

EDITORIAL

Towards an International Treaty on Human Rights and Biomedicine? Some Reflections Inspired by UNESCO's Universal Declaration on Bioethics and Human Rights

The 33rd session of the General Conference of UNESCO has adopted by acclamation on 19 October 2005 the Universal Declaration on Bioethics and Human Rights.¹ After the Universal Declaration on the Human Genome and Human Rights (1997), followed by the Universal Declaration on Human Genetic Data (2003), the Universal Declaration on Bioethics and Human Rights is the third instrument related to bioethics adopted by UNESCO. It is also the most encompassing until now. While the focus of the Universal Declarations of 1997 and 2003 has been on genetics and life sciences, the recently adopted Universal Declaration covers many areas of bioethics. According to article 1 paragraph a, this Declaration addresses ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions.

The Universal Declaration on Bioethics and Human Rights contains 28 articles, divided over 5 titles. Articles 1 and 2 contain the "General Provisions". The already cited article 1 describes the scope of the Declaration while article 2 proclaims its eight aims. The backbone of the Declaration is made up by the "Principles", spread over the articles 3 to 17. They range from topics that (European) health lawyers will recognize immediately – such as human dignity and human rights (article 3), benefit and harm (article 4), autonomy (article 5), consent (article 6), persons without the capacity to consent (article 7), respect for human vulnerability and personal integrity (article 8), privacy and confidentiality (article 9), equality, justice and equity (article 10) and non-discrimination and non-stigmatization (article 11) – to themes they are in general less acquainted with such as respect for cultural diversity and pluralism (article 12), solidarity and cooperation (article 13), social responsibility and health (article 14), sharing of benefits (article 15), protecting future generations (article 16) and the protection of the environment, the biosphere and biodiversity (article 17). The next title, "Application of the Principles" deals with matters as decision-making and addressing bioethical issues (article 18), ethics

¹ See the text on www.unesco.org. At the moment of writing this text was still subjected to linguistic and editorial modifications.

committees (article 19), risk assessment and management (article 20) and transnational practices (article 21). The fourth title is devoted to the “Promotion of the Declaration” through appropriate measures taken by the States (article 22), bioethics education, training and information (article 23), international cooperation (article 24) and follow-up action by UNESCO (article 25). The last three articles (26 to 28) are grouped under the heading “Final Provisions”.

For health lawyers, one of the most intriguing aspects of the newly adopted Declaration is in the title because the combination of bioethics and human rights raises questions. As Tom Faunce recently wrote “academia and professional regulators are accustomed to viewing medical ethics and international human rights law as distinct normative systems”.² An illustration of this attitude was the criticism voiced against the abbreviated working title of the European Convention on Human Rights and Biomedicine when it was in its early stages of preparation: the “Bioethics Convention”.³ This reference to non-binding norms (Bioethics) and binding rules (Convention) in one title was at that time generally considered to be an impossible marriage and therefore the abbreviated title has been changed into “Convention on Human Rights and Biomedicine”.

One may object that in the case of the UNESCO Declaration on Bioethics and Human Rights this criticism is not relevant because such a declaration is not a legally binding document. This is certainly true but one should not exaggerate the differences in daily life between an international declaration and a treaty in the field of bioethics. Take as an example, the Universal Declaration on Human Rights, adopted by the United Nations in 1948. It did not directly create binding human rights norms under international law. But it can come to be accepted as representing international customary law if sufficient states implement it with the sense of being obliged to do so.⁴ Although none of the three UNESCO Declarations on bioethics are binding documents in the legal sense as they are not subject to ratification by the Member States, they nevertheless call on the States to take all appropriate measures, whether of a legislative, administrative or other character,

2 T.A. Faunce, “Will international human rights subsume medical ethics? Intersections in the UNESCO *Universal Bioethics Declaration*”, *Journal of Medical Ethics*, 2004, 174.

3 *Preliminary draft Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine: bioethics convention*, *European Journal of Health Law*, 1994, 382; M.A.M. De Wachter, “The European Convention on Bioethics”, *Hastings Center Report*, 1994, n° 1, 13.

