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Chapter 4 Deliberating bioethics

UNESCO's standard-setting activities

UNESCO is a traditional IGO in that it is comprised of member states. It is these states which make final decisions on the organization's activities, including the elaboration and adoption of international declarations. In this sense, then, UNESCO's declarations on bioethics and human genetics form a state-centric regime. Non-state actors were involved in their drafting, however, notably UNESCO's International Bioethics Committee. This chapter explains the infrastructure of the Bioethics Programme, before exploring relations between member states of UNESCO in the drafting of the three declarations and the debate on the governance of human cloning, as well as the roles played by other actors, such as UNESCO's sister UN agencies and NGOs. Lenoir, first President of the IBC, wrote in 1996 that 'to involve the developing countries in the debate [on bioethics] is itself an ethical imperative' (Lenoir 1996). The extent to which this imperative has been met is a major focus of the analysis.

The infrastructure of the UNESCO Bioethics Programme

The main bodies within the UNESCO Bioethics Programme are the International Bioethics Committee (IBC) and the Intergovernmental Bioethics Committee (IGBC). These are supported by a secretariat based in Paris. The IBC was the prime actor in the elaboration of the text of all three declarations. Although one of the committee's defining characteristics is that it is made up of independent experts, its authority is seen to derive from the fact that it sits within an intergovernmental body. Hence during the drawing up of the UDHGHR (1997) it was considered to be 'the only international body working in the field of bioethics' (UNESCO 1999a: 1). The IBC has various functions, including promotion of reflection and education around ethical issues, cooperation with IGOs, NGOs and bioethics committees and follow-up on the three declarations (UNESCO 1998c: 1; UNESCO 2003b; UNESCO 2005s). Some of these tasks are carried out by smaller working groups, which focus on particular topics.

The whole committee meets once a year. Members are selected by the Director-General according to recommendations by member states, but as independent advisors:

The Director-General appoints the IBC's 36 members to serve in their personal capacities for four year terms. The selection is made taking into account cultural diversity, balanced geographical representation and nominations from States of qualified specialists in the life sciences and in the social and human sciences, including law, human rights, philosophy, education and communication.

(UNESCO 2004h)

Achieving this cultural, geographical and disciplinary diversity can be a challenge. Whether a nominee is appointed will depend partly on whether they meet the necessary profile to secure a balanced membership. In the early years there was a high proportion of legislators, but there has since been a shift towards health. For the two-year period during which the UDBHR (2005) was elaborated, the committee had several medical experts but would have welcomed more bioethicists (interviews with F_01 and F2_03). At the seventeenth IBC session in Paris in October 2010, the IBC Chair was glad to note the increased membership from Africa (UNESCO 2011i: 1).

The IGBC's mandate, as agreed by the Executive Board in 1998, is to 'examine the advice and recommendations of the IBC, including those concerned with the follow-up of the Universal Declaration' (that is, the 1997 UDHGHR). According to the IBC's statutes, the IGBC is to inform the IBC and the Director-General of its opinions, including options for following up on the work of the IBC, which the Director-General may then submit to member states, the Executive Board and the General Conference (UNESCO 1998c: 3). More informally, at the committee's second session in 2001, then Chair Najib Ouariti suggested that 'the IGBC must act as an essential relay between the IBC and all the Member States on the one hand and between the IBC and civil societies on the other' (UNESCO 2001c: 1). The IGBC converges every two years, with meetings open to the public unless it decides otherwise. States hold seats for four years, half the membership being elected at each biennial General Conference (for example, 18 members served terms from 2005–2009 and 18 from 2007–2011) (UNESCO 1998c: 3; UNESCO 2011h: 2).

With 36 seats, under a fifth of states are directly represented on the IGBC (Kenya was a member during the elaboration of the 2003 and 2005 declarations but South Africa was not, for example). This is mitigated by seats being allocated according to UNESCO's regional groupings, in accordance with 155 EX/Decision 9.2 (1998) of the Executive Board, where the seats are allocated in the same way. Which states from each group get the seats is subject to a certain amount of 'political wheeling and dealing' (interview with F_01 [quoted]; informal conversation, IGBC meeting, September 2011). The composition of the committee is as follows:

- Group I: Western European and North American states, 7 seats (from 27 members);
- Group II: Eastern European states, 4 seats (25 members);
- Group III: Latin American and Caribbean states, 6 seats (33 members);
- Group IV: Asian and Pacific states, 7 seats (44 members);
- Group Va and Vb: (a) African and (b) Arab states, 8 and 4 seats respectively (64 members) (UNESCO 1998a: 67; UNESCO 2006b; UNESCO 2012d: 64–6).

