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Chapter 5 Implementing bioethics

UNESCO's efforts to realize and enforce the declarations

The three declarations – 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) – are by nature non-binding. They are, nevertheless, the product of an intergovernmental body and thus qualitatively different (some would claim) to the bioethics guidelines and codes of conduct devised by professional organizations. This has implications for what UNESCO can demand of its member states and, conversely, what member states can expect of UNESCO. Focusing especially on dissemination and capacity-building activities, this chapter examines the content and strength of the UNESCO norms and the organization's efforts to ensure they are realized. It also assesses the degree to which these efforts overlap with those of the WHO and the potential long-term repercussions of UNESCO's failure to agree on a binding convention on human cloning.

The nature and content of the declarations

UNESCO gave very similar reasons for the choice of a declaratory rather than conventional (binding) format for all three declarations: first, declarations are generally adopted more quickly than conventions; second, states would be more likely to agree to non-binding norms; and third, greater flexibility might be beneficial in the rapidly changing fields of bioethics and genetics. For the UDHGHR (1997), the IBC decided:

> An instrument not requiring ratification, accession or acceptance, is likely to be adopted more quickly than a formal agreement, whereas the binding nature of a convention could well discourage certain States from committing themselves in so complex and changeable an area.
>
> (UNESCO 1999a: 79)

For the IDHGD (2003), it was thought that a declaratory instrument would not only facilitate consensus during the negotiation period, but also 'allow for adaptations in a domain where the variety of situations covered, and the complexity of the subject, is constantly evolving with new scientific discoveries' (UNESCO 2003k). For the UDBHR (2005), the IBC again argued that a declaration would have the greatest impact, because it 'would be better adapted to a constantly changing environment and would enable a broader consensus among Member States to be achieved rapidly' (UNESCO 2003i: 7–8). The views of a Kenyan official at the Ministry of Foreign Affairs chimed with this reasoning. They corroborated that states are more likely to agree to declarations than conventions. As Kenya would not be legally bound by a declaration, they said, it would not be too worried if not all its requirements were met during negotiations (interview with K_30).

Declaratory instruments were also considered appropriate because states would be able to interpret them as they saw fit within their national contexts. UNESCO's aim has been to elaborate universal norms that take account of the different traditions of its member states. Accordingly, the UDHGHR (1997) is intended to 'transcend different cultural, political and religious sensitivities' (UNESCO 1999a: 28). Lenoir (1998–9: 546) has claimed that the UDHGHR is 'on another plane' to European directives on genetics, as it 'does not seek to govern specific practices; rather, it spells out universally-accepted ethical principles'. (During the drafting of the declaration, by contrast, Alastair Iles [1996: 43] had predicted that the declaration would be 'constrained in its vision and transformative potential' because of the need to accommodate 'vast cultural and political diversity'.) For the IDHGD (2003), 'the declaratory form of the instrument was chosen for its appropriateness in the elaboration of principles that States can interpret taking into account their legal systems and different cultural, economic and social circumstances' (UNESCO 2003c: 3). The General Conference commissioned a similarly balanced approach to the drafting of the UDBHR (2005), judging that universal standards were needed in bioethics, but that these should be set 'in the spirit of cultural pluralism inherent in bioethics' (UNESCO 2004p: 47).

In order that these mandates be fulfilled, the declarations contain only general principles, to which all states were able to agree without conceding their cultural and political particularities. Andorno (2007: 150), a member of the IBC during the drafting of the UDBHR, writes of the declaration, 'Regardless of the weaknesses inherent to this kind of instrument, the very fact that virtually all states reached an agreement in this sensitive area is in itself a major achievement.' This resonates more with Young's observations about the messy process of regime negotiation than with Victor *et al.'s* on non-binding agreements encapsulating less compromised standards than binding ones. Articles in the declarations are more or less specific, depending on the issue concerned. Some appear reasonably detailed. All three declarations, for example, lay out guidelines for authorization for research with persons without the capacity to consent and the IDHGD (2003) and UDBHR (2005) offer concrete suggestions on what benefit sharing might actually entail, such as provision of new diagnostics and drugs or capacity building in data collection and research. Even so, these are minimal in comparison with the equivalent sections of the *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (2002) of the Council for International Organizations of Medical Sciences (CIOMS), which run to several paragraphs.

A significant feature of the UDHGHR (1997) is that it says of the human genome, 'In a symbolic sense, it is the heritage of humanity' (article 1). Although UNESCO considered this conceptually innovative, the stronger formulation 'common heritage of humanity' was used in earlier drafts, a recognized term in international law (as applied to the sea and outer space, for example) and the one adopted by the Human Genome Organisation. Lenoir (1996), as president of the IBC, described the application of this legal term to the human species as 'the main originality' of the draft declaration. Member states made the change, concerned that the idea of 'common heritage' could be misconstrued to justify the appropriation of human genetic sequences for commercial purposes (Andorno 2003: 107). Relatedly, they added article 4 on commercialization just before the declaration was adopted: 'The human genome in its natural state shall not give rise to financial gains' (UNESCO 1997; Knoppers 1999: 24). This was in response to developing countries wishing to protect their genetic resources (Lenoir 1998–9: 553). While the article would appear to guard against gene patenting, the phrase 'in its natural state' renders it ambiguous in Andorno's eyes: 'Given that the ethical and legal problem is raised precisely by the patenting of human DNA sequences in something other than its natural form, … the Declaration gives the impression of having eluded the real problem' (Andorno 2003: 111). Kluge (2003: 124) makes a similar criticism, arguing that the article could be interpreted to justify gene patenting on the grounds that this concerns only parts of the human genome, which if separated from 'their contextual DNA' would not be in their natural state.

Several commentators have criticized the declarations for being vague and indeterminate (Taylor 1999: 510; Abbing 2004: 93; D. Benatar 2005: 221; Harmon 2005: 33; Landman and Schüklenk 2005: iv; Williams 2005: 213). IBC members, by contrast, have framed the declarations' generality more positively, as a necessary step in reaching an international consensus, from which states can draw in making more firm regulations (Andorno 2002: 960; Butler 2004: 369). Loretta Kopelman (2009: 262–70) takes the middle ground. The UDBHR (2005) fails in philosophical terms, she says, because it does not justify, rank, clarify or specify its principles, but its very vagueness may help to stimulate high quality public discourse among people of different backgrounds, of the kind Slaughter endorses. William Sweet and Joseph Masciulli (2011: 13) similarly defend UNESCO's use of the term 'human dignity', without definition, in all three declarations. They believe this is key to the 'global moral response' needed to advances in biotechnology, as it conveys the sense that human beings can never be used merely as means and are fundamentally equal. Andorno (2009: 228) also credits the UDBHR with making a 'significant contribution' to our understanding of the concept of dignity, as follows:

> The promotion of respect for human dignity constitutes not only the main purpose of the document (Article 2.c) but also the first principle that should govern biomedical issues (Article 3), the rationale for the prohibition of discrimination and stigmatization of individuals or groups of individuals (Article 11), the framework within which cultural diversity is to be respected (Article 12), and the interpretative principle for a correct understanding of all the Declaration's provisions (Article 28).
>
> (ibid: 234)

UNESCO puts great store by the fact that the declarations have been a dopted by consensus, believing this to confer on them normative legitimacy. Lenoir (1998–9: 558) wrote of the UDHGHR (1997) soon after its adoption:

> The active involvement of the states in the process of preparing the Human Genome Declaration is undoubtedly the best guarantee of its future effectiveness. The discussions were heated at times, and, naturally, the balance offered by the text remains fragile. Paradoxically, this fragility and controversy make the Human Genome Declaration's unanimous acceptance even more significant.

ten Have (2006: 341–2) has made a similar claim of the UDBHR (2005): 'The unanimous adoption by the member states is not merely symbolic but gives the declaration moral authority and creates a moral commitment.' This was echoed by the Bioethics Programme leader at the IBC's meeting of 31 May to 2 June 2011, who said that it had been a big achievement to get agreement among diverse countries and that it was particularly significant that a declaration on such a sensitive issue as bioethics had been adopted by acclamation, as this was not common practice (personal observation).

Yet the emphasis on decision-making by consensus can also be seen as a weakness. A number of issues arose during the drafting of the UDBHR (2005) that proved difficult or impossible to resolve. Group I (Western European and North American) and Group IV (Asian) states were at odds over whether the declaration should extend to the biosphere or be limited to humans and a definition of the term 'bioethics' had to be dropped because consensus on wording and scope could not be reached (UNESCO 2005m: 2–3). Of most relevance to research ethics was the furore over an article on risk assessment. States were unable to agree whether or not it should incorporate the precautionary principle (that is, that practices that have not been proved to be safe should be avoided). The eventual resolution at the June 2005 IGE session epitomizes many regime negotiations. The official records of the meeting state, 'The meeting decided to retain the article by amending it in such a way as to formulate a general principle without going into detail' (UNESCO 2005m: 7). Hence the article's rather nebulous wording:

> Appropriate assessment and adequate management of risk related to medicine, life sciences and associated technologies should be promoted
>
> (UNESCO 2005s: article 20)

as compared with draft formulations, for example:

> When scientific evidence of serious or irreversible damage to public health or human welfare or the environment is not sufficient, provisional, adequate and proportionate measures shall be taken in a timely manner. Such measures shall be based on the best scientific knowledge available and on procedures that are specially designed for evaluating the ethical issues at stake. These measures should be carried out in accordance with the principles set out in this Declaration and with respect to human rights and fundamental freedoms.
>
> (UNESCO 2004b: 8)

Despite the non-binding nature of the declaration, then, the 'lowest common denominator' effect could not be avoided in this case. This was affirmed by a member of the Bioethics Programme secretariat, who said:

> We had an article on risk management, which was in fact arguing the precautionary principle without mentioning it. And then some of the delegations, they took the whole text out and they changed it for a very general text, which has been accepted. So now the text there is an open door, it's just a generality.
>
> (interview with F_01)

How controversial issues in bioethics might be included in the text also proved irresolvable (Macpherson 2007: 589; Snead 2009: 210). Thus no mention is made of gene therapy or stem cell research, for instance. Instead, general and procedural principles are intended to provide a basis for 'the search for common positions' on issues for which no such position could be found in specific terms (UNESCO 2004k: 1 [quoted]; Snead 2009: 221). The IBC tried to make provision for these issues to figure in future revisions to the declaration, with the following clauses:

> 31 (c) Five years after its adoption and thereafter on a periodical basis, UNESCO shall take appropriate measures to examine the Declaration in the light of scientific and technological development and, if necessary, to ensure its revision, in accordance with UNESCO's statutory procedures

and

> With respect to the principles set forth herein, this Declaration could be further developed through international instruments adopted by the General Conference of UNESCO, in accordance with UNESCO's statutory

> procedures.
>
> (UNESCO 2004b: 10)

The governmental representatives removed the clauses at their June 2005 IGE meeting, however, considering them inappropriate (UNESCO 2005i: 7–8). Thus it appears that the declaration will be less flexible in a 'constantly changing environment' than the IBC initially hoped (UNESCO 2003i: 7–8).