4 T.A. Faunce, *o.c.*, 174.

to give effect to the principles set out in the Declarations in accordance with international human rights law.⁵

Next, one has to consider the binding character of the European Convention on Human Rights and Biomedicine also in a balanced way. On the one hand article 1, second paragraph of the Convention stipulates that each Party shall take in its internal law the necessary measures to give effect to the provisions of this Convention. This paragraph has been added in the last preparatory stage of the Convention in an effort to enhance the conformity between the Convention and the internal law of the Parties. According to the Explanatory Report, it is largely up to the Parties to determine how they endeavour to comply with this obligation: “with regard to each provision, the means will have to be determined by each Party in accordance with its constitutional law and taking into account the provision in question”.⁶ On the other hand, the European Court of Human Rights has already referred to the European Convention (twice, to my knowledge) as a standard in cases where Member States of the Council of Europe were involved that did not ratify (France) or not even sign it (the United Kingdom). In *Glass v. United Kingdom* the Court remarked “that it does not consider the regulatory framework in place in the United Kingdom is in any way inconsistent with the standards laid down in the Bioethics (sic) and Human Rights Convention in the area of consent”.⁷ According to Elaine Gadd, this was an important step as it is now probable that in relevant cases those consent standards will be applied to Member States who have not ratified the European Convention on Human Rights and Biomedicine

5 See article 23 (a) of the Declaration on Human Genetic Data and article 22 (a) of the Declaration on Bioethics and Human Rights. See also article 1 (a) of the Declaration on Human Genetic Data that aims “to set out the principles which should guide States in the formulation of their legislation and their policies on these issues”. Article 22 of the Declaration on the Human Genome and Human Rights calls on the States to make every effort to promote the principles set out in the Declaration and to promote, by means of all appropriate measures their implementation. In the “Guidelines for the implementation of the Universal Declaration on the Human Genome and Human Rights” (adopted by the General Assembly of UNESCO on 16 November 1999) this is further elaborated: “In order to guarantee the application of these principles, the Declaration recommends that they be made known, disseminated and give shape *as measures, especially in the form of legislation or regulations*”.

6 A.Hendriks, note, Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine: Convention on human rights and biomedicine, *European Journal of Health Law*, 1997, 89-90.

7 9 March 2004, Application N° 61827/00, §75.

itself.⁸ A few months later, in *Vo v. France*, the Court referred again to the “Oviedo Convention on Human Rights and Biomedicine” and also to its first additional protocol on human cloning and the, at that moment, draft protocol on biomedical research with human beings.⁹

The previous considerations bring me to the question whether the UNESCO International Declaration on Human Rights and Bioethics has the potential to become an International Convention on Human Rights and Biomedicine. The European Convention on Human Rights and Biomedicine has clearly served as a source of inspiration to the UNESCO Declaration, especially its articles 3, 6, 7 and 9. Non-members States of the Council of Europe may accede to the European Convention upon invitation of the Committee of Ministers of the Council of Europe (article 34 paragraph 1). Thus, the European Convention may serve as a vehicle to “mutate” the UNESCO Declaration into a binding international treaty. But, as already said, there are also marked differences between both documents. Taking into consideration cultural, religious, linguistic, political and many other differences between the Member States that deserve respect, this is quite understandable. Let us therefore carefully evaluate how the Member States of UNESCO will give effect to the Universal Declaration on Bioethics and Human Rights in the years to come before engaging ourselves in more binding scenarios.

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8 E. Gadd, “The global significance of the Convention on Human Rights and Biomedicine”, in J.K.M. Gevers, E.H. Hondius and J.H. Hubben (eds.), *Health Law, Human Rights and the Biomedicine Convention, Essays in Honour of Henriette Roscam Abbing*, Leiden, Martinus Nijhoff Publishers, International Studies in Human Rights, 85, 2005, 44.

9 8 July 2004, Application N° 53924/00, §84.