The UNESCO Bioethics Programme: A Review

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UNESCO's Bioethics Programme was established in 1993. In twenty years it has adopted three international declarations, on the human genome (1997), human genetic data (2003) and bioethics (2005); produced reports on a wide range of bioethics issues; and developed capacity building and public education programmes in bioethics. Yet UNESCO has sometimes struggled to assert its authority in the wider bioethics world. Some bioethicists have criticized the 2005 declaration and suggested that the World Health Organization might be better placed to advance bioethics. In 2011, after four years of debate, UNESCO decided not to draft a convention on human reproductive cloning, because consensus on the issue proved impossible. This article reviews the standard setting and capacity building activities of the UNESCO Bioethics Programme. While the Programme faces challenges common to most intergovernmental organizations, its achievements in expanding international law and building bioethics capacity should not be underestimated.

KEYWORDS UNESCO, bioethics, human rights

Introduction

The United Nations Educational, Scientific and Cultural Organization (UNESCO) was founded in 1945 to build peace ‘on the basis of humanity’s moral and intellectual solidarity’ (UNESCO n.d.). Its Bioethics Programme was established almost fifty years later, in 1993, with the appointment of an International Bioethics Committee (IBC) tasked with deliberating on the ethical challenges advanced by the life sciences (UNESCO 1994). An Intergovernmental Bioethics Committee (IGBC) followed in 1999. As UNESCO deals in both the human and social sciences, it claims a particular resonance with the field of bioethics (ten Have 2005: 745; UNESCO 2012c).

The Bioethics Programme comprises the two committees and a secretariat based in Paris. It also hosts the permanent secretariat of the United Nations Inter-Agency Committee on Bioethics. The IBC is made up of independent experts in bioethics.
and the IGBC of government representatives. Each has 36 members. The Programme’s work falls into two broad areas, standard setting and capacity building. These areas are related in that the capacity building activities are specifically designed to promote the implementation of the standards in UNESCO’s three bioethics instruments to date, the *Universal Declaration on the Human Genome and Human Rights* (1997), the *International Declaration on Human Genetic Data* (2003) and the *Universal Declaration on Bioethics and Human Rights* (2005). This article introduces the Bioethics Programme’s work in these two areas and assesses its impact in the field of bioethics. Although UNESCO’s bioethics mandate has not always been universally accepted and its declarations are considered by some to be weak instruments, its achievements should not be underestimated. Its programmes have added significantly to the bioethics capacity of several developing countries and the *Universal Declaration on Bioethics and Human Rights*, in particular, has broadened the relationship between bioethics and human rights in international law.

The Bioethics Programme’s standard setting activities

The developments in genetics of the 1990s – the sequencing of the human genome and the cloning of Dolly the sheep – were the impetus behind the first international declaration that came out of UNESCO’s Bioethics Programme, the 1997 *Universal Declaration on the Human Genome and Human Rights* (UDHGHR). The title demonstrates UNESCO’s concern to balance scientific progress with the protection of human rights. The preamble states:

> The General Conference, … recognizing that research on the human genome and the resulting applications open up vast prospects for progress in improving the health of individuals and of humankind as a whole, but emphasizing that such research should fully respect human dignity, freedom and human rights, as well as the prohibition of all forms of discrimination based on genetic characteristics, proclaims the principles that follow and adopts the present Declaration. (UNESCO 1997)

The *International Declaration on Human Genetic Data* (IDHGD) followed in 2003, the year the sequencing of the human genome was completed. It gives more specific guidance on the collection, processing, storage and use of genetic data than its predecessor. Two years later UNESCO adopted the *Universal Declaration on Bioethics and Human Rights* (UDBHR). This encompasses several of the principles in the first two declarations (such as informed consent, confidentiality, autonomy and freedom of research), but broadens them out to apply to ‘ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions’ (UNESCO 2005f: article 1). The link with human rights is again explicit, both in the title and the preamble, which cites the *Universal Declaration of Human Rights* of 1948.