Drafting and negotiating the declarations

The Universal Declaration on the Human Genome and Human Rights (1997)

The elaboration of the UDHGHR (1997) has been documented in detail elsewhere and need not be revisited here. A previous volume in this book series, *The International Legal Governance of the Human Genome* (2009), by Chamundeeswari Kuppuswamy, carefully analyses the IBC's reports of its meetings during the negotiating period, while UNESCO's own book, *Birth of the Universal Declaration on the Human Genome and Human Rights* (1999a), includes the proceedings of the Legal Commission (the group of IBC members charged with drafting the outline text), its make-up in terms of membership and the various drafts of the declaration. A broad range of state and non-state actors participated in the elaboration process. At its second meeting, the Legal Commission decided that 'one of the major objectives of the IBC is to set back the debate on ethics into a planetary context, by giving the opportunity to representatives of countries from the global South to voice their concerns, often neglected in such discussions' (UNESCO 1999a: 37). Roberto Andorno (2003: 106) notes that 81 member states sent representatives to the 1997 intergovernmental meeting of experts that finalized the draft of the declaration adopted by the General Conference later that year. Non-state actors were given the opportunity to share their opinions in a 'vast and informal' consultation in 1995–6, in line with then Director-General Federico Mayor's wish that the declaration be used as 'an instrument of intercultural dialogue' (Lenoir 1996). The outline text was sent to around 300 institutions and individuals, including other UN agencies, national bodies, NGOs, ethics committees, universities and prominent intellectuals. Responses were discussed in detail by the Legal Commission and the IBC and formed the basis of the preliminary draft of March 1996 (*ibid*; UNESCO 1999a: 57–8, 61 and 67).

The International Declaration on Human Genetic Data (2003)

Although the idea of a separate declaration on human genetic data was mooted in 2001, two years after the establishment of the IGBC, the committee appears to have played no role in the drafting of the declaration (UNESCO 2003j: 19). Nevertheless, member states of UNESCO were able to contribute to the elaboration process on various occasions. The first opportunity came in January 2003, with the launch of an international consultation. An outline of the draft declaration and a questionnaire were sent to international, regional and national organizations and more than 100 bioethics experts, as well as states. Very few replies were received at first, so the deadline for submission was extended. 42 member states eventually responded, 10 from Group I (out of 27 members), eight from Group II (24), six from Group III (33), six from Group IV (42) and 12 from Group V (64). Proportionally, then, there were more replies from developed countries than developing ones. Replies were also received from the Office of the United Nations High Commissioner for Human Rights, 12 NGOs (including the Council for International Organizations of Medical Sciences, the Human Genome Organisation and the Joint Programme Commission on Science and Ethics, which then had 32 member organizations), 22 ethics bodies, six data protection agencies and 21 'eminent personalities' or former IBC members (UNESCO 2003e: 1 and 12–15).

The consultation was followed by a Public Hearings Day in Monaco in February 2003, at which Pierre Sané, Assistant Director-General for the UNESCO's Social and Human Sciences sector, stressed 'the importance that should be attached to the involvement of civil society in the bioethical debate and the transparency of the IBC's work'.

Speakers representing interest groups, developing country researchers and international bodies such as the World Medical Association (WMA), as well as insurance and pharmaceutical companies, duly made statements. These were discussed by a broad audience, comprising the drafting group and some 30 observers attending in a personal capacity or on behalf of member states or other IGOs, including the World Health Organization (WHO). The drafting group then took these discussions into consideration at its subsequent meeting (UNESCO 2003g: 1 and Annex II, 3–5). In light of both the Public Hearings Day and the returned questionnaires, it refined the draft declaration in preparation for the intergovernmental meeting of experts (IGE meeting) in June 2003, with greater emphasis placed on issues pertinent to developing countries, such as benefit sharing and international cooperation (UNESCO 2003e: 1–2 and 11).

The IGE meeting was poorly attended. Only 57 member states sent delegates, of whom 34 took part in the meeting's general debate. The reason for this low attendance is not clear; perhaps some states did not consider the draft declaration of particular relevance to their national needs or interests. Group I was more strongly represented than the other four, despite its being one of the smaller regional groupings (UNESCO 2003c: 1). Furthermore, consonant with Chasek and Rajamani's findings, the larger delegations were chiefly from Group I states. While most countries sent one or two representatives, the US (at the time not even a member of UNESCO) sent six, Germany five, France six and, as an exception to the rule, Tunisia five (UNESCO 2003d). The meeting supported the revised provisions on benefit sharing and international cooperation, particularly those concerning donor communities and scientific researchers in developing countries. Some delegates wanted to see these provisions strengthened further, but others objected, foreseeing clashes with the patent system and national standards for sample donation and research. As is often the case in regime negotiations, a compromise was reached: the draft text was retained, with the addition of a clause stressing the need to build the capacity of developing countries to collect and process human genetic data (UNESCO 2003c: 6–7).

