

**Informal meeting with Permanent Delegations
organized by the Chairperson of the intergovernmental meeting of experts
(category II) aimed at finalizing a draft declaration on
universal norms on bioethics**

(UNESCO Headquarters, 17 May 2005)

SUMMARY

I. INTRODUCTION

1. Following the first intergovernmental meeting of experts aimed at finalizing a draft declaration on universal norms on bioethics (Paris, 4-6 April 2005), the Chairperson of the meeting, Mr Pablo Sader (Uruguay), was invited to encourage and to lead open-ended consultations between States on diverging views in order to prepare and facilitate the work of the second session of the intergovernmental meeting of experts in June 2005 (ref. Recommendations of the meeting).

2. Mr Sader thus invited all States to take part in an informal meeting at UNESCO Headquarters in Paris on 17 May 2005, in order to continue the discussions and consultations and to pave the way for negotiations.

3. Eighty (80) participants from the following fifty-five (55) Member States took part in the informal meeting: Andorra, Argentina, Austria, Australia, Belgium, Benin, Bolivia, Brazil, Canada, China (People's Republic of), Chile, Colombia, Costa Rica, Czech Republic, Denmark, Dominican Republic, Ecuador, El Salvador, Finland, France, Germany, Honduras, India, Indonesia, Italy, Japan, Lebanon, Luxembourg, Madagascar, Malawi, Mauritania, Mexico, Monaco, Namibia, Oman, Peru, Portugal, Republic of Korea, Romania, Russian Federation, Saudi Arabia, Senegal, Slovakia, Sri Lanka, Sweden, Switzerland, Thailand, Tunisia, Turkey, Ukraine, United Kingdom, United States of America, Uruguay, Venezuela, Vietnam. The representative of the Holy See also took part in the meeting.

4. By way of introduction, Mr Sader recalled the dual mandate conferred upon him by the intergovernmental meeting of experts: firstly, to bring before the Director-General and the Chairperson of the Executive Board the Recommendations of the first meeting and, secondly, to lead open-ended consultations between States in order to prepare and facilitate the work of the second intergovernmental meeting in June 2005 and, on these occasions, to play the role of facilitator between the different parties. Mr Sader then underlined the informal character of the meeting and reiterated that it should not be considered as a negotiation meeting but rather as an opportunity for free and open discussion and the results of which, albeit indispensable, would remain informal and would facilitate negotiations during the intergovernmental meeting of experts in June. The Chairperson felt that, whilst the April meeting had revealed the difficulties and extent of the challenge, it had also shown the political willingness of all participants to be able to present a draft declaration of high technical quality to the General Conference in October 2005, thus allowing an important void to be filled at the international level.

5. The Chairperson had prepared a "Non-paper" (Annex), provided to all participants, containing a number of thoughts and questions aimed at opening paths for agreement on the major points of divergence.

II. SUMMARY OF THE DISCUSSION

6. The discussion was organized around the four points proposed in the Chairperson's non-paper: use of terms and scope, aims, principles and transversal and other issues.

Articles 1 (Use of terms) and 2 (Scope)

7. There seemed to be a favourable tendency towards the possibility of merging Articles 1 and 2 into a single article focused on the scope of the declaration that would define "what" and "to whom" the declaration applies. In this way, entering into detail of an academic definition of bioethics could thus be avoided and could allow for a description of bioethics in the field of application of the declaration.

8. Three aspects should underpin the text of the declaration and be reflected in the provision on scope: the medico-health aspect, covering issues raised by the ethics of medicine, life sciences and their applications and biomedical research; the social aspect, including access to health care and treatment; and the environmental aspect, particularly in terms of responsibility of the human being towards other forms of life and the biosphere. In this respect, the notion of responsibility was raised as a possible key to the drafting and reading of the declaration.

9. As to the recipients of the declaration, the participants were unanimously in favour of explicit identification of States as the first recipients, without excluding all the other actors concerned for whom the declaration should constitute a document "of inspiration".

10. At the conclusion of the discussion on these articles, the Chairperson invited the delegations who so desired to meet together to continue the discussions and to work on the drafting of a text that could be the object of informal consultations open to all delegations and facilitate the work of the meeting in June.