The declarations have been criticized by several bioethics scholars for their imprecise and non-committal language (Taylor 1999: 510; Abbing 2004: 93; Benatar 2005: 221; Harmon 2005: 33; Landman and Schüklenk 2005: iv; Williams 2005: 213). Certainly the drafting process for all three declarations was
subject to the interest-based bargaining characteristic of most international
negotiations, which led to fudged wording in areas such as risk assessment and
beginning and end of life issues. The UDBHR does not address controversial
bioethical issues such as gene therapy, stem cell research and sex selection, as
consensus on these proved impossible to reach (Schmidt 2007; Langlois 2011;
Langlois 2013). Yet it is its status as an intergovernmental body which UNESCO
claims sets it apart from other ethics organizations, such as the World Medical
Association, a professional body (ten Have 2006: 342); for example, the
UDHGHR is described on UNESCO’s website as having been ‘the only
international instrument in the field of bioethics’ at the time of its adoption
(UNESCO 2012a). The UDBHR is considered to go beyond pre-existing ethics
instruments, like the World Medical Association’s Declaration of Helsinki: Ethical
Principles for Medical Research Involving Human Subjects, in other ways too, as it
is broader in scope (UNESCO 2005b: 6; ten Have 2006: 341). Justice Kirby (2010:
794), chair of the UDBHR drafting committee, proclaims, ‘It lifts the eyes of
bioethicists from the patient’s bedside and the hospital ward to a new insistence on
the relevance to the bioethics discipline for society, the community, humanity, all
living beings and the biosphere.’

Bioethics and human rights in the 2005 declaration

Article 14 of the UDBHR (2005), on social responsibility and health, generated
much debate during the drafting of the declaration. Some parties felt that to
include development issues was to go beyond the remit of both UNESCO and
bioethics (UNESCO 2005d: 3–4 and 38). The idea of including such an article was
first mooted by Latin American states; Asian and African states later lent their
support (interview with a member of the Bioethics Programme secretariat, August
2005). In a written consultation on an early outline of the proposed declaration, in
which social responsibility only featured in the preamble, Brazil and Paraguay
lobbied for a stronger focus on second generation rights. Brazil stated, ‘The draft
text … is too narrow in scope in relation to the development of aspects connected
to economic, social and cultural rights, which represent the “social agenda” of the
draft declaration’ (UNESCO 2005c: 2). Paraguay similarly argued:

The Declaration has left out or has yet to include themes closely tied to bioethics, such
as access to health care and drugs and the right to a life of dignity and a healthy
environment … A declaration cannot be universal if it leaves out these and other
problems which affect perhaps the majority of the world’s population, who are faced
with poverty, hunger, illness, social exclusion and, in many cases, violence. (UNESCO
2005c: 7)

At the June 2005 meeting that finalized the draft declaration before its adoption by
the UNESCO General Conference later that year, the social responsibility article
was approved by consensus, after developing countries asserted its ‘paramount
importance’ (UNESCO 2005e: 6). The UDBHR thus declares that both state and
society have a duty to promote health and social development. More specifically,
science and technology should enhance access to healthcare, nutrition and water,
improve living conditions, reduce poverty and illiteracy and eliminate social exclusion (UNESCO 2005f: article 14). UNESCO’s decision to identify the pursuit of these social goals as a bioethical principle mirrors earlier developments in the philosophy of human rights. Just as human rights expanded beyond first generation civil and political rights to include economic, social and cultural rights, bioethics has moved beyond a narrow concern with individual rights in a medical or research setting. The UDBHR also alludes to third generation solidarity or group rights, as ‘groups of special vulnerability should be protected’ (article 8) and ‘the importance of cultural diversity and pluralism should be given due regard’ (article 12), as should ‘the impact of life sciences on future generations’ (article 16).