The Universal Declaration on Bioethics and Human Rights (2005)

As for the IDHGD (2003), the first contributions by states to the drafting of the bioethics declaration were made through a written consultation. A questionnaire on what the declaration's aims, structure and content should be was sent to all member states, associate member states and permanent observer missions in January 2004 (UNESCO 2005j: 1). Of the 67 questionnaires returned, 21 were from Group I, 10 from Group II, six from Group III, eight from Group IV, 21 from Group V and one from a permanent observer (UNESCO 2005q). The greater number of responses to this questionnaire in comparison to that for the IDHGD is thus mainly attributable to states in Groups I and V. Cheryl Macpherson (2007: 588), in an article provocatively titled 'Global bioethics: did the Universal Declaration on Bioethics and Human Rights miss the boat?', laments that neither the questionnaire nor the results have been made available online, as they might 'contribute significantly to the bioethics literature regarding global and universal bioethics'. Such an impact is unlikely, however, as the questionnaire was very basic, with only yes/no questions (Snead 2009: 207–8).

Participation by member states at meetings on the UDBHR was ostensibly fair and equal. The IBC and IGBC held a week of separate and joint meetings in January 2005. (The IGBC met to discuss the draft declaration on 24 and 25 January 2005. On 26 and 27 January it continued this discussion at a joint meeting with the IBC. On 28 January the IBC held a further meeting, attended by several IGBC representatives, to revise the draft in light of the week's discussions.) The chairs of these meetings went to great pains to ensure that members had equal opportunities to contribute, as enjoined by the IGBC rules of procedure: 'The Chairperson shall call upon participants in the order in which they signify their wish to speak' (personal observations, IBC and IGBC meetings, January 2005; UNESCO 2011h: 2). This practice was also stipulated for the IGE meetings held in April and June 2005 (UNESCO 2005d: 3; UNESCO 2005n: 3). An attendee confirmed these were conducted in said fashion: 'From my own observations everybody had a right to say whatever he or she wanted to say. After all, they were representing their states' (interview with K_01). Nevertheless, some participants played a greater part in these sessions than others. At the January 2005 IBC and IGBC meetings, representatives from Germany, the US, the Russian Federation, Brazil and Egypt each made fifteen or more comments, whereas those of Malawi, Mozambique and Togo made none at all (personal observations). Furthermore, some attendees at the IGE negotiations commented in interviews that the coffee breaks were when things were really decided, which also seemed to be the case at the January meetings (*ibid*; interviews with UK_01 and UK_02).

A Kenyan participant at the IGE meetings felt that those countries that had a long history in bioethics had an advantage over those just starting in the field (interview with K_01). This mirrors the concerns of Chasek, Rajamani

and Held about differences between countries in levels of expertise at international negotiations. Some also felt ill-prepared. One African delegate to the January 2005 joint IBC and IGBC sessions described how it had been difficult for them to access the relevant documents before the meetings because their office did not have an internet connection (informal conversation). In terms of numbers, the lists of delegates reveal that, as for the IDHGD (2003) negotiations, some countries were able to send bigger entourages than others to both the January IBC and IGBC sessions and the two IGE meetings. A conference on biodiversity was being held in the same week as the former, with at least one African delegate obliged to cover both at once; representatives of other African countries were not present for significant periods of the meetings (interview with F_02; personal observations, IBC and IGBC meetings, January 2005; UNESCO 2005f). Of the 75 and 90 states that attended the April and June IGE meetings, 59 and 68 respectively sent only one or two delegates. By contrast, Canada, France and the US sent six, seven and eight delegates respectively to the April meeting and five, eight and nine to the June meeting (UNESCO 2005e and 2005o). The chief South African representative at the June meeting commented, ‘I was left as the sole representative from South Africa (unlike other countries that were much more organized and had a panel of experts representing them).’ They went on to say, ‘The bigger boys came with a whole network of people that spoke and contributed to each thing... I felt uniquely alienated... without that intensive support’ (interview with SA_23).

Some countries sent no representative at all. Of UNESCO’s 190 member states at the time, exactly half attended the April or June meetings. As at the IGE meeting for the IDHGD (2003), there were proportionately more countries from Group I than from the other four groups, as Table 4.1 shows. Some developing countries may have considered bioethics to be a First World issue and therefore of little importance to them. One West African delegate at the January 2005 IBC and IGBC meetings commented anecdotally that bioethics was not of general concern in their country, as people had more immediate problems to deal with. Several representatives from developed countries would have had the double bonus of greater funding for travel combined with a shorter distance to cover, compared with their developing country counterparts.

A member of the Kenya National Commission for UNESCO, who had attended a number of meetings in Paris on different issues, noted that, in general, ‘The participation from the developing countries is quite low.’ This can be problematic, they said, because if countries do not participate in negotiations their interests cannot be addressed (interview with K_16). The Kenyan UNESCO Chair in Bioethics, who attended the April and June IGE meetings, made a similar observation, citing lack of resources as the reason why several African countries could not send representatives. (For both the IGBC and IGE meetings, states had to cover their attendance costs.) They thought it would be harder for these states to visualize how to implement the declaration, having not been involved in its elaboration (interview with K_01). Although not the poorest country, South Africa’s first real input into the negotiation process was at the June IGE meeting, by which time, in line with Chasek and Rajamani’s observations, it seemed to one of its delegates too late to bring anything new to the table, ‘when we hadn’t had a voice *a priori*’ (interview with SA_23). As only cosmetic changes were made at the 2005 General Conference, when the Declaration was adopted, those states that did not attend the IGE meetings can have had little input into the UDBHR beyond the final vote.

