

A Summary of the National Discussion in the Context of the Elaboration of the Declaration on Universal Norms on Bioethics

National consultations in the context of the elaboration of the Declaration on Universal Norms on Bioethics were held on 13 September 2004 in Vilnius, at the Regional Bioethics Information Centre, based at the Faculty of Medicine of Vilnius University.

The participants in the discussion were divided into three working groups. Each group was organised to reflect a diverse representation of academic and professional backgrounds. The discussion groups were assigned a moderator and a rapporteur.

The discussion in the groups was intense, and participants demonstrated a high level of involvement.

The Sphere of the Application of the Declaration

Some participants in the discussions did not have an exact definition of the terms that were used in the text of the Declaration. They claimed that definitions would have made the discussions more articulate and productive.

For example, while discussing the scope of the Declaration on Universal Norms on Bioethics, ambiguities in the use of the terms were especially evident. Many participants in the discussion emphasized the necessity to present a definition of the concept of “bioethics” in the Declaration. It was not clear whether the Declaration should cover only biomedical ethics, or whether it should also cover the topics of environmental ethics, such as respect for the biosphere and biodiversity, the protection of animal rights, etc:

- ü If we adhere to the narrower definition of bioethics, namely, bioethics as biomedical ethics, then the discussed text is relevant, although a bit too broad to be covered in one single instrument;
- ü If we adhere to the broader definition of bioethics, which covers ecological ethics, then the principles dealing with the treatment of other living beings should be made more explicit in the text of the Declaration.

If the Declaration is limited to biomedical ethics, then issues of environmental ethics and the protection of animal rights deserve a separate instrument to be initiated by UNESCO.

The Distribution of Principles set out in the Declaration

In general, the majority of participants endorsed the partition of the principles into “general/fundamental” and “derived” ones, as “derived” principles were patently supervenient to the “general/fundamental” principles; they were more specific and narrower. Thus, the integration of all the principles would result in the repetition of the content or the loss of some important emphasis of the values and principles of the Declaration.

In contrast to this opinion, the other group still hesitated to divide the principles because of the ambiguity of the partition criteria. Moreover, some were not convinced that the principles set out in the Declaration (“general/fundamental”, “derived” and “provisional”) were bioethical ones (in which case they would correspond to the title of the document) and they tended to interpret fundamental principles as common ethical principles.

The Priority of the Principles set out in the Declaration

The partition of the principles into “general/fundamental” and “derived” sections is closely connected to their hierarchical division. This was evident as the attempts of the participants in the discussion at the repartition of “derived” and “general/fundamental” principles emerged from the different perceptions of the priority of the principles.

For instance, participants suggested moving the principle of “Autonomy and Responsibility” (Article 10) to the section “general/fundamental” principles, emphasizing its significance in the history of bioethics and its importance to bioethics in developing countries.

It was also proposed to move the principle of “Sharing of Benefits” (Article 13) to the section “general/fundamental” principles, as UNESCO is the only international organization which covers both the developed and the developing world; thus, its concern for developing countries could be emphasized more in the Declaration.

It was proposed to move the principle of “Responsibility towards the Biosphere” (Article 7) to the top of the chapter as being very important in the general context of bioethics.

The single discussion was on the principle of “Human Dignity, Human Rights and Justice” set out in the Declaration as one of “general/fundamental” principles (Article 1). According to some participants, this wording refers to a complex of different principles; thus, human dignity should be distinguished from the principle of justice, which signifies the equitable treatment of human beings. Therefore, it was proposed to distinguish justice as a separate principle, or to integrate it with the principle of “Solidarity, Equity and Cooperation” (Article 6), supposedly formulating a new, more general, title for the article. The use of the concept of “universal justice” attracted some criticism. It was claimed that the principle of “universal justice” in the context of bioethics is used mostly while speaking about social justice. Therefore, it was proposed to leave out the term “universal”.

The Question of the Practical Application of the Principles

If the principles listed in the Declaration are not sorted according to priorities, and there is no special order for the principles, their practical application will be rather complicated.

For instance, the application of the principle “Primacy of the Human Person” (Article 8) could attract controversial interpretations. Some participants in the discussion saw a contradiction between this principle and the protection of the rights of other living beings. They noted that the principle “Primacy of the Human Person” is adequate in the field of biomedical research; however, it is rather controversial in the context of the Declaration. The opinion was expressed that adherence to this principle might pose the serious danger of ignoring other important requirements of bioethics. For example, it might go against the requirement to acknowledge and protect animal rights, to allocate health resources in a just and equitable way, or to treat public health as a priority of health care.