The normative power of the declarations

Although the declarations, by definition, cannot be binding on member states, what states might seemingly be obligated to do was still of concern during negotiations. There was substantial debate during the drafting of both the IDHGD (2003) and the UDBHR (2005) over whether states 'shall' or 'should' implement their principles. At the IDHGD IGE meeting, the experts representing their governments 'agreed that insofar as possible the word "shall" would be replaced by "should" or by "may" in the text of the preliminary draft'. Only in relation to the IBC and IGBC was 'shall' retained (UNESCO 2003c: 4). For the UDBHR, some states felt that 'shall' could be used as an indication of moral commitment, without compromising the non-binding nature of the text, while others, including the US, Canada and Germany, were adamant that only the conditional form was appropriate within a declaration, except in regard to actions prescribed for UNESCO (interview with UK_01; UNESCO 2005c: 3; UNESCO 2005j; Snead 2009: 210). A more specific example concerns the free flow and sharing of scientific and technological knowledge. An article in the draft UDBHR asserting that states should 'make every effort to guarantee' these was softened so that they should merely 'encourage' them, after several member states of the IGBC (namely Canada, Germany, Saudi Arabia, Latvia and the US) objected to the stronger formulation at the IBC–IGBC meetings in January 2005 (UNESCO 2004b: 9; personal observations).

UNESCO places a high value on the commitment of states to the implementation of the declarations that each of the texts articulates. Jan Helge Solbakk (2007), chief of the Bioethics Programme from 2007 to 2008, remarked in a presentation on the UDBHR that this commitment made the declaration 'harder than soft law', in that it differed from a document like the *Declaration of Helsinki* of the World Medical Association (WMA), which can have only moral weight. Macklin (2005: 244) agrees, seeing the UDBHR's 'greatest strength' in its 'stature as an international declaration issued by a United Nations Organization'. Andorno (2009: 225–6) similarly places emphasis on the declarations' intergovernmental origins. He refutes the idea that their non-binding nature reduces them to 'purely ethical or rhetorical recommendations deprived of any legal effect'. Echoing Goodin (p. 39), he sees the declarations as 'potentially binding', as states gradually take them on board. ten Have (2005: 746) goes further, claiming that the value and strength of the UDBHR 'are in no way diminished' by its non-binding nature. 'For the first time in the history of bioethics,' he writes, 'all States in the international community are solemnly committed to respect and to implement the basic principles of bioethics, set forth within a single text.'

The three declarations vary slightly in what is expected of member states in terms of compliance. While several articles of the UDHGHR (1997) allude to national law in relation to research ethics, confidentiality and reparation for damage, the section on promotion of its principles requires states to do this 'through education and relevant means' and 'all appropriate measures' (whatever those might be), rather than through codification *per se* (UNESCO 1997: articles 20 and 22). In her paper published soon after the adoption of the declaration, Lenoir (1998–9: 546 and 548) stated that its primary purpose is to enable states to enact legislation. Yet she went on,

> Their [states] commitment is, above all, political and moral. It is also motivated by the advantage that states and the scientific community saw in introducing stability into a field which is strongly affected by the vagaries of the public response to new discoveries. States saw a need to establish points of reference which could serve as guidelines for researchers, practitioners, and policy-makers.
>
> (Lenoir 1998–9: 553)

In the IDHGD (2003) and the UDBHR (2005) the legislative push is stronger: states are to 'take all appropriate measures, whether of a legislative, administrative or other character', to give effect to the declarations' principles (UNESCO 2003b: article 23; UNESCO 2005s: article 22). This stipulation is reinforced in the UDBHR, one of its stated aims being to provide a universal framework to guide states in formulating legislation, policies or other instruments on bioethics (article 2(a)).

In several of its reports concerning the declarations, UNESCO refers to the practice within the UN of first adopting a declaration and then following up with a binding instrument at a later date (as was the case with the Universal Declaration of Human Rights and the subsequent covenants on civil, political, social, economic and cultural rights). Lenoir (1998–9: 549–50) noted that the UDHGHR (1997) was intended as a precursor to a convention, although there was 'no guarantee' this evolution would happen. Federico Mayor, former Director-General of UNESCO, wrote in the preface to UNESCO's 1999 book on the history of the UDHGHR, 'Eventually, UNESCO should perhaps, on the basis of a searching evaluation of the measures taken and the prevailing situation, take the initiative once again so as to entrench the principles enshrined in the Declaration more firmly in law' (UNESCO 1999a: III). Mayor's use of the word 'eventually' is telling. A member of the Bioethics Programme, when interviewed in 2005, thought it might be possible to combine the 1997 and 2003 genetics declarations to form a convention in the future, to include a prohibition on cloning, but said that this would depend on the global political climate; for conventions, they observed, 'the politics is much heavier' (interview with F_01). Another member of the Programme, interviewed in 2011, did not believe this development would unfold, as it would entail several difficulties and disagreements (interview with F2_03).

Implementation and enforcement

In his book on environmental politics, *The Global Commons*, Vogler (1995: 152) states, 'The question of effectiveness should be at the heart of any discussion of regimes.' Andreas Hasenclever *et al*. (1996: 178) explain how this effectiveness is measured: 'First, a regime is effective to the extent that its members abide by its norms and rules. Second, a regime is effective to the extent that it achieves the objectives or purposes for which it was intended.' The real key to whether UNESCO's declarations can be successful as instruments of governance lies in the extent to which they are taken up by states and other actors; having formalized norms is only a first step. Koïchiro Matsuura made this point in his speech as Director-General of UNESCO at the first meeting of the IBC after the General Conference had approved the UDBHR in 2005. He 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). This section examines UNESCO's attempts to ensure its member states take up the bioethics and genetics declarations. 'Harder than soft law' they may be, but UNESCO's implementation activities tend to take a management approach, aimed at encouragement and facilitation.

UNESCO's capacity-building activities

Dissemination

One of UNESCO's foremost activities in promoting the declarations is dissemination, in order that they reach as wide an audience as possible. Within two years of its adoption, the UDHGHR (1997) had been distributed to IGOs and other international institutions, UNESCO National Commissions, Permanent Delegations and field offices, ethics committees, universities, NGOs, the media and various specialists, through brochures (120,000 copies), posters, journals and conferences (UNESCO 1998b: 29 and 53–4; UNESCO 1999b: 2–3). By October 2001, half a million copies of the declaration had been published, in 20 languages, more than 80 articles on the declaration had been written worldwide and over 40 television and radio interviews had been given. The International Society of Bioethics awarded its 2002 Prize to UNESCO, for its work on the UDHGHR and in bioethics in general (UNESCO 2001a: 6–7). The second declaration, the IDHGD (2003), is perhaps less well-known. Almost two years after its adoption, many countries were 'not even aware that there is such a declaration', said a member of the Bioethics Programme in September 2005. Portugal, Israel and Turkey were exceptions, where IBC members had liaised with their National Commissions to provide local translations (interview with F_01).

Since 2005 the Bioethics Programme has focused particularly on dissemination of the UDBHR. By 2007 the declaration had been translated into 24 languages (none African) on top of UNESCO's six official ones (Arabic, Chinese, English, French, Russian and Spanish), in cooperation with National Commissions (UNESCO 2007e). At the joint IBC–IGBC meeting in October 2010, Evans stressed that dissemination was UNESCO's most important activity. As the declarations and other publications are costly to produce (in terms of airfares, for example), it is imperative that they do not just gather dust, but rather take root in the lives of people around the world. The declarations must actually make a difference to how states view their citizens with regard to science and technology, he said. They should also have an impact on institutions, as they are not addressed exclusively to states. But, at a world conference of universities he had recently attended, only one of 1,000 delegates had heard of the UDBHR (personal observations).

At the same meeting, IBC and IGBC members suggested several ways to raise the profile of the declarations. Some said that members of both committees had a responsibility in this regard and should try to ensure that local and regional UNESCO offices publicize the declarations to schools, universities, the general public and, in the case of IGBC members, governments. Two IBC members pointed out that, as independent experts, they have no official mandate to work under UNESCO's umbrella, leaving a question mark over their role that hinders such efforts. Echoing Held's observations about chains of delegation, the need for better communications between (a) the Bioethics Programme secretariat and National Commissions, (b) the secretariat and national bioethics committees (NBCs) and (c) National Commissions and ethics bodies within their countries was also highlighted. This would give national level institutions a bigger role in distributing the declarations and, crucially, adapting information to the local context. As one Latin American IBC member explained, documents may be on the internet, but access is not always easy or part of a society's culture (personal observations, IBC–IGBC meeting, October 2010).