Developing countries may have been disproportionately few in number at negotiations, but the UDBHR represents a significant effort to address their needs and concerns. As with the UDHGHR (1997), this had been the intention from the outset. The IBC, in its initial report on the possibility of a bioethics declaration, suggested the priorities of such an instrument should be meeting vital needs and increasing access to drugs (UNESCO 2003h: 4). Then the drafting group, at its first meeting, decided that the UDBHR should ‘above all respond to the concerns of developing countries’ (UNESCO 2004f: 3). By forming common regional fronts on some issues, these countries were able to voice their concerns relatively loudly, echoing Chasek and Rajamani’s observations on the power of coalitions. This represented a compromise on states’ individual views on certain points, in order to strengthen their negotiating positions overall. Describing the difficulties in balancing the national interest with broader concerns, the Kenya National Commission for UNESCO representative said, ‘It’s a challenge, because you as a country may be having certain inclinations, but we are also bound by what they call the “African Unity”’ (interview with K_16). The South African delegate to the June IGE meeting also noted that people from the same region would speak with a common voice. They remarked that, on issues such as women and vulnerable communities, the Latin American countries, together with India, were the most vocal: ‘So it seemed as if the world dynamics are still based on the developed and the developing worlds and it’s the fact of life’ (interview with SA_23).

The issue for which the regional groupings were most visible was social responsibility and health. This was initially introduced by the Latin American states and later also backed by the Asian and African Groups (interview with F_01).

Carter Snead (2009: 213–4) writes, ‘Most obviously, there was a very strong “development agenda” supported by the Group of 77 (G-77), the largest coalition of developing countries in the UN, who agreed to vote together for purposes of this negotiation.’ A second written consultation, this time targeting IGOs, NGOs, national bioethics committees and independent experts as well as member states, had been launched in October 2004, to which only 31 member states and permanent observers responded (UNESCO 2005q). It was during this consultation and a series of regional meetings towards the end of 2004 that the issue of social responsibility gained real prominence. Brazil and Paraguay argued strongly for a greater emphasis on a ‘social agenda’. The former wrote, ‘The draft text … is too narrow in scope in relation to the development of aspects connected to economic, social and cultural rights, which represent the “social agenda” of the draft declaration’ (UNESCO 2005j: 2). Paraguay’s response was in a similar vein:

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

(ibid: 7)

In the light of such comments, the IBC drafting group added an article on social responsibility to the draft text, the concept having previously featured in the preamble only (2005j: 3).

The formulation of the article came in for much discussion at the January 2005 IBC and IGBC meetings, where it was described by Justice Kirby, Chair of the IBC’s drafting group, as softer than the ‘right to health’, but innovative (personal observation). Several Latin American delegates emphasized the importance of the article and argued that it should go further. Other participants thought that developmental goals were outside the remit of the declaration. The dichotomous opinions did not represent a straightforward split between North and South; Chile expressed the view that issues such as poverty and illiteracy were not bioethical issues, while Finland supported the inclusion of access to nutrition and water, seeing these as important in preventing ill-health (personal observations).

At the final IGE session in June 2005, developing countries are reported to have declared the article on social responsibility to be of ‘paramount importance’ (UNESCO 2005m: 6). It was approved by consensus by the meeting, a somewhat unexpected outcome given the previous opposition of some member states. Germany and the US, for example, had continually opposed the inclusion of articles dealing with social and economic development, not because they considered these issues unimportant, but rather as beyond the scope of bioethics and being dealt with in other fora (interviews with F_01 and F_02; UNESCO 2005k: 3–4 and 38). Moreover, the final article is more strongly worded than its original formulation, pronouncing ‘the enjoyment of the highest attainable standard of health’ a human right (UNESCO 2005s: article 14).

Snead sheds some light on this turn of events in his first-hand account of the negotiations, which had mirrored the split over cloning at the UN a few months before. The US found itself in a bind. With developing countries (most notably Costa Rica), it wished the UNESCO declaration to include a reference to respect for human life, which had been excised from earlier drafts. Its allies on the development issue opposed the reinstatement of this reference, for fear that it would proscribe research on embryos. As a compromise, the US suggested a change of wording to the article on social responsibility, borrowing language from the WHO’s constitution. The delegation explained that it had come to realize that the proposed declaration was not ‘an academic or scholarly treatise on bioethics’, but rather ‘a more comprehensive document that was meant to express and acknowledge matters of human concern that arose at the nexus of science, medicine, and technology’. The suggestion proved acceptable to all (as did the re-insertion of the principle of respect for human life, in the interests of consensus) (Snead 2009: 210–18). This aspect of the declaration may help to dispel the belief, highlighted in Chapter 2, that ‘universal’ bioethics is in fact simply Western bioethics (interview with F_01; comment by Justice Kirby, IGBC meeting, January 2005 [personal observation]). Faunce and Nasu (2009: 316–17) have compared the social responsibility article, together with those on benefit sharing and transnational research (14, 15 and 21 respectively), with cosmopolitan norms.