A conflict may also arise between the principles of “Beneficence and Non-Maleficence” (Article 4) and “Autonomy and Responsibility” (Article 10). For example, if a patient’s religious convictions do not allow her/him a blood transfusion, is it justifiable to follow the declared principle of “Beneficence and Non-Maleficence” in a case when refusal to perform a blood transfusion would endanger his/her life?

Another example would be to consider the situation of not telling a patient the truth in order not to harm him/her psychologically. Would respect for autonomy and responsibility be infringed when a terminally ill patient is not told the truth about the state of her/his health?

Still another example, mentioned by some participants in the discussion, was related to the conflict between the principle of “Beneficence and Non-Maleficence” and the principle of “Respect for Cultural Diversity and Pluralism” (Article 5). If a society which follows its cultural tradition intrudes upon the behaviour of an individual who does not share the tradition (for example, in the use of contraceptives), should such interference be treated as an act in accordance with the principle of “Beneficence and Non-Maleficence” or as disrespect for cultural diversity and pluralism?

All the examples mentioned above were used by the participants in the discussion to show the difficulties in finding practical solutions if there is no priority in the principles of the Declaration. Therefore, some participants offered two possible solutions to the issue of the practical application of the principles. These solutions can be summarised in the following way:

- Ü the decision about the significance and order of the principles should be left to a particular society, according to its traditions and values;
- Ü the principles should be interpreted in a particular context of application; for instance, the principle of “Primacy of the Human Person” is very well understood in the context of biomedical research.

The Sphere of the Application of “Procedural Principles”

Some uncertainty arose while analyzing “procedural principles”, because the context of the application of these principles was not clear. Bioethical problems arise in very different contexts; for example, the health care provider-patient relationship, the work of ethics committees, or policy making at a government level. Therefore, it is a very ambitious task to formulate procedural principles which would be applicable to all the spheres and contexts of bioethics. According to the participants in the discussion, it would be very useful to provide an explanation of the context of the application of the principles listed in this section.

The Consideration of the “Specific Issues” Chapter

It was noted that some time ago member states were asked to fill in a questionnaire, which among other things dealt with specific issues to be included in the Declaration. Therefore, some participants in the discussion wanted a chapter dealing with specific issues of bioethics.

The inclusion of the specific questions in the Declaration would certainly enrich its content and help to define the scope of the instrument more clearly. However, many participants observed that in such a case the document itself would expand enormously. That is why the majority of participants welcomed the idea to supplement the Declaration with special protocols regulating specific issues of bioethics. However, it was proposed to include in the Declaration a chapter for “some” priority specific issues. For example, issues related to public health, the right to health care (emphasizing especially the rights of vulnerable persons), stem cell research, cloning, and biomedical research ethics were suggested as possible specific topics.

Other remarks

Some participants expressed their opinion that the concept of the “human person” is an ambiguous one, and its meaning differs considerably in philosophical and legal discourse. For example, in the legal

contexts of different countries, the concept of the “person” is attributed to different human beings (eg, should a foetus be regarded as a person?). Therefore, these participants suggested using the concept “human being” instead of “human person”.

There was also a suggestion to amend the title of Article 11 “[Informed] Consent” to “Free and Informed Consent” to emphasize the fundamental features of this important principle.

It was also proposed to shorten the fourth part of Article 2 (“Aims”) and to put it in the following way: “prevent scientific and technological practices contrary to human dignity, threatening human rights and fundamental freedoms”. The rationale of this suggestion was to avoid the repetition of the statement on the benefit of scientific and technological development already expressed in the Preamble.

Conclusions

In general, the participants welcomed warmly the idea of the Declaration and were positive about its structure and content. The critical remarks and suggestions expressed by the participants referred mostly to the application of the instrument; thus, the Declaration would probably be very relevant considering the practical implementation.

It was noted that modern society has come to a situation of increasing interdependence, caused by rapid technological development, which holds out extraordinarily prospects for humankind as a whole and for the individual. Bioethics, as a discipline encompassing the ethical, legal, social, cultural and economic dimensions of the life sciences and their related technologies, has the urgent responsibility of ensuring that, amid the onslaught of scientific advances, human dignity is respected and human rights and fundamental freedoms are protected. Therefore, UNESCO’s Declaration is regarded as an instrument which will provide essential guidelines to deal with emerging bioethics issues all over the world.

It was repeatedly noted that it is extremely challenging to determine the appropriate type and scope of this regulatory framework; thus, this system of consultation, seeking to reflect the public mood across many countries, was especially welcome. The participants expressed a wish to be informed about the process of developing the Declaration.