The Bioethics Programme’s capacity building activities

After realizing three declarations in less than ten years, at the close of 2005 UNESCO opted to take a ‘normative pause’ and instead focus on capacity building in bioethics (UNESCO 2005a: 4). At the first IBC meeting after the adoption of the UDBHR, Koichiro Matsuura, then Director-General of UNESCO, said, ‘Its adoption is just the beginning. To give full life to the Declaration and render it effective, the most important part of the work remains to be done’ (UNESCO 2005a: 3). Each of the three declarations emphasizes the need for public education and dialogue on bioethics (UDHGHR, articles 20, 21 and 23; IDHGD, articles 6(a), 23(a) and 24; and UDBHR, articles 2(3), 18(2/3), 19(d), 22(1) and 23(1)) and for trained ethics committees at local to national levels (UDHGHR, articles 16 and 23; IDHGD, article 6(b); and UDBHR, article 19). It is in this regard that the Bioethics Programme engages in a whole range of bioethics capacity building activities. The Assisting Bioethics Committees (ABC) initiative trains national bioethics committees, the Ethics Education Programme (EEP) produces educational materials, trains ethics teachers and appoints bioethics chairs and the Global Ethics Observatory (GEObs) provides a resource database online, containing details of ethics experts and institutions, education programmes, legal instruments and guidelines and other resources (see www.unesco.org/shs/ethics/geobs). To celebrate 20 years in the bioethics field, in 2013 the Bioethics Programme published a report outlining its achievements to date. By January 2013, 10 countries had taken part in the ABC programme; 17 countries had, with UNESCO’s support, set up a national bioethics committee; 11 countries had established a UNESCO Chair in Bioethics; 10 countries had hosted an Ethics Teachers’ Training Course (some multiple times); and universities in 14 different countries were using the Bioethics Core Curriculum (UNESCO 2013a).

These successes notwithstanding, the Bioethics Programme faces considerable challenges in making sure its capacity building activities make an impact. The ABC programme is tailored to suit the needs of each country and provides three years of technical support (UNESCO 2010a: 2–3). This technical support is designed to ensure the sustainability of the committees, but longevity is ultimately dependent on the country itself providing the necessary resources. As it is mostly developing countries that have undergone the ABC training, these resources may not be forthcoming (UNESCO 2010b: 19–20; UNESCO 2010c; ten Have et al. 2011:
The Ethics Teachers’ Training Course (ETTC) has faced similar problems. A 2008–9 evaluation of UNESCO’s ethics activities by its Internal Oversight Office (IOS) raised concerns about the efficacy and value of the ETTC programme, as several participants on the five courses held up to and including 2008 were no longer teaching ethics, although most said they had found the training useful (UNESCO 2010b: 3, 22–24). The evaluation was also ambivalent about the UNESCO Chairs in Bioethics, finding their contribution to be ‘uneven’ (UNESCO 2010b: 23).

Another branch of the Bioethics Programme’s capacity building work involves the dissemination of bioethics materials. 500,000 copies of the UDHGHR had been published by October 2001, in 20 languages (UNESCO 2001: 6–7). Since 2005 the Programme has focused on the UDBHR. By 2007 the declaration had been translated into 30 languages (although no African ones) (UNESCO 2007). Three reports by the IBC elaborate particular articles of the declaration, on informed consent (articles 6 and 7), social responsibility and health (article 14) and human vulnerability (article 8) (see UNESCO 2008a, 2010d and 2013e). The Programme has also produced guidebooks on how to establish, run and educate bioethics committees in all six of UNESCO’s official languages (UNESCO 2011c). But IBC and IGBC members have expressed concern that these materials are not reaching as wide an audience as they should. At a joint meeting in 2010 they called for better communications between the Bioethics Programme secretariat, UNESCO National Commissions, national bioethics committees and other ethics bodies within countries (personal observations, IBC–IGBC meeting, Paris, October 2010). One of the issues is that National Commissions are often housed within ministries of education, whereas bioethics usually falls under the remit of ministries of health or science and technology (interview with a member of the Bioethics Programme secretariat, August 2005). The need for better networking within and beyond UNESCO was highlighted by a 2011 review of relationships between different parts of the organization (UNESCO 2012b: 2).

UNESCO’s relationships with other bioethics organizations

UNESCO is not the only organization working in the field of bioethics. The World Health Organization (WHO), the US National Institutes of Health, the European Union and the Bill and Melinda Gates Foundation all support or conduct ethics training programmes and/or house online ethics databases (Nyika et al. 2009: 190; Ijsselmuiden et al. 2012: 76–8). During the drafting of the UDBHR, some commentators felt that UNESCO was invading WHO territory (Landman and Schüklken 2005: iii; Williams 2005: 212). Certainly, at first glance there appears to be a significant overlap in the activities of the two UN agencies. WHO published the manuals Research Ethics Committees: Basic Concepts for Capacity-Building in 2009 and Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants in 2011. But these are aimed at institutional research ethics committees, whereas UNESCO’s guidebooks are primarily for national level committees. In fact, WHO acknowledges UNESCO’s contribution to the 2011 document as ‘especially valuable’ (WHO 2011: viii).
WHO also coordinates the Global Summit of National Bioethics Advisory Bodies, which has met biennially since 1996 (WHO 2012). While this would appear to encroach on to UNESCO’s turf, there are again signs that the two organizations are working together. On the webpage of the 10th summit, to be held in Mexico in June 2014, the UNESCO icon appears alongside that of WHO and various Mexican bodies. Moreover, the name of the summit has been changed to the Global Summit of National Ethics/Bioethics Committees (Bioethics Summit n.d.).