While the Latin American countries were successful in keeping social responsibility on the agenda during the drafting of the UDBHR, this was not the case for every issue. Members of the Executive Board from Group III (Latin American and Caribbean states) had wanted the declaration to cover reproductive human cloning, sex selection, pharmacogenetics, germ-line interventions and beginning and end of life, but these were deemed too controversial (UNESCO 2004c: 4; UNESCO 2004e: 2). Developing countries as a whole were very concerned with intellectual

property rights, but agreement on this subject was also considered impossible (interview with UK_01). (One participant at the IGE meetings commented that it was left out because it would ‘bring a lot of politics’, although the explanation given in the report of the June meeting was that it falls within the competence of other IGOs [interview with K_01; UNESCO 2005m: 3]). Overall, however, the declaration is seen to cover several themes particularly pertinent to developing countries. Indeed, those from Kenya involved in the drafting process declared themselves mostly satisfied with the final outcome (interviews with K_01 and K_16).

UNESCO considered the involvement of actors other than member states to be crucial to the drafting of the declaration. Its website read, ‘only the participation of all the actors concerned could ensure that all the different perceptions of ethical and legal issues were taken into account’ (UNESCO 2004o). As well as the invitation to make written comments on the third outline of the text in October 2004, there were comprehensive verbal consultations. Before even the first meeting of the drafting group, the IBC held an extraordinary session in order to gauge the opinions of ‘the actors concerned’ on the scope and structure of the proposed declaration (namely other IGOs, organizations such as the WMA and the Human Genome Organisation and national bioethics committees) (UNESCO 2004d: 1–6). At its eleventh session in August 2004, representatives of different ‘religious and spiritual perspectives’ gave presentations. This meeting also hosted a public discussion and was attended by more than 250 participants from 80 countries (UNESCO 2005b: 1). In 2005, national and regional expert consultations were held in several states, including Argentina, Mexico and Indonesia, as part of an ‘Ethics Around the World’ project (UNESCO 2005h: 4; UNESCO 2005q). It was hoped that meetings would also be held in the African and Arab region, but this did not prove possible within the time available. Pharmaceutical companies were invited to make contributions at various sessions, but were ‘quite quiet’ (interview with F_01).

In terms of formal negotiations, other IGOs and non-state actors took part to a limited degree. Only 11 NGOs attended the two IGE meetings (UNESCO 2005e: 15; UNESCO 2005o: 17–18). The Provisional Rules of Procedure, published in February 2005, stated, ‘All plenary sessions shall be held in public, unless the Meeting decides otherwise’ (UNESCO 2005d: 3). The meetings were classified as category II, however, meaning that all observers had to be approved by the Executive Board. The Board approved the list of invitations in September 2004, fully five months before the rules of procedure were made public (personal e-mail, 16 March 2005). The only UN agencies other than UNESCO to attend the meetings were the World Trade Organization and the WHO, although IGOs had other opportunities to feed into the declaration, through the UN Inter-Agency Committee on Bioethics (UNESCO 2005e: 14; UNESCO 2005o: 16). At the Inter-Agency Committee’s third meeting in June 2004, participants ‘reiterated their full support for the drawing up of a declaration providing a universal ethical framework in the field of science and technology’, but wished to clarify the scope of the declaration (UNESCO 2004g: 2). Their concerns on this front were carried through to the fourth meeting, in December 2004, when some committee members commented that the declaration ‘should not go beyond the field of competence of UNESCO’ (UNESCO 2005p: 1).

The low attendance of non-state actors at formal negotiations notwithstanding, the Director-General highlighted at the first IGE meeting in April 2005 the ‘transparent and participatory nature of the elaboration process’ (UNESCO 2005c: 1). Similarly, at the 2005 UNESCO General Conference, member states expressed satisfaction that the drafting process had been an open one, involving a wide range of actors (UNESCO 2005a: 2). The Director-General attributed this transparency partly to the availability of relevant documents on the UNESCO website, which he said made the drafting process open to ‘the greatest possible number’ (UNESCO 2005h: 1 and 7). At the January 2005 IBC meeting, the Chair of the drafting group, Justice Kirby, had declared that all documentation concerning the draft declaration would be put on the website, under a principle of transparency (personal observation). For ten Have (2005: 747), then Head of the Division of the Ethics of Science and Technology, this meant that people from ‘the four corners of the world’ were able to participate in the elaboration process, thereby ‘nourishing intercultural dialogue’.