In answer to the comments about NBCs, the Bioethics Programme chief responded that some are still very young and thus need to be built up further before they can fully engage with the public, although awareness-raising events always form part of their training (see below). An African IBC member sounded another note of caution in this regard. NBCs can function as hubs for exchanges of experiences and capacity building, they said, but goodwill is insufficient: networking requires resources. Sometimes NBCs are ignored by authorities or exist on paper but have no premises, so UNESCO also needs to work more with decision-makers (personal observations, IBC–IGBC meeting, October 2010).

The Bioethics Programme secretariat, despite having a small staff, makes a plethora of information on its activities freely available on the UNESCO website. But when it comes to actively distributing materials to member states, there can be problems. Members of the Programme interviewed in 2005 (F_01) and 2011 (F2_03) explained that they cannot be sure whether information is always getting to the most appropriate government departments, because UNESCO deals primarily with ministries of education (where National Commissions often sit), even though these might not be the most natural ports of call with regard to bioethics and genetics. This can also be the reason behind communication problems between National Commissions and existing NBCs, several of which have been developed through ministries of science and technology or health (interview with F2_03). This issue was discussed informally by attendees at the IBC's eighteenth session in May–June 2011. It would be natural for a health ministry to hold an event on bioethics, they said, but if organized through a National Commission the official host would most likely be the ministry of education. Persuading an education ministry of the importance of bioethics might not be easy, but it would be diplomatically awkward for a ministry of health to take the lead.

Several committee members also raised the issue of language at the 2010 joint IBC–IGBC meeting, saying that more translations of UNESCO documents are needed if they are to reach the widest audience possible. One IBC member from an Arab state used the ironic example of a 2008 report on bioethics in Arab countries being available in French and English but not Arabic. The Kenyan IGBC representative appealed for the UDBHR (2005) to be translated into Kiswahili, which is widely spoken in sub-Saharan Africa and one of the official languages of the African Union. Members also felt that more could be done to engage the public through the mass media (although another Arab state IBC member warned that messages have to put together carefully, since some people in developing countries are not entirely trustful of international organizations, seeing them as a new form of colonialism). The IGBC Chair wanted to see bioethics on YouTube and Facebook, to reach young people. The following year, at the IGBC's September meeting, he asked how UNESCO could particularly target the main stakeholders. The head of the Bioethics Programme replied that in 2012–13 they would be focusing on the media, parliamentarians and judges, as well as civil society. The Programme is trying to reach out to both decision-makers and the general public in new ways, such as television and the internet, in collaboration with UNESCO's information and communications and external relations sectors (personal observations, IBC–IGBC meeting, October 2010 and IGBC meeting, September 2011).

As well as the declarations themselves, UNESCO disseminates reports by the IBC, which give guidance on particular articles. Lenoir (1998–9: 575) has described this role of the IBC, mandated in articles 24 of the UDHGHR (1997) and 25 of the UDBHR (2005), as unique, because it is an independent body. Héctor Gros Espiel made a similar point in his 1998 report to the IBC on the implementation of the 1997 declaration:

> The Universal Declaration on the Human Genome and Human Rights is innovative in that it entrusts the IBC with a role in the monitoring of its implementation. It is, indeed, the first document of a declarative nature that stipulates the existence of a system of follow-up and implementation.

(UNESCO 1998b: 28)

Since member states sometimes arrive at a formulation for an article that is 'open to multiple interpretations', one of the IBC's duties is to work out how to go from 'the very general level of the principle to much more practical guidelines, how to do it in different countries and cultures' (interview with F_01). The aim is to produce usable, practicable documents that will guide states, institutions and individuals in operationalizing the declarations, rather than academic treatises (comments by Donald Evans, IGBC meeting, September 2011 [personal observation]). To this end, a new series of reports was launched in 2008, on the principles of the UDBHR (2005). The report on informed consent provides explanations of the relevant principles in the UDBHR and gives examples of how they might be applied in certain contexts (UNESCO 2008g), while the report on social responsibility and health outlines 'possible concrete strategies and courses of action' for translating the principles of article 14 into specific policies (UNESCO 2010h: 5).

In the biennium 2008–9, the IBC began to explore issues around article 8 of the UDBHR, on human vulnerability and personal integrity. It continued this work in 2010–11. The topic garnered considerable discussion and disagreement at meetings, demonstrating some of the difficulties of operating by consensus. The final report contains no definition:

> Attempts to define vulnerability in general risk drawing the concept too widely or too narrowly, thereby triggering disputes rather than resolving them. In most cases, however, it is relatively easy to recognise vulnerability when it arises: something fundamental is indeed at stake.

(UNESCO 2011g: 2)

This was because neither the assigned working group, nor the IBC more broadly, could agree on one (echoing the debate over the definition of 'bioethics' during the UDBHR negotiations). At the IBC and IBC–IGBC meetings in October 2010, some IBC members were concerned that it would look weak to write a report but not be able to say what it was about, but others applauded the working group's decision not to get bogged down with a complex philosophical discussion, which might have alienated prospective readers. IGBC members were similarly split (personal observations). Nevertheless, the final report was welcomed by states at the IGBC meeting in September 2011, with the representative of the Dominican Republic commenting that it would be an extremely useful tool in developing countries lacking services and legislation, where people have been exploited in clinical trials and stem cell research (personal observations).

The IBC also publishes reports on contemporary bioethical issues, such as gene therapy (1994), embryonic stem cells (2001) and pre-implantation diagnosis (2003). Alongside its work on cloning and vulnerability, in 2010–11 it decided to examine the ethical implications of traditional medicine. 'Traditional medicine' has proved as difficult to define as vulnerability, in terms of the scope of the report, as what is 'alternative' or 'complementary' in one country may be 'mainstream' in another. The use of the contrastive term 'Western medicine' was objected to at meetings by some IBC and IGBC members, as well as invited speakers, as being indicative of the arrogance of the developed world rather than an accurate description of the provenance and use of allopathic medicine ('modern medicine' was preferred). Despite these obstacles, the topic was considered important enough to warrant another year's work. At the IGBC's September 2011 meeting, for example, the Ghanaian representative, backed up by Kenya's, described it as a 'hot metal' issue, but pleaded that it should stay on the agenda, particularly as it ties in with UNESCO's two global priorities, 'Africa' and 'gender equality' (personal observations).

The September 2011 IGBC session also debated other possible topics for the biennium 2012–13. Suggestions at the IBC meeting earlier in the year had included biobanking, regenerative medicine, neuroscience, benefit sharing, genetic testing and organ transplantation. Of these, biobanking proved to be the most popular with IGBC members (personal observations). This has become an increasingly important issue for developing countries, with several NBCs requesting that it be addressed in their training (see below; interview with F2_03). As one African IBC member explained at the May–June 2011 meeting, scientists based in the global South are tired of being treated as little more than a 'post office box' for biological samples (personal observation). There was a push from UNESCO's Director-General, via Pilar Álvarez-Laso, the Assistant Director-General for Social and Human Sciences, for the IBC to concentrate on articles in the UDBHR, namely those on non-discrimination and non-stigmatization (article 11) and benefit sharing (article 15) (personal observations, IBC meeting, May–June 2011 and IGBC meeting, September 2011). The Work Programme for 2012–13 duly uses article 11 as a catch-all:

> The Committee will focus on the principle of non-discrimination and nonstigmatization as set forth in article 11 of the Declaration, by using this principle as a "conceptual umbrella" under which the new risks and responsibilities arising from progress in different sensitive areas of medicine, life sciences and associated technology (including but not limited to biobanks; access to drug [sic]; organs, tissues and cells transplantation and trafficking; neuroscience; HIV/AIDS, and nanotechnologies) could be transversally analyzed.
>
> (UNESCO 2012m)

A third information source provided by UNESCO is the Global Ethics Observatory (GEObs), launched in December 2005 at the IBC's twelfth session in Japan (UNESCO 2006c: 9). GEObs can be accessed via UNESCO's website (www.unesco.org/shs/ethics/geobs) and is available in all of the organization's official languages. Hosting six web-based databases – comprising ethics experts, institutions (including NBCs), teaching programmes, legislation or guidelines, codes of conduct and ethics resources – GEObs covers the ethics of science and technology and the environment as well as bioethics. UNESCO sees GEObs as a 'crucial platform' for supporting member states in their ethics activities, providing models for legislation or policy (UNESCO 2006c: 9; UNESCO: 2007c; Ang *et al*. 2008: 740). It is also intended to have a broader reach (ten Have and Ang 2007: 16; UNESCO 2010c: 15). People designing new ethics courses might use the education section to seek the advice of those with previous experience, for example. 'It's a kind of facilitator of contacts among different people', said a Bioethics Programme representative a few months before its official launch. In particular, they hoped that GEObs would enable people in developing countries to access resources such as reports and guidelines from other regions quickly, to which they did not previously have access (interview with F_01).

Tee Wee Ang *et al*. (2008: 740) write of GEObs, 'it could also inform the discourse and work of the scientific community, civil society and the private sector, with the potential for cross-fertilisation of ideas on bioethics regulations across countries and regions'. Thus it has the capacity to become a Slaughter-like information network, but to fulfil this potential people must know about it and consider it worthwhile (hence, perhaps, ten Have's several publications on the initiative in prominent ethics journals). The efforts are starting to bear fruit. An evaluation of UNESCO's ethics activities in 2008–9 by its Internal Oversight Office (IOS) surveyed 375 GEObs users, 75 per cent of whom were very satisfied or satisfied with the resource. The evaluation also noted that member states were more willing to supply information to UNESCO than to databases compiled by NGOs or universities, although there were still information gaps (UNESCO 2010c: 5–6). The head of the Bioethics Programme reported at the IGBC meeting in September 2011 that GEObs is used increasingly in Asia and Latin America and has now been linked with the European project ETHICSWEB, to boost visibility (personal observation).