Article 3 (Aims)

11. This article did not seem to pose major problems even though it was pointed out that all parts of this article should be reviewed in the light of the final drafting of the article on scope. For some, the reference to the social aspect of bioethics did not seem to be sufficiently developed, while others felt that the text drawn up by the International Bioethics Committee (IBC), which devoted a principle (Article 13 entitled "Social Responsibility"), already constituted the result of a compromise between the different positions. Some participants also felt that the notion of the responsibility belonging to bioethics should be reflected at this level. Others wished for the relationship between this declaration and the already existing UNESCO instruments in this field (the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data) as well as the relationship to future instruments be defined here.

Articles 4 to 10 (Principles)

12. Generally speaking, the participants expressed their satisfaction with the section devoted to principles. It was recalled that the declaration aimed to draw up a general framework of principles and that, consequently, the broad formulation of principles should be respected and considered in the light of Article 29 on the interdependence and complementarity of the principles and Article 30 on restrictions to the principles. In this connection, a number of participants favoured this approach and recognized that the content and the drafting of the principles had already been measured by the International Bioethics Committee (IBC) during the drawing up of the Preliminary Draft.

13. Special observations were made concerning specific articles, e.g. in Article 5 “Equality, Justice and Equity”, some participants emphasized the need to include explicit reference to the risk of double standards. On the other hand, others pointed out that, in setting out universal principles the declaration in its entirety already aimed at avoiding differences in treatment. The question of drafting an alternative “positive” formulation was raised. As to Article 8 “Non-Discrimination and Non-Stigmatization”, some wished for reference to be made to gender equality and others felt that it was important to specifically qualify the different social groups subject to discrimination. Concerning Article 10 “Informed Consent”, whilst recognizing the balance of the article and the value of a simple and concise text adapted to all legislations, some participants reiterated the importance of specifying more the conditions for protection of persons who do not have the capacity to consent.

Transversal and other issues

14. Within the framework of the transversal issues, the discussion dealt with the use of the verb of obligation “shall” and “should”. The different positions were once again presented, i.e. those who feel that the non-binding character of the declaration calls for the use of verb in its conditional form (should), and those who feel that the non-binding character of the declaration allows for the use of this word in the indicative sense (shall), thus emphasizing the moral commitment. A possible solution could be to use “should” as a general rule and to use “shall” for the provisions that aim to reaffirm in the context of bioethics the rights and obligations already established in the international law of human rights. Some participants nevertheless expressed reservations on the matter.

15. With regard to the formulation “any decision or practice”, there was no particular objection to the possibility of studying its relevance on a case by case basis. In any event, no-one insisted that this term be defined in Article 1.

16. As to the use of “human being” or “human person”, while “human being” appeared to be acceptable to all, its use should also be examined on a case by case basis.

17. Respect for human life was also raised, some considered it important for reference to be made in the same way as for respect for human dignity and others were clearly against this reference, evoking the divergence of definition of this notion in domestic law. One possibility to explore further would be to include this reference in the preamble.

18. Concerning biopiracy and traditional knowledge, some insisted on a reference to be made to the issues linked to this in the declaration but at the same time taking care to avoid duplications and conflicts of competence with other institutions of the United Nations system.

19. Finally, as to the title of the declaration, there seemed to be clear preference for including the mention of human rights, even though some reservations were expressed insofar as the declaration does not deal directly with human rights. The idea of a sub-title where mention would be made was also raised.

20. In conclusion, all participants appreciated the organization of this meeting which had proven to be most useful through its open dialogue and spirit of cooperation which had led to a rich exchange, proof of the willingness of States to reach a consensual text in the time allowed. Mr Sader welcomed this meeting which had been conducted in a spirit of constructive and productive cooperation and which had allowed the way to be paved towards consensus on a number of issues.

NON PAPER

THOUGHTS AND QUESTIONS RAISED BY THE CHAIRMAN

1. Use of terms and Scope (articles 1 and 2)

The fundamental underlying conceptual divergence seems to be the extent of the notion of bioethics as applied to this declaration. There are two schools of thought: a broader one that locates bioethics in its social and environmental context and another one that restricts the concept to the ethical issues arising from medicine and life sciences.

This basic divergence permeates the entire text of the draft declaration but it shouldn't be irresolvable. The Chair hopes that it could be dealt with in the Use of terms and Scope articles, therefore facilitating the negotiation of the remaining articles.