Those who had not been involved did not share these insider views on transparency. Even among those with ready internet access in Kenya and South Africa, several potential stakeholders had simply not thought, or had not had time, to look at the UNESCO website in connection with bioethics and genetics (interviews with SA_03 and SA_27 and informal conversations with geneticists in Kenya). One South African ethicist (SA_25) commented:

You don’t just want a faceless committee designing this. Maybe some of them do have experience, but why not make it an open process? What would be the problem with that? Why have they not involved individuals with expertise and wide recognition or standing in the international bioethics community?

Another (SA_19) said that the initial draft of a document such as the declaration should be drawn up by experienced committees, but then made open for public scrutiny ‘in such a way that people know about it and it’s readily accessible’. These sentiments are reflected in the bioethics literature. John Williams, then Director of Ethics at the WMA, in a September 2005 special issue of *Developing World Bioethics* devoted to the draft UDBHR, was critical of the fact that the version of the declaration approved by the June IGE meeting had not been through the same broad consultation procedures as earlier drafts (Williams 2005: 211). Macpherson (2007: 588) accuses UNESCO of having limited its consultations to its affiliates, thereby sidelining ‘mainstream bioethicists’ and the broader public. She found the documentation on the website hard to find and would have liked details on the deliberations behind the drafts, as well as the texts themselves. Snead (2009: 209) similarly laments that ‘the substance of the deliberations was a jealously guarded secret’.

Whereas ten Have (2005: 746) has stated that ‘the transparency and the active participation of all the actors concerned ... has already largely contributed to the visibility and general acceptance of the text’, Macpherson (2007: 589–90) feels that the declaration’s credibility and impact have been damaged by UNESCO’s failure to seek out or respond to peer review. Aside from the website’s limitations, her main evidence for this failure is UNESCO’s apparent ignorance of the September 2005 special issue of *Developing World Bioethics*. She also bemoans the lack of engagement with marginalized groups (*ibid*: 589). This echoes almost exactly the concerns of some of the Kenyan and South African interviewees in 2005–6 (K_07, SA_17 and SA_25). One (SA_17) commented:

The declarations have made decisions for the international public, but which international public? I mean, for me, the research participants in South Africa are the rural research participants on the ground. How much have they had a say in terms of the declaration? Have we had our tribal leaders being involved in these discussions?

Howard Wolinsky (2006: 355) describes the negotiations as ‘a dance between government and bioethics groups’. Although the texts of all three declarations were drawn up by the IBC, the body of independent experts, decisions on content of final drafts and whether they should be adopted ultimately lay with member states. (Similarly, it was states that determined whether the declarations should be drafted in the first place. When the IBC presented its report on the possibility of elaborating an instrument on bioethics to the IGBC, the latter was reminded that this was merely a ‘feasibility study’ and that it was for states to decide, at the General Conference, whether the elaboration should go ahead [UNESCO 2003i: 8].) This was not without its problems. For the UDBHR (2005), some countries sent civil servants or embassy representatives (that is, members of the Permanent Delegations to UNESCO based in Paris) to the IGE meetings that finalized the draft, rather than bioethicists. Describing the relationship between experts and states as ‘always a tension’, a member of the Bioethics Programme said this meant that what had been put together logically and rationally by a body of non-state experts was then overridden in a political process by inexpert state representatives (interview with F_01). Attendees at the April and June IGE meetings corroborated this tension, with one observing that, although there were several non-state actors present, they had fewer opportunities to speak than the state representatives, even though they perhaps knew more about the subject matter (interviews with UK_01 and UK_02).

Another illustration of the tension is provided by the debate at the January 2005 joint IBC and IGBC meetings over whether the UDBHR (2005) and implementation guidelines for the IDHGD (2003) were to include reporting mechanisms, under which states would have to periodically inform UNESCO about measures taken to realize the declarations. A member of the IBC remarked informally that the committee would try to include more concrete obligations than in the past, but that this was a ‘shot in the dark’, as these would probably get watered down by states. Describing the room as having a metaphorical Red Sea down its middle that the meeting would have to try to bridge, Justice Kirby (Chair of the UDBHR drafting group) told those assembled that there would be some issues, such as the reporting mechanism, on which the two committees would take different views. The IBC members were independents, while the IGBC representatives were not, he said; each should fulfil their function, but it would be the states that would make the final decisions on such matters, through the political processes of UNESCO. The states duly decided at the June IGE meeting that it would be inappropriate to include any such mechanism in the UDBHR (UNESCO 2005m: 7–8).