Usage increased steadily year on year up to 2012, which saw a slight drop (see Table 5.1). The amount of data in GEObs has also multiplied impressively over the last five years, despite constraints on human and financial resources (the IOS evaluation found that 'the amount of data that needs processing and inputting into the GEObs databases exceeds the resources that have been assigned to the task' [UNESCO 2010c: 2]). The data are gathered and inputted by the Bioethics Programme secretariat, which ensures quality control. As Table 5.2 shows, the legislation and resources databases continue to grow significantly, with the former gaining a lot of users (interview with F2_03). Specific sections of legal documents are cross-referenced with articles in UNESCO's 2003 and 2005 declarations, for policy-makers to draw upon should they wish to codify the declarations within their own domestic law (Ang *et al*. 2008: 740).

Capacity-building programmes

Alongside information dissemination, UNESCO has more active programmes aimed at facilitating uptake of the three declarations. Under the auspices of the Bioethics Programme, it supports the establishment of NBCs where they do not already exist. When the UDBHR was adopted in 2005, only about a quarter of member states had a NBC (Wolinsky 2006: 355). UNESCO (2010b: 1) states, 'Providing technical assistance in the process of establishment of National Bioethics Committees (NBCs), as well as the subsequent capacity-building for ensuring their viability and sustainability, are essential elements of UNESCO's *capacity-building action* in the field of bioethics.' These committees can provide a clear point of contact for the Bioethics Programme secretariat and are seen as intermediary steps towards the long-term goal of state level legislation (ibid; interview with F_01). Without such bodies of experts to advise policymakers, say ten Have *et al*. (2011: 380), it is unlikely that states will make efforts to effect the declarations. According to a report from 2001, UNESCO was then helping seven countries to set up national committees, including South Africa (although this was not mentioned by a single participant during fieldwork). The other countries were Algeria, Côte d'Ivoire, Jamaica, Morocco, Nepal and Senegal (UNESCO 2001a: 6). More recently, this work has continued under an initiative entitled Assisting Bioethics Committees (ABC). It has focused mainly on Africa, where there has until recently been a lack of ethics infrastructure (sub-Saharan Africa is the only region not mentioned in a 2005 report to the German National Ethics Council on NBCs, for example) (Fuchs 2005: 7).

In 2008–9, ABC activities were held in 14 African countries (out of 30 in total), costing USD 170,000 (53 per cent of the total ABC budget) (UNESCO 2010c: 25). As well as this direct support, the Bioethics Programme distributes guidebooks on how to set up, run and educate bioethics committees, with further volumes on public policies and public debate forthcoming. Like GEObs, the guidebooks are available in all six official languages of UNESCO (UNESCO 2011m). The IOS 2008–9 evaluation surveyed the chairs of nine newly established NBCs. Of the five who responded, four had used the guide *Establishing Bioethics Committees*, three had used *Bioethics Committees at Work* and two had used *Educating Bioethics Committees* and had found them useful. The evaluation spins these numbers positively, although it might have been expected that all the committees would have used all the guides, given that they had been established under the ABC programme (UNESCO 2010c: 5 and 18–19).

The ABC initiative derives from article 19 of the UDBHR (2005), which commits states to instituting ethics committees at different levels. As medical and research ethics committees are already in place or are being set up by states themselves or other organizations, UNESCO decided to focus on helping states to establish NBCs (Bioethics Programme progress report, IBC meeting, May–June 2011). Under UNESCO's definition, NBCs' mandates go beyond ethical review, to include policy promotion and dialogue. Echoing IBC members at the 2010 meetings, ten Have *et al*. (2011: 380) outline this expanded role thus: 'As a forum for intercultural exchange, a national (bio)ethics committee can provide a platform to engage citizens and society as a whole in dialogue about (bio)ethical issues on a regular basis.' The ABC programme has a particular methodology for building the capacity of NBCs in this and other respects, devised by a committee of experts in 2006 (ibid: 383). Yet there is also considerable flexibility, to ensure that training is tailored to the needs of the country (UNESCO 2010b: 2; Bioethics Programme progress report, IBC meeting, May–June 2011).

The process is usually instigated by a member state, which will request assistance from UNESCO. The first step is a 'diagnosis' of what ethics capacity exists in the country already. Next comes an exploratory mission, to ascertain what the 'optimum modalities' of the NBC will be and the practicalities of setting it up (UNESCO 2010b: 3). The programme conducted 14 such missions in 2007–9, all in Africa and Latin America (ten Have *et al*. 2011: 383–4). The launch of the committee is usually combined with an awareness-raising event and a formal signing of a Memorandum of Understanding (MoU) with UNESCO, concerning the three-year period of technical support to follow (UNESCO 2010b: 3). Ideally, a government minister (of health, education or science) should conduct the inauguration, to signify its significance (UNESCO no date b). Of the 14 countries that hosted exploratory missions, nine had established NBCs and six had signed MoUs by November 2011, with the rest still considering their options. Some countries with already established NBCs, such as Côte d'Ivoire and Kenya, also signed MoUs, to avail themselves of the ABC training programme (ten Have *et al*. 2011: 384; UNESCO 2011b).

The technical support aims to ensure sustainability of the committees. A series of intensive two or three day sessions (one per year) largely follow the pattern of the guidebooks, training the nascent NBCs in, *inter alia*, working methods, building up documentation, establishing a secretariat, principles and practices, public engagement and legislation, as well as issues considered particularly relevant to the national context (UNESCO 2010f). Members of the Bioethics Programme secretariat lead the sessions, with support from teams of experts from countries with long-established NBCs (ten Have 2006: 346). This transferral of experience and expertise is considered a very valuable aspect of the ABC programme by UNESCO (UNESCO 2010b: 2). Teams have thus far been English, French or Spanish speaking, but at the IGBC meeting in September 2011 the delegate from Portugal said that their country would be willing to participate in the programme to develop NBCs in lusophone African countries. As Cape Verde was, at the time, still considering establishing a committee after the exploratory mission of 2008, this was a timely offer (ten Have *et al*. 2011: 384; personal observation, IGBC meeting, September 2011). Beyond the scheduled trainings, the ABC methodology includes six-week internships for NBC secretariats and longer-term partnerships with experienced committees. These partnerships are a means to promote North–South and, at some stage, South–South collaboration. The Swiss and Belgian NBCs are working with their Togolese and Guinean counterparts respectively, for example (ten Have *et al*. 2011: 387; Bioethics Programme progress report, IGBC meeting, September 2011).

Although the technical support stage is aimed at sustainability, there are doubts about the viability of NBCs in resource-poor countries in the long term. ten Have *et al*. (2011: 387) note, 'Experiences in the ABC project show that sustainability is a serious challenge.' At the IBC–IGBC meeting in October 2010, an IBC member expressed their concerns about the make-up of committees, asking whether they are genuinely pluralist and independent (personal observation). The IOS 2008–9 evaluation also raised these issues, linking independence with financial sustainability (UNESCO 2010c: 19–20). Political considerations may also have an impact. Whether a NBC gets up and running even is dependent on the will of the government. UNESCO can only explain why a committee is needed and offer expertise: 'The actual decision is up to them' (ten Have *et al*. 2011: 384). Internal power struggles can delay procedures. ten Have *et al*. (ibid) give the example of Mauritius, where there was a dispute about whether the process should be led by the university or the Academy of Sciences. This was eventually resolved at parliamentary level, through a bill to create a NBC.

Ongoing governmental backing is crucial. The IOS 2008–9 evaluation warned that, while the ABC programme was instrumental in establishing NBCs, the committees would only survive if they enjoyed the commitment of national stakeholders (UNESCO 2010c: 2). The limited resources of the programme itself are another challenge, as more states look to establish NBCs. One option being explored is online modules (to be delivered through e-learning, teleconferencing and webcasting, to the journalists, parliamentarians and judges who are to be the focus of efforts in the 2012–13 biennium). A study commissioned from The Open University in the UK found that this would enable a broader, more efficient reach, but that the face-to-face nature of the existing methodology plays a key role in its success (Bioethics Programme progress reports, IBC meeting, May–June 2011 and IGBC meeting, September 2011; UNESCO 2011b). Furthermore, as ten Have *et al*. (2011: 387) point out, the internet is not always easily accessible in developing countries. When interviewed in September 2011, a member of the Bioethics Programme secretariat (F2_03) wondered what the results of a future evaluation would reveal about the quality of the committees that have been set up, as some may not be able to conduct their work due to funding constraints. Overall, however, they were positive about the ABC programme, seeing the partnerships with peer bodies as a means of supporting and strengthening the newer committees.

UNESCO's second capacity-building activity is the Ethics Education Programme (EEP), which helps states to fulfil their obligations under the various articles in the three declarations on ethics education and training (UDHGHR, articles 20, 21 and 23; IDHGD, articles 6(a), 23(a) and 24; and UDBHR, articles 18(2/3), 19(d), 22(1) and 23(1)). UNESCO launched the EEP in 2004, in the wake of a report by the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST, a UNESCO body) from the previous year on the teaching of ethics. The report recommended that, *inter alia*, UNESCO develop ethics courses, support ethics teaching in developing countries, establish fellowships and chairs in ethics and appoint a board of ethics experts to focus specifically on ethics teaching (ten Have 2008: 57–8). UNESCO hopes the EEP (together with the education section of GEObs) will ensure that 'future generations of scientists and professionals' learn the principles in the declarations, whether or not states develop legislation (interview with F_01).

