



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



*Comité international
de bioéthique (CIB)*

*International Bioethics
Committee (IBC)*

Towards a Declaration on Universal Norms on Bioethics

**Extraordinary Session of IBC
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OUTLINE FOR THE PREPARATION OF THE WRITTEN CONTRIBUTION OF ORGANIZATIONS AND INSTITUTIONS ON THE POSSIBLE SCOPE AND STRUCTURE OF A DECLARATION ON UNIVERSAL NORMS ON BIOETHICS

The purpose of the present document is to guide organizations and institutions in the preparation of their written contributions concerning the possible scope and structure of the future declaration on universal norms on bioethics. The outline is set out in groups of questions to allow the International Bioethics Committee of UNESCO to have a comprehensive overview of all opinions and perceptions expressed. Other issues could obviously be put forward and room has therefore been made for those organizations and institutions who so wish, to address these issues at the end of the paper.

Contributions should not exceed 5-7 standard pages (around 2000 words) and should clearly indicate the following information: name of organization/institution, type of organization/institution (intergovernmental, non-governmental - international, regional, national - or national bioethics committee) and contact information (name of person to contact, mailing address, telephone, fax, e-mail, Internet address).

Contributions should be sent by 30 March 2004 at the latest to the IBC Secretariat at the following address:

IBC Secretariat

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I. Aims and Scope of a Declaration on Universal Norms on Bioethics

- I.1 How, in your opinion, could the declaration contribute to better assess the ethical implications of scientific progress and its applications? At what level (policy-makers, scientific community, academic circles, media, society, etc.) and how?
- I.2 Should the declaration be limited to human beings and why?
- I.3 If the answer to I.2 is yes, does this mean that the declaration should deal only with ethical issues related to the human person and the human body in a biological and medical context? Or, should the declaration also deal with ethical issues concerning the human being's relationship with other living organisms? And to what extent?
- I.4 If the answer to I.2 is no, what other issues could be covered (for example, issues such as the use of animals in biomedical research, the use of animals in transplantation, biodiversity, genetically modified organisms (GMOs), environment, etc.)?

II. Structure and Content of a Declaration on Universal Norms on Bioethics

- II.1 How should the declaration be structured? Should it include a preamble? Should it be organized into sections? If yes, please indicate which sections could be included and why (general provisions, health care, scientific research, public consultation, international cooperation, education and awareness-raising, promotion and implementation, etc.)?
- II.2 Which fundamental principles should be reaffirmed in the declaration (autonomy, benefit sharing, confidentiality, freedom of research, free and informed consent, justice, non-discrimination, respect for human dignity, respect for privacy, solidarity, etc.)?
- II.3 In reaffirming these fundamental principles, should the declaration state only general principles of broad application (such as the general principle of consent in research) or should it attempt, where appropriate, to define a more detailed framework (for example, requirements for consent in specific cases)?
- II.5 Whatever the structure and scope of the declaration may be, should it, where possible, provide guidance on specific subject areas? If yes, which subject areas could be explicitly mentioned and why?

(The list below is given simply for purposes of illustration)

- beginning of life
 - o abortion
 - o prenatal diagnosis
 - o preimplantation genetic diagnosis
 - o reproductive technologies
 - o sex selection
- end of life
 - o concepts of death
 - o prolongation of life
 - o euthanasia
 - o palliative care
- genetics and molecular biology
 - o genetic counseling
 - o genetic screening and testing
 - o gene therapy
 - o gene patenting
 - o genetic enhancement
 - o GMOs
 - o population genetics
 - o cloning
 - reproductive cloning
 - non-reproductive cloning
- intellectual property rights
- health care systems
 - o access to drugs
 - o access to health care
 - o allocation of health care resources
 - o quality of care
 - o right to health care
 - o rights of vulnerable persons
- human genetic data and other personal healthcare data
- organ and tissue transplantation
- public health
 - o HIV infection and AIDS
 - o other infectious diseases (malaria, tuberculosis...)
 - o policies regarding vulnerable populations
- research
 - o research with human subjects
 - o embryo research
 - o behavioural research
 - o international and transnational research