Members of the two committees have diametrically opposed views on which was the more qualified to finalize the UDBHR. Justice Kirby (2010: 796) bewails the changes the IGBC made to the IBC’s final draft: ‘In part, some obfuscation must be laid at the door of the IGBC, and of the governmental representatives and so-called governmental “experts” who played with the IBC text, after it had been concluded.’ He cites their changes to the text on informed

consent as an example, which moved from broad principle to highly specific contexts, against the grain of trends in bioethics. By contrast, Snead (2009: 220), an IBC member from 2008–11 but the lead US representative at the joint IBC–IGBC meeting in January 2005 and the May and June IGE meetings, writes, ‘It is worth noting that many of the flaws in the process of elaboration resulting from the work of the IBC drafting committee were (painstakingly) corrected by the subsequent negotiation and drafting sessions of the Government Experts.’ ten Have (2006: 336) recognizes that having two bioethics committees is a challenge as well as a strength:

Policy development and political decision making regarding bioethics need to be informed by expert scientific advice, and bioethical expertise, if it wishes to be translated into policies and legislation, needs to be associated with politics. The unique link between IBC and IGBC also brings to light some of the difficulties with the connection between ethics and policymaking.

The human cloning debate

UNESCO’s pattern of consultation on the governance of human cloning has been different from that on the three declarations. The debate has not been over the content of a legal instrument, the necessity of which is already recognized, but on whether there is even a call for such an instrument. There have been several opportunities for discussion since the debate launched in 2008, mainly at the regular meetings of the IBC and IGBC in September/October each year. The first opportunity came when the IBC’s Working Group on Human Cloning and International Governance, consisting of members from Estonia, Israel, China and Egypt, met for three days from 30 June to 1 July 2008. One day was devoted to public hearings, to which experts and member states were invited, allowing ‘transparency and clarity as per the work of the Committee’ (UNESCO 2008d: 1). Twenty-six states plus the Holy See attended the hearings, the majority from developing countries, including eight Latin American and Caribbean states (Group III) and six African states (Group Va). All representatives were members of their country’s Permanent Delegation to UNESCO in Paris (or Brussels in Malawi’s case) (UNESCO 2008d, Annex II: 3–6). There were no outside observers, although one of the experts asked to give a presentation was from the WHO.

More states engaged in the IBC and joint IBC–IGBC sessions in October 2008, which discussed the Working Group’s interim report (published in September) and heard further presentations by experts and stakeholders. Alongside the 35 (of 36) IGBC member states that attended, 38 non-IGBC states had representatives at the meetings (as observers), about half of which were developing countries. There were also several representatives of intergovernmental and non-state actors, such as the WHO, the European Commission and the International Council of Women (UNESCO 2008c; UNESCO 2008f). The IBC meeting included further public hearings on cloning, with presentations from members of the national bioethics committees of Indonesia, Madagascar and Brazil and the International Society for Stem Cell Research (UNESCO 2009d: 4). Claiming once again UNESCO’s unique position in the field of bioethics, the report of the IBC meeting reads, ‘Only through the multidimensional, multidisciplinary and multicultural reflection facilitated by IBC can sustainable solutions be devised for the complex ethical issues concerning cloning of human beings’ (*ibid*: 1).

In its interim report of 2008, the Working Group had found that a new, binding instrument to ban human reproductive cloning was indeed justified, given developments in the field such as induced pluripotent stem cells (iPSCs), increasing commercial interest in the technology, growing public awareness, updated national regulations and ongoing concerns for the health of women and foetuses (UNESCO 2008h: 3–4). Participants at the October IBC meeting differed on whether there was likely to be a strong enough consensus on the need for a ban to avoid a repeat of what had happened at the UN in 2005 and on whether recent scientific advances (especially iPSCs) were significant enough to warrant a new instrument (UNESCO 2009d: 5–6). Those at the joint IBC–IGBC meeting, which followed immediately, were similarly concerned to avoid a repeat of the UN debacle, but some emphasized how useful a binding international agreement would be to those developing countries which had not yet adopted national legislation on cloning and asked the committees not to shy away from ways to realize effective international governance (UNESCO 2010i: 12–13).

The Working Group erred on the side of caution in its final report of June 2009, concluding that a fresh international normative instrument would be premature, despite the potential benefit to those developing countries still lacking specific cloning regulations. Instead, it argued that increased and focused global dialogue, to include developing countries particularly, was ‘crucially needed’ (UNESCO 2009e: 7–8). This was endorsed by the IGBC at its sixth session a month later, where several participants noted that, because many developing countries lack ‘a well developed national bioethics infrastructure’, they benefit from international level discussions such as those at IBC and

IGBC meetings. Nevertheless, some IGBC members asked that a disclaimer be added to the IBC report, to the effect that it expressed the views of the IBC rather than the official position of member states or UNESCO as an organization (UNESCO 2009f: 4).

On the advice of the IGBC, the IBC mandated an expanded Working Group to continue its work on cloning in 2010–11, focusing on three issues: (a) terminology, (b) dissemination and (c) options for regulation (UNESCO 2010g: 1). (The IGBC sixth session report states that the committee invited the IBC to ‘further explore and elaborate different modalities and tools of soft regulation and governance’ [UNESCO 2009f: 4]. In the official conclusions of the meeting this became a suggestion that the IBC review ‘other possible options for its regulation’ [UNESCO 2009b: 2]. The IBC moved back towards hard law, asking the Working Group to examine ‘different options for legal regulation of human reproductive cloning (including the possibility of a moratorium)’, after discussions at its sixteenth session in November 2009 [UNESCO 2010g: 1; UNESCO 2010j: 10].)