Whereas UNESCO's reputation as primarily an educational institution may have hindered its efforts to liaise with ministries of health or science and technology in some countries, it has been a boon in relation to the EEP. ten Have (2008: 59) writes, 'In many countries, even if there is the motivation to introduce ethics teaching, problems will be encountered in the implementation, because of a lack of adequate resources. … Unesco, with its experience in education, is in a position to remedy this situation.' Similarly, Nouzha Guessous-Idrissi (2010: 98), a member of the IBC from 2000 to 2007 and of UNESCO's Advisory Expert Committee for the Teaching of Ethics (see below), has commented that it is 'absolutely logical' for UNESCO to encourage its member states to promote ethics education and training, as education is 'the foundation on which it is built'. At the IBC–IGBC meeting in October 2010, two IBC members called for National Commissions to use their connections with education ministries to suggest curricula for primary and secondary schools on the UDBHR, to aid dissemination (personal observation).

There are four main aspects to the EEP, all of which closely align with the COMEST recommendations. Alongside the database of teaching programmes in GEObs, UNESCO has written a Core Curriculum in bioethics, appointed Chairs in Bioethics and developed a training course for ethics teachers. The curriculum is based on the UDBHR (2005). Thus it has a global reach, given that the UDBHR was agreed by international consensus. Nevertheless, it is designed to be sufficiently flexible that it can be moulded to suit the requirements of different regions. Intended primarily for use in medical and science schools, it can also be deployed much more widely (Bioethics Programme progress reports, IBC–IGBC meeting, October 2010 and IBC meeting, May–June 2011). The curriculum was developed by the *ad hoc* Advisory Expert Committee for the Teaching of Ethics, appointed to assist the Bioethics Programme secretariat with the EEP. The committee consisted of four IBC members and representatives of the Third World Academy of Sciences, the WMA and COMEST (UNESCO 2008b: i). (Ironically, the member from WMA was its former Director of Ethics, John Williams, who had been critical of the UDBHR during its drafting, as we saw in the previous chapter [Williams 2005].) After several committee meetings and a consultation with 24 further experts, mostly from developing countries, the curriculum was finalized and published in early 2008 (UNESCO no date c). Study materials and casebooks on *Human Dignity and Human Rights* and *Benefit and Harm* followed in 2011 (UNESCO no date f).

Details on the instigation of the Core Curriculum in universities are somewhat hazy. There were plans to pilot it in Kenya, Israel and the Philippines in 2008, but no documentary record of the outcome appears to exist (UNESCO 2007e). At the IBC–IGBC meeting in October 2010, the chief of the Bioethics Programme reported that several universities were willing to act as potential test sites. MoUs had been signed with five institutions in Asia and the Pacific, four in Europe and North America and one in Latin America and the Caribbean, with several others from these regions showing an interest, as well as three in Africa and two in the Arab world. Moreover, the curriculum had already been largely adopted by the Standing Committee of European Doctors, received the backing of the British Medical Association and the UK’s General Medical Council and contributed to the Master in Bioethics of Saudi Arabia’s National Guard Health Affairs. There would be a probable global deployment in 2011. In September the following year, however, in the update to the IGBC on the Bioethics Programme’s activities, the test sites were not mentioned, although it was reported that the study materials had been requested widely. The global deployment appears to have been delayed a year, as the Advisory Committee was to meet again in November 2011, to assess feedback from the pilot phase and prepare for a global rollout (no information on this meeting is available) (UNESCO 2010f; Bioethics Programme progress reports, IBC–IGBC meeting, October 2010 and IGBC meeting, September 2011). The course materials are freely available on the UNESCO website.

One handicap to the rollout of the Core Curriculum may be the lack of faculty qualified to teach bioethics. This is something the EEP’s Ethics Teachers’ Training Course (ETTC) – developed in cooperation with the UNESCO Chair in Bioethics of Haifa, Israel – aims to address (ten Have 2008: 59). The ETTC is targeted at early career educators, introducing them to methods and resources for ethics teaching and giving feedback on their technique (UNESCO 2011m). It has proved particularly popular in the former Eastern Europe, where courses have been held in Romania (2006), Slovakia (2007), Belarus (2008), Serbia (2011), Croatia (2010, 2011 and 2012), Lithuania (2012) and Azerbaijan (2012). Courses were also held in Saudi Arabia and Kenya in 2007 and Namibia in 2012 (UNESCO no date d).

The 2008–9 IOS evaluation, which focused on the five courses held up to and including 2008, raised serious doubts about the efficacy and worth of the ETTC programme: ‘The teacher training courses involved a small number of individuals, some of whom are no longer teaching in ethics, which raises the question of whether UNESCO needs to continue with this type of training’ (UNESCO 2010c: 3). Feedback from the participants themselves proved positive. Of the 38 (of 68 in total) who responded to the IOS survey, 86 per cent had found the training useful, 78 per cent used the skills they had acquired once a month or more, 65 per cent were members of regional ethics networks and 59 per cent had taken part in national debates on ethics. Of concern to the IOS was the rate of attrition, with only 79 per cent still teaching ethics, despite the short space of time since they had been on the course (ibid: 5, 22 and 24).

The UNESCO Chairs in Bioethics also received mixed praise in the IOS evaluation. There are 12 chairs in all, in Israel, Slovakia, Argentina, Peru, Brazil, Mexico, Kenya, Côte d’Ivoire, the US, Spain, Portugal and Italy (UNESCO 2011m). The evaluation found that the contribution of the chairs (then nine in number, with two appointed only in 2009) had been ‘uneven’, with those from Spain, Israel, Kenya and Brazil proving more active than the others (UNESCO 2010c: 23). The Bioethics Programme is trying to address this by working with both the Chairs in Bioethics and those in related disciplines to bolster bioethics programmes at university level. There was a Symposium of UNESCO Chairs in Bioethics, Peace, Human Rights, Democracy and Tolerance in Italy in March 2011, for example (Bioethics Programme progress reports, IBC meeting, May–June 2011 and IGBC meeting, September 2011). At the IGBC meeting in September 2011, the Kenya representative supported these efforts and lobbied for the chairs to get more involved on the ground, to aid sustainability of programmes. They also hoped to see the sharing of best practice between the chairs (personal observation). The former Kenyan Chair in Bioethics would also like to see networking among chairs, to stimulate cross-fertilization of ideas (interview with K2_01).

In addition to its EEP activities, UNESCO is supporting the International Association for Ethics in Education (IAEE), created in 2011. Although an independent body, the IAEE was founded by ten Have (now at Duquesne University in Pittsburgh in the US, where the IAEE secretariat is based) and aims to provide a global platform for exchanging information and experiences in ethics teaching (broadly framed), so there are close connections with UNESCO in both personnel and mandate (UNESCO no date e; Duquesne University 2012). Thus far, the Association has held its inaugural conference, which was attended by more than 200 delegates from 29 countries, including India, Kenya, the Dominican Republic, Tunisia and Romania. Further conferences are planned for 2014 in Turkey and 2015 in Brazil. Until then, the IAEE will work on creating a website to enable ongoing knowledge exchange, through which users will be able to link to GEObs and the Core Curriculum (UNESCO 2012g). The IAEE mirrors in structure Reinicke's Global Public Policy Networks (see p. 32). As the Association is still young, it is perhaps too early to tell how well it will sit alongside UNESCO's activities, or whether its semi-independence will be a help or hindrance in its becoming respected and valued by the (bio)ethics community.

The final activity of the Bioethics Programme is awareness-raising about ethics among the general public, with a view to ensuring that civil society engages with policy-makers and experts in ethical debate around science and technology. From 2004 to 2007 this was done primarily through the Ethics Around the World conferences, organized by the Division of the Ethics of Science and Technology in conjunction with UNESCO National Commissions and field offices, as well as academic and research institutions. The conferences had the specific purpose of stimulating debate at national and regional levels and thus focused on topics of relevance to the host country. There were 15 in total, with at least one in every region. Conferences and seminars have since been organized on a more *ad hoc* basis and have targeted the ethics community more than civil society generally. Three have taken place at the initiative of the Chairs in Bioethics, in Kenya (2008), Israel (2009) and Brazil (2009) (ten Have 2006: 347; UNESCO 2007e). Another, the Joint Action for Capacity Building in Bioethics (JACOB) between the European Commission and UNESCO (funded by the EU's Seventh Framework Programme), followed the IBC's sixteenth session in Mexico in 2009 (UNESCO 2010e: 9).

There is little independent evaluation of UNESCO's capacity-building endeavours. The large majority of academic papers reviewing its activities have been written by people either currently or previously associated with the Bioethics Programme, as members of the IBC or the secretariat. The 2008–9 IOS evaluation was independent of the Programme, but still fell under the auspices of UNESCO. One of its recommendations was that the Programme should strengthen its monitoring frameworks. Another was that it should consolidate its efforts where it has most impact, to make the most of its limited human and financial resources (UNESCO 2010c: 2–3). In line with Young's estimation of IGO resources, the Bioethics Programme's ambitions for encouraging implementation of the declarations may be curtailed by funding limitations. For the secretariat to engage in more follow-up activities, more money and staff would be needed (interview with F2_03).