In that spirit:

- a. Would it be acceptable not to have a definition of bioethics as presently contained in article one?
- b. Would the merger of article 1 and 2 be acceptable?
- c. Would the concept of description rather than definition be acceptable?
- d. If the answer to the three previous questions is yes: Can we focus in the new article onto what and whom the declaration applies?
- e. If so, and in reference to whom it applies, the Chair believes that some formulations based on the States as primary objectives of the Declaration and other actors as secondary recipients in a more residual capacity as appropriate, could be a possible compromise.
- f. As to the "what": As bioethics does not evolve in a vacuum, can we include a contextual reference to social issues and the biosphere there?
- g. Would it be possible to drop definitions of "decisions and practices" at this stage and come back to using these terms on a case by case basis, when they are applicable in other parts of the draft declaration?

2. Aims

If the question of the scope is satisfactorily dealt with, the aims should not pose an insurmountable problem.

- a. This applies particularly to (i): some drafting could be found to bridge the problem of how the Declaration reaches individuals or institutions without by-passing the sphere of the States
- b. As to (ii) there are different formulations not necessarily contradictory. The chair feels that a compromise is feasible
- c. The same applies to (iii) recognition of the freedom of research in the framework of ethical principles, human dignity, human rights and fundamental freedoms.

- d. As to (iv), it seems not to be an opposition to the fostering of a dialogue on bioethics: A collective refining of the concept should help clearing the differences
- e. Some compromise could be found for (v). There are different formulations in the compilation that could complement each other, even if by now they may seem at odds.
- f. Numerals (vi) and (vii) have received different comments and been the object of different proposals but not real contradiction. Reasonable chances for finding compromise.

3. Principles

- a. There is a proposed re-ordering of the section.
- b. Article 4. The bulk of it seems to be acceptable to Delegations, with a few drafting options. Problems subsist when it comes to the interest of society. There is at least one formulation that tries to bridge that gap: it would be advisable to explore this alternative further.
- c. Article 5. Could the question of the double standards be addressed in a positive formulation? There is at least one alternative that has been proposed.
- d. Article 6. Not real contradiction perceived. There are a couple of additions seemingly uncontroversial, including a new article 6.b that we might be able to consider with relative ease.
- e. Article 7. First half of the article does not present substantive problems with the exception of the ``shall or should`` issue. However, the second part shows some divergence. Still, there is at least one formulation that could be used to attempt to reach consensus.
- f. Article 8. No fundamental differences in drafting proposals compiled. ``Shall and should `` as well as ``decision and practices`` issues present.
- g. Article 9. The same comment applies.
- h. Article 10. Many proposals put forward. We might consider the desirability of keeping this fundamental article as simple as possible, keeping the text equidistant to national legislations. Original text could remain as a basis.
- i. We might wish to give early consideration to article 13 and 14. They include a number of ideas and principles that are particularly relevant to delegations and, at the same time, offer some reservations to others. In any case, they seem to be part of a broader possible arrangement with regard the scope of this declaration.

4. Transversal and other issues

5.

- a. Shall and should. Would it be acceptable to establish a general criteria stating that, for example, ``shall`` applies to questions arising from Human Rights instruments and ``should`` would apply to issues of any other nature
- b. Any decision or practice. Would it be acceptable not to include the expression in any definition and then proceed on a case by case basis?

- c. Human beings. From April's discussion it seems that the expression "human beings" is generally acceptable. Would we be in a position to conform that?
- d. Human life. Important for some delegations, causes fundamental problems to others. Is it conceivable to make some lateral mention to the concept, for instance in the preamble without stating anything of consequence?
- e. Bio-piracy and traditional knowledge. Would the following approach work: recognize the problem, state principle and refer implementation to appropriate fora.
- f. The value of preamble to paper out some controversial issues like human life, emerging or pre-existent issues, some aspects of the social concerns, relations with other instruments and organizations.
- g. Title of the Declaration. Although it should be an issue to be addressed at the end of our deliberations, it might be important to start thinking on some consensual alternatives. Some Delegations have expressed their preference to include Human Rights in the title. Others have stated problems with that approach. Would it be possible to reach a consensus on a mixed approach, for instance a sub-title including the mention of Human Rights and perhaps human dignity?