

Scottish Council on Human Bioethics

15 Morningside Road, Edinburgh EH10 4DP, Tel: 0131 447 6394 or 0774 298 4459

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Consultation response to the International Bioethics Committee (IBC)

Possible Scope and Structure of a Declaration on Universal Norms on Bioethics

Consultation response on behalf of the Scottish Council on Human Bioethics:

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?

Scottish Council on Human Bioethics Response:

A Declaration on Universal Norms on Bioethics would, if constructed ethically, ground scientific progress and its applications on the principle of human dignity which should represent the basis of all bioethical reflection. Such a declaration could then be used as a normative standard against which all biomedical interventions and procedures could be appraised and assessed. To do this, all levels and sections of society should be encouraged to seriously consider their involvement, commitment and engagement in human bioethics since the ethical issues relating to the consequences of being human and human dignity cannot be separated from the whole of society.

I.2 Should the declaration be limited to human beings and why?

Scottish Council on Human Bioethics Response:

Yes, the UNESCO declaration should only be limited to human beings in order to specifically address the crucial and unique importance of human dignity with which only humans are endowed. It would also limit the scope of the declaration which would, otherwise, become too broad, complex and heterogeneous. The only exception should be the consideration of human-animal hybrid embryos and the issues relating to xenotransplantation which raise serious questions with respect to human dignity.

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?

Scottish Council on Human Bioethics Response:

Yes, the UNESCO declaration should only deal with ethical issues related to the human person and the human body (including the brain) in a biological and medical context in order to specifically address the particular issues pertaining to humanity which are not shared with the animal species. An additional declaration or recommendation could be considered, at a later stage, by the UNESCO to address the ethical issues concerning the relationship between human beings and other living organisms.

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.)?

Scottish Council on Human Bioethics Response:

The UNESCO declaration should be structured to include a preamble and be organized into relevant sections which could, for example, be added to a general declaration. This would enable a more flexible and subject-specific approach to be established. In other words, the declaration could be structured into similar sections and in a similar manner to:

- The Council of Europe's Convention on Human Rights and Biomedicine (ETS - No. 164) and its additional protocols:

- (1) On the Prohibition of Cloning Human Beings (ETS - No. 168)
- (2) Concerning Transplantation of Organs and Tissues of Human Origin (ETS - 186), and
- (3) On Biomedical Research (forthcoming).

Moreover, the following texts from the UNESCO should be considered:

- The Universal Declaration on the Human Genome and Human Rights¹
- The International Declaration on Human Genetic Data²

In this respect, it should be noted that many years of international co-operation and investment in debates and discussions, at the uppermost levels, have gone into the drafting of the UNESCO declarations and the legally binding texts of the Council of Europe. Therefore, these important documents should be used as a basis and foundation for the proposed UNESCO declaration on bioethics.

If this is not done, much time will be spent on "reinventing the wheel". Moreover, the wording in the proposed UNESCO declaration on bioethics should be similar to that of the other UNESCO and Council of Europe texts in order to obtain an international standard and common language in human bioethics. In doing so, the creation of misunderstandings and confusion between national and international legal texts will be avoided.

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.)?

Scottish Council on Human Bioethics Response:

The principle of 'human dignity' should be the most important fundamental principle to be affirmed in the UNESCO declaration. All other principles are the result and consequence of this fundamental principle.

Human dignity, in this respect, should also be considered as being associated to the concept of personhood which does not have as its source a limited reality constrained by biological or physical substance. Instead, personhood should be understood as the primary and absolute concept of existence which enables human dignity to exist.

The term 'person' also implies a relationship between human individuals; a person can never exist in isolation. Thus, human dignity is based on the existence of what is in 'essence' human and with which others can have a relationship. In other words, in a relationship between persons, each *individual* obtains his or her *personal* identity from the *other*.

In this regard it should additionally be noted that human dignity does not change or develop within the 'time' of existence of a person.

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)?

Scottish Council on Human Bioethics Response:

In affirming the bioethical principles, the UNESCO declaration should state only general principles of broad application and leave the more detailed framework to national legislation. The document would, otherwise, become too extensive and rigid.

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?

Scottish Council on Human Bioethics Response:

The UNESCO declaration should, where possible, give guidance on specific subject areas in order to provide universal norms on ethical procedures.

And in this respect, it should be noted that only a universal and world-wide declaration on human bioethics from the UNESCO will be able to appropriately address some of the very grave ethical challenges already facing the international community. In other words, the UNESCO should make sure that it embraces the issues which it is uniquely capable of addressing such as:

- organ trafficking
- bioethical tourism
- the differences in health care provisions between rich and poor countries
- the lack of appropriate care in psychiatry

- the new threats relating to the protection of human embryos
- the threats to the human species arising from the creation of human-animal hybrid embryos
- the lack of public engagement in bioethics

Other subject areas which can be addressed are (additional subjects in bold):

beginning of life:

- abortion
- prenatal diagnosis
- preimplantation genetic diagnosis
- reproductive technologies
- sex selection
- **new procedures for the creation of human embryos (parthenogenesis, use of gametes created from stem cells, etc.)**

end of life

- concepts of death
- prolongation of life
- euthanasia
- palliative care
- **assisted suicide**

genetics and molecular biology

- genetic counseling
- genetic screening and testing
- gene therapy
- gene patenting
- genetic enhancement **and eugenics**
- population genetics
- cloning, reproductive cloning, non-reproductive cloning
- **human-animal hybrid embryos**

intellectual property rights

health care systems

- access to drugs
- access to health care
- allocation of health care resources
- quality of care
- right to health care
- rights of vulnerable persons

human genetic data and other personal healthcare data

organ and tissue transplantation

public health

- HIV infection and AIDS
- other infectious diseases (malaria, tuberculosis...)
- policies regarding vulnerable populations
- research
- research with human subjects
- embryo research
- behavioural research
- international and transnational research
- **research in emergency situations**

¹ http://portal.unesco.org/en/ev.php@URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html

² http://portal.unesco.org/shs/en/file_download.php/6016a4bea4c293a23e913de638045ea9Declaration_en.pdf