During the biennial period 2004–5, out of UNESCO's USD 610 million budget for its regular programme, the amount devoted to 'ethics of science and technology, with emphasis on bioethics' was a shade over USD 3.25 million (just over 0.5 per cent). As the 'principal priority' of the Social and Human Sciences Major Programme, this represented 26 per cent of the amount dedicated to activities (excluding cross-cutting projects), compared to 15.3 per cent in the previous biennium (UNESCO 2004a: 13–14 and 147). For 2006–7 funding for both the Major Programme and the ethics section was slightly reduced, although ethics remained the principal priority and its percentage share rose to 30 per cent (UNESCO 2006a: xiii–xiv and 123–4). The ethics budget more than doubled in 2008–9, to just over USD 7.2 million, representing 2.6 per cent of UNESCO's total budget for programme activities (UNESCO 2008a: xi and 270). 2010–11 saw another slight increase, to just under USD 7.4 million, followed by a drop in 2012–13 to just over USD 6.5 million (1 per cent of the total budget of USD 653 million) (UNESCO 2010a: 270; UNESCO 2012a: 324 and 340). To put these figures into context, in a 2004 document seeking to attract funding partnerships for various projects, the foundation and running costs of GEObs over three years were projected at nearly USD 3.4 million (UNESCO 2004m: 53).

Duplication of activities

Chapter 3 described how, in an *ad hoc* international system, the mandates and programmes of IGOs have a tendency to overlap. This tendency has been mitigated to some extent in bioethics through the formation of the United Nations Inter-Agency Committee on Bioethics. The committee was initiated by UNESCO, expressly to avoid duplication and promote collaboration and information exchange among its membership. According to then Director-General Koïchiro Matsuura, this action confirmed the organization's role as a 'catalyst for international cooperation' in the field of bioethics (UNESCO 2005i: 39). The Committee is made up of mainly UN agencies, but also other relevant regional and international IGOs, at UNESCO's suggestion (interviews with F_01 and F2_03; UNESCO 2003i: 9–10). UNESCO provides the permanent secretariat, although members take turns to host meetings. The UN members are the Office of the High Commissioner for Human Rights, the International Labour Organization, the Food and Agriculture Organization, the World Intellectual Property Organization, the United Nations University and WHO; the non-UN associate members are the European Commission, the Council of Europe, the Organization for Economic Cooperation and Development, the African Union, the Arab League Educational Cultural and Scientific Organization, the International Centre for Genetic Engineering and Biotechnology and the World Trade Organization (UNESCO 2011m; UNESCO no date a). Henriette Abbing (1998: 155) recommended this kind of coordination in an article on the UDHGHR (1997) and similar texts:

> From a point of view of effectiveness, efficiency and transparency it would be more fruitful if international discussions could be centered around a particular subject, rather than being framed according to the statutory mandate of an international organization. Bringing together the various international organizations involved to discuss on equal footing a topical issue avoids a shattering of the debate, and guarantees an integrated approach of all aspects involved through the input of the particular focus of each single organization involved.

The first task of the Inter-Agency Committee was to contribute to the drafting of the UDBHR (2005). Since then it has met periodically to tackle issues of common interest. Although the ethics of genetics has taken something of a ‘backseat’ compared with the UDBHR within the Bioethics Programme’s capacity-building activities, this is not the case at inter-agency level. In 2008 the UN’s Economic and Social Council (ECOSOC) requested that UNESCO investigate the possibility of an inter-agency coordination mechanism on genetic privacy and non-discrimination (ECOSOC Decision 2008/233). As per ECOSOC instructions, UNESCO consulted with UN agencies and member states, as well as other relevant international organizations and the Inter-Agency Committee. Via questionnaires (which, like those on the draft UDBHR, remitted low response rates), it found that, in several cases, both states and IGOs had legislation and/or programmes in place to protect genetic data. As during the cloning debate, some states pressed for international initiatives to help build national capacities, on genetic privacy and non-discrimination (ECOSOC 2011: 4–8; Bioethics Programme progress report, IGBC meeting, September 2011).

In 2010, ECOSOC requested that UNESCO defer its report for another year, to enable further consultation with member states and analysis by the Inter-Agency Committee (ECOSOC Decision 2010/259). At its tenth meeting, in May 2011, the committee discussed UNESCO’s findings and heard from a variety of experts, who suggested that genetic data should not be treated in isolation, but as part of a broader concern with privacy and non-discrimination in health settings more generally. Both UNESCO and the committee concluded that there is a call for information exchange and collaboration in this area, but that a specific coordinating mechanism is not needed, as the Inter-Agency Committee is well placed to fulfil this mandate (ECOSOC 2011: 9–10). At the July 2012 ECOSOC meeting, in line with UNESCO’s recommendations, the Council passed a resolution inviting the Inter-Agency Committee to continue to consider genetic privacy and nondiscrimination and to promote international cooperation in this area, with the issue to be removed from the Council’s agenda (ECOSOC 2012). A remarkably similar outcome, then, to the culmination of UNESCO’s four years of work on the governance of human cloning.

The 2008–9 IOS evaluation of UNESCO’s ethics activities found that UNESCO was the ‘lead agency’ internationally on bioethics, having established ‘comparative advantages’ in the field (UNESCO 2010c: 2). In reality, there is as much cooperation as there is competition between organizations. UNESCO has worked with its interagency partners and others on several initiatives. On the back of the JACOB conference in Mexico in 2009, the European Commission supported the publication of UNESCO’s *NBCs in Action* in 2010 (UNESCO 2010e: 9; UNESCO 2011m). In 2010–11 UNESCO contributed to a WMA expert conference on the ethics of placebos, a CIOMS-hosted panel on how to integrate research and treatment and (alongside WMA and CIOMS) a meeting of the US Presidential Commission for the Study of Bioethical Issues, on human subjects protection (Bioethics Programme progress report, IGBC meeting, September 2011; PCSBI 2011).

Perhaps the UN agency with which UNESCO’s bioethics and genetics activities might be seen to overlap the most is the World Health Organization. The WHO’s 2002 report *Genomics and World Health*, published after the adoption of UNESCO’s UDHGHR in 1997 and during negotiations on the IDHGD of 2003, described the WHO as ‘in a position to adopt a crucial leadership role in bioethics’. This would enable it to ‘exercise its normative function for setting standards and guidelines and harmonization of procedures’, partly through helping member states to regulate genomics (WHO 2002: 8 and 10–11). The WHO has indeed been active in bioethics, through its Ethics and Health Initiative, launched in October 2002. It produced the *Research Ethics Committees: basic concepts for capacity-building* manual in 2009 and *Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants* in 2011. It also hosts the Opinions submitted by National Ethics Committees (ONEC) online database, which contains details of both committees and their opinions (available at http://apps.who.int/ethics/nationalcommittees/). As of May 2012, there were 107 committees listed (WHO 2012b).

ONEC was developed after the eighth Global Summit of National Bioethics Advisory Bodies in 2010. The Ethics and Health team provides the permanent secretariat to the Summit, which meets biennially (WHO 2012c). Perhaps ironically, considering the nascent IAEE, ten Have *et al*. (2011: 387) have questioned the usefulness of such international gatherings, claiming that they do little to build NBC operational capacity or stimulate knowledge exchange between meetings. The WHO has also recently established a Global Network of WHO Collaborating Centres for Bioethics. There are six centres so far, all in developed countries (the Joint Center for Bioethics in Toronto is one of them), but the WHO is encouraging partnerships between centres in high- and low-income countries (WHO 2012a).

While all these activities appear to duplicate UNESCO's, the two organizations often work in partnership. It is the Ethics and Health Initiative that represents WHO on the Inter-Agency Committee. UNESCO, the WHO and the Council of Europe contributed to meetings on bioethics and research ethics in Cyprus and Lithuania in May 2004 and a regional meeting of NBCs in Cairo in 2007 was a joint WHO–UNESCO initiative (WHO 2005–6: 1–6; ten Have *et al*. 2011: 382). More recently, UNESCO's input into the *Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants* was considered by the WHO to be 'especially valuable' (WHO 2011: viii). This belies the claims of the 2005 *Developing World Bioethics* special issue on the UDBHR that, in promulgating the declaration, UNESCO was encroaching on the mandate of the WHO (see Landman and Schüklenk 2005: iii and Williams 2005: 212). In fact, ten Have responded in a *SciDevNet* article that the contributors were perhaps not *au fait* with how UN agencies work (Shetty 2005). Andorno also directly answered the *Developing World Bioethics* criticisms, claiming that the work of the two organizations can 'perfectly coexist', as UNESCO tends to elaborate general norms, whereas the WHO produces more technically focused guidance (Andorno 2007: 151–2).

Since Andorno made these comments, UNESCO has clearly expanded its remit to include provision of technical support. But the fact that UNESCO has produced guidebooks primarily aimed at NBCs, whereas the WHO's guidance is targeted at institutional RECs, is indicative of what should be a clear-cut division of labour between the two organizations. It is the WHO's work with NBCs, through the Global Summit, that muddies the waters. Another potential clash concerns the specialisms of each agency. At the discussion of future topics for IBC reports at the IGBC meeting in September 2011, a representative of the WHO's Ethics and Health Initiative outlined how several of the suggested areas were already being covered by the WHO or other bodies, namely traditional medicine, biobanks and organ transplantation and trafficking (personal observation). Since these topics, as well as activities with NBCs and RECs, were to be discussed at the Inter-Agency Committee meeting in May 2012, perhaps the overlap issue is being resolved (UNESCO no date e).

In September 2011 the IGBC Chair had encouraged the two agencies to systematically work out their responsibilities, not only to avoid duplication within the UN, but also for the sake of end-users in hard-pressed ethics committees, who find it tiresome to answer similar enquiries from different bodies. Álvarez-Laso, Assistant Director-General for Social and Human Sciences, responded that the division of labour is clear, having been approved by the governing bodies of UNESCO and the WHO (personal observation). In contrast, a member of the Bioethics Programme secretariat felt that there needed to be further clarification on which type of ethics bodies each organization works with, which could only come from a higher level. The matter was becoming urgent, having been raised by both the IGBC and member states more generally (interview with F2_03). If these uncertainties can be addressed, the organizations' programmes will be mutually reinforcing, as per Young's observations on international institutions.

