the Supreme Soviets to begin inter-governmental consultations and talks within the framework of international organizations (the UN Commission for Human Rights, the World Health Organization, UNESCO, etc.) to work out the basic principles for international medical law;

The Soviet Fund for Charity and Health, other public organizations working for charity and beneficence, and the Soviet public to form an association for the development of clinical transplantology which would unite transplantologists, patients with transplanted organs, lawyers, philosophers, clergy, and journalists. The main task of the association should be the implementation of economic, legal and ethical decisions, without which the development of clinical transplantology in our country is impossible;

Scientific academies, societies, and organizations, financing research, to organize independent committees to perform legal, ethical, and economic assessment of the projects to be financed;

Committees for Public Education to include in the school, college, and university curricula courses of bioethics which would prepare the future generations for extraordinary situations that will be created by new biomedical technologies;

Health Ministries and other interested bodies and individuals to prepare an agreement on an international exchange of informational and educational TV programmes on the latest developments in biology and medicine and organize an international system of exchanges of experts between scientific and medical organizations, legal bodies, and committees and commissions for bioethics.”