UNESCO and human cloning

Latin American states were able to push for the article on social responsibility and health during the drafting of the UDBHR (2005), but they were not as successful with regard to other matters. They had also wanted the declaration to address human reproductive cloning, for example (UNESCO 2004a: 4; UNESCO 2004b: 2). Somewhat ironically, the rationale for leaving out such issues was that social concerns are of more immediate consequence, as expounded by Henk ten Have, Head of UNESCO’s Division of the Ethics of Science and Technology 2003–10: ‘Research into stem cells and cloning does not for now affect the lives of most people. They remain a hope for the future, but right now, people are dying because of poor health conditions. We must concentrate on this problem’ (Tousni 2006). Nevertheless, in 2008 UNESCO decided to investigate whether an international convention on human cloning is needed.

This decision was a response to the United Nations University’s Institute of Advanced Studies’ 2007 report, *Is Human Reproductive Cloning Inevitable: Future Options for UN Governance*, which had suggested that the IBC tackle the issue. At the invitation of Koïchiro Matsuura, then Director-General of UNESCO, the IBC set up a Working Group on Human Cloning and International Governance, to see whether ‘the scientific, ethical, social, political and legal developments on human cloning in recent years justify a new initiative at international level’ (UNESCO 2008d: 1). Over a period of four years, in consultation with the IBC, the IGBC and other interested parties, the Working Group oscillated between recommending a binding international convention to ban human reproductive cloning and the far softer promotion of further international dialogue on the issue (UNESCO 2008b; UNESCO 2009; UNESCO 2011a). As agreement on the stronger option both within and between the IBC and IGBC proved elusive, the topic was relegated to ongoing monitoring in the IBC’s 2012–13 Work Programme (UNESCO 2011b: 4; UNESCO 2012d).

Conclusion

The human cloning episode highlights the limitations of the UNESCO Bioethics Programme’s standard setting activities. The declaratory format was deliberately chosen for the three genetics and bioethics instruments of 1997, 2003 and 2005, because this is non-binding in international law. As there is already an international declaration on human cloning, the *United Nations Declaration on Human Cloning* of 2005, this was not an option, but member states would not agree to a binding
convention. The non-binding nature of the three existing declarations means that states are not obligated to implement them in legal terms, but UNESCO credits them with a high degree of normative power, the commitment of states being written into the texts and further implied by the adoption of the declarations by acclamation at the respective General Conferences (ten Have 2005: 746; Solbakk 2007). The UDBHR (2005), in particular, is having an observable impact on the bioethics regimes of some states. Kenya’s newly reconstituted National Bioethics Committee drew inspiration from the declaration in formulating its rules of procedure, for example (National Council for Science and Technology 2010: iii and 1). This demonstrates the importance of the Bioethics Programme’s capacity building work in promoting the implementation of the declarations, Kenya having been the first country to complete the ABC programme (UNESCO 2013a).

The majority of this capacity building takes place in developing countries that need to strengthen their bioethics infrastructures (UNESCO 2013a) and where UNESCO’s broadening of bioethics beyond medical and research ethics, to include the promotion of economic, social and cultural rights in the context of social responsibility and health, has particular resonance. Like all UNESCO’s activities, this work was threatened by the 22 per cent cut in UNESCO’s proposed total budget for 2014–15, in the wake of the US and Israel withdrawing funds after Palestine was admitted as a member state in 2011 (UNESCO 2011d; UNESCO 2013b). The high value that UNESCO accords the Bioethics Programme is revealed by the fact that its budget allocation has largely been protected (2013d). This enables the Programme to consider how it can continue contributing to the bioethics field over the next 20 years (UNESCO 2013c).

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