Enforcement

UNESCO pursues its programme of encouragement through capacity-building activities in part because it does not have the power to compel its member states to adopt the declarations. Lenoir's words on the draft UDHGHR (1997) illustrate the limitations: 'The idea of the IBC is to propose a Declaration which could serve as a reference, a pattern or a source of inspiration to the States *willing* to adopt legislation on bioethics' (Lenoir 1996; italics added). A Bioethics Programme member (F_01), interviewed in 2005, lamented that the organization is blamed by some for the lack of implementation of the declarations, when in fact it 'cannot do much more than what the member states allow us to do'. Another member, speaking in 2011, similarly felt that states could do more to keep up with their own commitments. The secretariat can help, but it is states' responsibility to implement the declaration (interview with F2_03). There has been a reluctance among states to even self-report to UNESCO on their bioethics and genetics activities. Allyn Taylor argued in 1999 that the lack of a formal supervisory mechanism for the UDHGHR (1997) was of 'significant concern'. She recommended that selfreporting by states on their implementation of the declaration be combined with fact-finding and review by an independent body, to promote a 'truly constructive dialogue' and predicted that the 'growing sense of urgency' on the need for international cooperation on genetics might serve to 'soften national opposition to substantial organizational supervision under a voluntary auditing process' (Taylor 1999: 480, 513, 527, 531 and 535–6). The negotiations for the UDBHR (2005) would suggest otherwise.

Early in the formulation of the UDHGHR (1997), it was decided that if the declaration was to have a 'real impact' a follow-up mechanism would be needed (that is, a system of implementation review or SIR) (UNESCO 1999a: 38). Implementation guidelines, endorsed by the General Conference in November 1999, thus stipulated that an evaluation should be carried out five years after the adoption of the declaration (UNESCO 2000b: 9–10). The IDHGD (2003) similarly suggests that states should submit reports to the IBC and IGBC on their implementation of the declaration (article 25) and the IBC's early recommendations on what became the UDBHR (2005) were that it should include such a proviso (UNESCO 2003h: 12). Whereas the 2002 evaluation of the UDHGHR duly took place in the form of a questionnaire, the proposals for the two later declarations met with resistance from member states (contrary to the trend identified by Victor *et al*., that states are becoming more favourably disposed to SIRs). At the January 2005 IBC and IGBC meetings (which discussed possible implementation guidelines for the IDHGD as well as the text of the draft UDBHR), several government representatives felt that reporting mechanisms were inappropriate to non-binding instruments, as did those attending the IGE meeting in June 2005. The states most vocal in their opposition to periodic reporting were the US, Canada, Germany and India (personal observations; UNESCO 2004i; UNESCO 2005m: 8).

According to a member of the Bioethics Programme, the reaction of member states to the IBC's initial suggestion that the UDBHR require biennial reports by states was, 'Well, that's out of the question' (interview with F_01). This attitude was picked up on several years later, at the October 2010 IBC–IGBC meeting. An IBC member noted that dissemination seemed to be the main concern, even five years after the UDBHR had been adopted. They attributed this sluggishness to the one-way communications between the secretariat and field offices and harked back to the early drafts of the declaration, which had called for reports from member states. They suggested that, in lieu of an official reporting mechanism, the secretariat should ask states for unofficial reports, which could go on the website as a form of information exchange. The IGBC representative from Romania proposed a special department in UNESCO to disseminate documents and collect information from all member states (personal observations). The issue was raised again at the IGBC meeting in September the following year. The IGBC Chair asked whether it was possible to have some kind of feedback system, to ensure UNESCO's work is of benefit. When the head of the Bioethics Programme replied that systematizing feedback when resources are limited is a big challenge, but that IGBC members could play an important role by providing information on their countries, the Chair put forward the idea of an electronic template (personal observations). The official conclusions of the session include this suggestion:

> [The IGBC] recognizes the significant role Member States can play in assessing the impact of UNESCO's action at regional and national level, and towards this end encourages the Secretariat to offer means to the Member States for providing feedback on a range of bioethics activities within their borders, including the promotion and dissemination of the Declaration, through a standardized and user-friendly template.
>
> (UNESCO 2011c: 2)

This lack of a reporting mechanism for both the IDHGD (2003) and UDBHR (2005) would seem to render them weaker instruments than their predecessor. In reality, however, it makes little difference, because the 2002 evaluation exercise on the UDHGHR (1997), like many SIRs, was something of a failure (despite being deemed an 'essential ingredient' of UNESCO's bioethics work by the then Director-General [UNESCO 2002b: 2]). Around 2,500 questionnaires were sent to states, IGOs, NGOs, national ethics committees, universities and academic institutions, the private sector and prominent individuals. Since only 100 or so questionnaires were returned, with very few from states, the results were of limited significance, as the Assistant Director-General for Social and Human Sciences acknowledged when reporting the results to the IGBC. He appealed to members to consider new evaluation methods that would engage stakeholders (UNESCO 2003i: 8–9). The official report of the evaluation to the General Conference was not so candid, concluding that the survey provided a 'rich variety' of information on the impact of the declaration, which had clearly become 'an authority in bioethics' (UNESCO 2003f: 7).

The Bioethics Programme representative (F_01) interviewed in 2005, agreeing with the Assistant Director-General, felt that the evaluation process was too timeconsuming, given the poor response rate. They described how as a secretariat they were in something of a no-win situation: 'They [member states] don't want to be compelled to report on what they do. At the same time they're always asking us, "How is the declaration impacting the member states?"' They hoped that GEObs would enable the gathering of information on the implementation of the declaration independently of political processes and thus in a way that is non-threatening to member states. The member of the secretariat interviewed in 2011 (F2_03) confirmed that GEObs was working as intended, in terms of data collection. They did not see it as an alternative to self-reporting, however, as the information is collected by the secretariat rather than submitted by governments (interview with F2_03).

Adoption by member states

All three UNESCO declarations require states to take 'all appropriate measures' to instigate their principles at national level. If they are not to 'remain paperwork', as non-binding instruments they must be effected by states (ten Have 2006: 343). Precisely because they are non-binding, however, there is no obligation on states to do so. That declarations can only persuade rather than compel states to modify their laws was reiterated by an official at the Kenyan Ministry of Foreign Affairs. A South African ethicist likewise said that as 'merely declarations' the UNESCO instruments serve to 'remind governments of their responsibility' (interviews with K_30 and SA_27). Lenoir (1998–9: 575) drives home this point in relation to the UDHGHR (1997):

> The implementation of the Human Genome Declaration depends, first and foremost, on the will of states. For instance, it may be hoped that some states will publish the Human Genome Declaration in their official gazettes or journals. It is for states to incorporate the principles of the Human Genome Declaration into their legislation, where appropriate. It is for them to set up ethics committees which can refer to the Human Genome Declaration. Finally, it is chiefly for states to develop curricula on bioethics. The first aim of the text is to encourage the states deprived of any legislation on bioethics (including most developing and Eastern European countries) to legislate in the field in accordance with the principles of the Human Genome Declaration.

The UDHGHR (1997), as the oldest of the three declarations, might be expected to have been enacted to the greatest degree. In this regard, at a Round Table at the 2001 UNESCO General Conference, 53 ministers of science (or their equivalents) made the following statement:

> In conclusion, we, the participating and represented ministers of science: (i) undertake to participate actively in the promotion of the principles set out in the Universal Declaration on the Human Genome and Human Rights and in its implementation, in particular by drawing inspiration from it in the formulation of our legislation or regulations, and by considering possible extensions to the Declaration when it is evaluated in 2002–2003.
>
> (UNESCO 2003a: 12)

Since very few countries responded to the 2002 evaluation, it is difficult to measure whether they have fulfilled this undertaking (the claim of the 2003 IDHGD's preamble notwithstanding, that its predecessor had received 'firm support' internationally and had been adopted by member states within their legislation, regulations or ethical codes [UNESCO 2003b]). The IBC's 2001 paper on solidarity between developed and developing countries reported a paucity of efforts to fulfil articles 17 to 19 of the declaration, on disease research, knowledge sharing and capacity building: 'States rapidly recognized the implications of the new scientific advances, but they have not always been so prompt in undertaking projects of solidarity and international co-operation as set out in the Universal Declaration on the Human Genome and Human Rights' (UNESCO 2001b: 14).

It is worth noting that the UDHGHR (1997) and the IDHGD (2003) do not appear on the agendas of IBC sessions after 2003. From that point, with regard to standard setting at least, all the attention appears to have fallen on the drafting and follow-up of the UDBHR (2005). A member of the Bioethics Programme explained that, although the two earlier declarations are not being very actively promoted, they have not been abandoned. They are always referred to in trainings and so on, but there is less of a focus on them because they cover a more restricted area than the UDBHR. The Programme can accomplish more through the broader bioethics declaration, which can then act as a stepping stone towards more specific legislation on genetics. Some NBCs are indeed working on this, according to their countries' needs (interview with F2_03).

Lack of information from member states is not the only obstacle in assessing how far the declarations are being implemented at national level. Even when states enact legislation, it is difficult to measure how far this is a direct response to the declarations. The IOS 2008–9 evaluation found, 'There is evidence that national legislation (post-

2005) in numerous countries reflects the principles of the UDBHR. There is, however, insufficient evidence to attribute this to the work of UNESCO' (UNESCO 2010c: 1). The member of the Bioethics Programme interviewed in 2005 (F_01) averred that it is whether the declarations are being adhered to that is important, not whether this is being done deliberately or not: 'Even if we don't know if it's *post-* or *propter-* the declarations, it is just what we want, because UNESCO is making the declarations to have more policies in the area of genetics, whether or not it's our initiation of the whole process.'

If it is not the declarations that are inspiring regulatory innovations, it can be questioned whether they are really filling a gap, as UNESCO claims. A review of the legislation and guidelines database of GEObs reveals that, of the 54 domestic laws or guidelines from 19 countries cross-referenced with the IDHGD (2003) by July 2012, 45 had been developed before 2003, but only nine after. Of the 638 instruments from 34 countries (134 from Australia alone) cross-referenced with the UDBHR (2005), only 57 had been developed after 2005 (GEObs, accessed 6 July 2012). Some of the connections drawn are rather tenuous. Kenya's 2008 Water Act is cross-referenced with article 16 of the UDBHR on protecting future generations, for example. While this is a valid acknowledgement of UNESCO's broad understanding of bioethics, it seems very unlikely that the Act will have been inspired by the declaration rather than other international instruments more directly addressing environmental issues. Perhaps tellingly, when states have taken the opportunity at IGBC meetings to report on their ethics activities, they have listed workshops, university programmes, translations, media engagement and NBCs, but not legislation (personal observations, IGBC meetings, October 2010 and September 2011). The IBC meetings held in Kenya (2007) and Azerbaijan (2011) were different. In each case, the day of presentations devoted to informing the committee of activities to implement the declarations in the region (another means of finding out what is happening in states) touched on recent or needed legislative initiatives (UNESCO 2008e; UNESCO 2011p; interview with F2_03).

No documents in GEObs had been cross-referenced with the UDHGHR (1997) by July 2012 but an earlier initiative had conducted a similar exercise. General Conference resolution 29 C/17 (1997) had asked the Director-General to prepare a 'global report on the situation worldwide in the fields relevant to the Declaration, on the basis of information supplied by the Member States and of other demonstrably trustworthy information gathered by whatever methods he may deem appropriate' (UNESCO 1998d: 46). The Director-General duly wrote to all member states requesting information on legislation or regulations on bioethics, adopted or pending, with a particular emphasis on genetics and biotechnology (UNESCO 1998b: 58). The information provided and collected afforded a review of 41 states across all regions (UNESCO 1999b: 4). Arguably, then, this precursor to GEObs was a more fruitful enterprise than the 2002 evaluation.

Some states may be taking up the declarations' principles selectively, or putting their own interpretations on them. Such adaptability could be seen as a weakness or a strength. Shawn Harmon (2005: 37) writes of the UDHGHR (1997), 'By its frequent deference to domestic lawmakers, it fails to provide a universal response that will guard against piecemeal legislation and a "race to the bottom".' Andorno (2002: 962), by contrast, believes that to impose a comprehensive legal framework on countries with differing sociocultural backgrounds would be both impossible and unfair. Echoing Victor *et al*., Christian Byk (1998: 237) sees the UDHGHR's non-binding flexibility in a positive light: 'it facilitates adhesion to the Declaration by those states which have difficulty satisfying the implementation of the principles, but which intend to go further that way'. UNESCO, for its part, endorses national contextualization. In a 2006 paper outlining all UNESCO's bioethics activities, ten Have wrote: 'As principles they are universally adopted, but in practice their application must be tailored in multiple ways to accommodate different types of research and health care, categories of patients and problems, and cultural settings and traditions' (ten Have 2006: 342–3).

The lack of universal norms on cloning

In its June 2010 report, the IBC Working Group on Human Cloning and International Governance gave a list of tenets that it would like to see in a convention or moratorium on human reproductive cloning. These included: rendering reproductive cloning (defined as per the Working Group's revised terminology) a crime, with the practice to be tried before the International Criminal Court and under the domestic law of ratifying states; penalties and denials of funding for offending corporations and institutions; 'trade cross-retaliation' and embargoes on research cooperation against offending states; a trade prohibition on cloned embryos (but not cloned tissues or cells for research); and disputes between states to be heard by the International Court of Justice. The instrument would also outline the ethical and human rights responsibilities of states, corporations and individual researchers (with particular reference to the vulnerability of embryos, foetuses and children) and, in similar fashion to the *UN Declaration on Human Cloning*, juxtapose the cloning issue with immediate challenges such as inequalities of health.

The report gave three reasons why the Working Group considered a robust instrument necessary. First, the norms in existing international instruments (such as the UN declaration and the Council of Europe protocol) are vague and inconsistent. Second, none are enforceable at global level. Third, they may impede beneficial medical research while unintentionally sanctioning unethical practice (UNESCO 2010g: 11–12). The Group's draft final statement of 2011 added, 'the current non-binding international regulations cannot be considered sufficient in addressing the challenges posed by the contemporary scientific developments and to safeguard the interests of the developing countries that still lack specific regulations in this area' (UNESCO 2011d: 3).

If this is the case, UNESCO's inability to meet the need it has identified is problematic, as Maimets, Chair of the Working Group, recognizes. At the IBC and IBC–IGBC meetings in October 2010, he implored the assembled delegates to consider what the two committees will say when (not if) cloning happens, as key global bioethics bodies. The representative of the Russian Federation made a similar point, asking how the IGBC will react when, in the near future, a human clone is created in a jurisdiction without a moratorium (personal observations). Camporesi and Bortolotti (2008: e15) also highlight the urgency of the matter, in the *Journal of Medical Ethics*: 'To conclude, we propose that in the time left before human reproductive cloning is attempted successfully, progress on the ethical debates should be made and good regulatory measures adopted as a result.' The Working Group's 2010 report declared that any international instrument on cloning would best be elaborated by UNESCO:

> As an international organization that has a solid track record in standard-setting and capacity building in bioethics, UNESCO provides the best global platform to initiate the processes towards a moratorium or a prohibition on human reproductive cloning under international law.
>
> (UNESCO 2010g: 6)

The organization has failed to fulfil this self-stated role on two counts. As neither the 2010 report nor the 2011 draft final statement were formally adopted by the IBC, the final official verdict of the Working Group dates back to 2009. This means that all the Group's work in the biennium 2010–11, including the revised terminology, has essentially come to nothing. Furthermore, this work does not appear to have hit the radar of the scientific and ethical communities, as neither the proposed definitions nor the initiative more broadly have been discussed in the relevant journals.[1]

With regard to therapeutic cloning, the Working Group's draft final statement suggested that this should continue to be dealt with at national level, because of countries' different attitudes towards the status of embryos (UNESCO 2011d: 3). This could be seen as a cop-out, as was noted by one member of the IBC at its May–June 2011 meeting, where the statement was presented (personal observation). Isasi and Bartha Knoppers (2006) demonstrated the plethora of national approaches to embryonic and stem cell research in their review of policies in 50 countries. This diversity poses a challenge to international harmonization, but also makes it difficult for transnational research consortia to operate. In its 2008 interim report, the Working Group had sought to address this issue, recommending the development of guidelines at international level for states where human embryonic and stem cell research is legal, based on existing formulations by professional associations (UNESCO 2008h: 5). This idea did not survive in the later reports. The problem was that these plans, combined with a convention or moratorium specifically addressing human reproductive cloning, would have taken UNESCO very close to the initial proposals for the UN instrument, which proved abortive. Mindful of what had happened at the UN only a few years previously, member states chose the safe option, politically speaking. What this means is that the 'black hole' in international legislation on cloning that UNESCO has identified remains to be filled.

Member states of UNESCO have, arguably, shown more interest in the drafting of the three bioethics and genetics declarations than in their implementation, reflecting the compromise attached to non-binding international instruments. Despite UNESCO's considerable efforts to promote the declarations among policy-makers, experts and the general public, direct uptake by member states (as far as this can be measured) has been rather poor. This is partly because the declarations carry no legal obligations for sovereign states. It is also because, in some instances, states already have adequate policies in place. For those states that have not yet established bioethics systems, the declarations may galvanize them into doing so, or at least this is what the UNESCO Bioethics Programme hopes. Indeed, its capacity-building projects have engendered fledgling national bioethics committees and ethics education programmes in several countries, particularly in the global South. Thus it may be that the 'added value' of the declarations lies more in the initiatives they have spawned than in the documents themselves.

Footnotes

1 A search of the following journals was made on 31 May 2012: *Science, Nature, Nature Biotechnology, Nature Genetics, Nature Reviews Genetics, European Journal of Human Genetics, EMBO Reports, Annual Review of Genomics and Genetics, Trends in Biotechnology, British Medical Journal, PLoS Medicine, The Lancet, Journal of Medicine and Philosophy, Bioethics, Developing World Bioethics, Journal of Medical Ethics, Social Science and Medicine, International Journal of Biotechnology, Journal of Law, Medicine and Ethics*.

Tables

Table 5.1 Use of GEObs, 2005 to 2012

Year	**Number of unique users**
2005[a]	165
2006	2,298
2007	2,707
2008	3,323
2009	3,595
2010	3,623
2011	4,029
2012	3,796
Total	23,536

Source: UNESCO (2013).

[a] from launch on 8 December.

Table 5.2 Number of entries in GEObs, 2007 to 2012

		2007	December 2009	June 2012
Database 1:	Experts	851	1,405	1,515
Database 2:	Institutions	200	437	527
Database 3:	Teaching programmes	162	232	2,355
Database 4:	Legislation	58 (4 countries)	468 (22 countries)	738 (34 countries)
Database 5:	Codes of conduct	141	151	151
Database 6:	Ethics resources	N/A	211	416

Sources: UNESCO (2007e; 2010c: 14; 2011m); GEObs (accessed 29 June 2012).

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