The Working Group presented a draft report at the IBC and joint IBC–IGBC meetings in October 2010. The Chair of the Working Group, Toivo Maimets, emphasized that it was indeed a draft and asked for a lot of input from the two committees. It was at a ‘living document stage right now’, he said (personal observation). The report put forward new terms and definitions for reproductive and therapeutic cloning, which it was hoped would be taken up by the scientific community. This was partly because existing definitions tended to refer to cloning by somatic cell nuclear transfer (SCNT) only and thus did not account for current and future developments in the field, such as iPSCs. Echoing those who have argued that reproductive cloning will not produce identical human beings (only people with the same nuclear DNA), the Working Group found definitions based on this premise to be ‘scientifically incorrect’. It suggested keeping the term, given its widespread use in national and international law and guidelines, but reformulating the definition based on intention, to ‘using the linear DNA nucleotide sequence of an existing human being to create an embryo, which is implanted into womb with the purpose to produce human baby’ [sic]. Somewhat inconsistently, it found the terms ‘therapeutic cloning’ and ‘research cloning’ misleading and therefore to be avoided, precisely because they are based on intention. As an alternative, the Working Group recommended terminology describing the process of obtaining pluripotent stem cells: ‘derivation of pluripotent cells’. It stated, ‘This terminology has an advantage of being descriptive, technically accurate, simple, easily understandable, and capable of incorporating any future scientific and technological developments’ (UNESCO 2010g: 3–4).

Unfortunately, the IBC did not agree. It commended the Working Group for its work, but felt that terminology should encompass technology, procedures and intention (UNESCO 2011i: 6). One member suggested that the ethical issues cannot be dealt with holistically, but should be elaborated for each new technique developed. Others felt that if a certain process were allowed, it would be hard to regulate intentions for its use (one making the comparison with a nation’s stated intent for nuclear power), while another said that to define one type of cloning according to process and another according to purpose was ‘apples and pears’ (personal observations, IBC meeting, October 2010). At the joint IBC–IGBC meeting there was general agreement that a clearer distinction between reproductive cloning and therapeutic cloning is needed, as current definitions are ambiguous and unsatisfactory, bringing confusion to decision-making. Germany and Syria drew a connection between terminology and regulation, thus linking two of the Working Group’s areas of study. They argued that clear definitions are needed before international legislation can be developed (personal observations, IBC–IGBC meeting, October 2010).

The Working Group’s 2010 draft report also pressed again for a binding instrument on human reproductive cloning (a convention or moratorium), citing sufficient consensus among governments to enable this. UNESCO would provide the best international platform to enact such an instrument, the report claimed, because of its standing in the field. This would sit alongside activities to encourage global discussion and debate (UNESCO 2010g: 6–7), but the IGBC showed no appetite for the former. Reporting on the joint IBC–IGBC session, the UNESCO website (2010d) states:

IBC members were unequivocal in expressing concern that the recent scientific developments have raised a need for a binding international legal instrument. However, feedback by Member States of IGBC was indicative that the political hurdles that have prevented the realization of such instrument [sic] in the past are still in place.

The official report of the IBC meeting that took place earlier in the week (and which several IGBC members attended as observers) states that IBC members considered it ‘imperative’ to draw up a new legal instrument to ban human reproductive cloning as a matter of urgency, due to the speed of scientific developments in the field juxtaposed with the time it would take to draft such an instrument. They also noted the need to thoroughly investigate the feasibility of such an enterprise (UNESCO 2011i: 6). At both meetings, several IBC members argued strongly for a convention

specifically on human reproductive cloning, to be adopted as soon as possible, but members were not unanimous. Donald Evans, then IBC Chair, said at the beginning of the IBC discussion that it was time to ‘get the boxing gloves out’ and urged participants not to just be polite and say ‘what we’re supposed to say’. His opinion was that a convention or moratorium would require a very careful definition of the term ‘reproductive cloning’, specifying that the ban concerned the *bringing to birth* of a cloned embryo. In terms of the furore over other applications, he said, the ethical dilemmas cannot simply be defined away. He and Stefano Semplici, his successor as IBC Chair, were pessimistic about the chances of getting political agreement on a ban (personal observations, IBC and joint IBC–IGBC meetings, October 2010).

At the joint meeting, the US delegation (the first to comment) expressed puzzlement that the possibility of a convention was ‘back on the table’, thinking that this idea had been laid to rest in the 2009 report. They reiterated that such an initiative would be premature and advocated continued dialogue instead, coupled with support for states in developing regulations and policies. Germany and Brazil agreed, endorsing the *status quo*. Germany argued that existing regulations should be preserved and reinforced, not watered down, while Brazil described the current situation internationally as ‘very comfortable’, as it bans reproductive cloning but allows therapeutic cloning; UNESCO should instead focus on awareness-raising about the risks of cloning. This triumvirate prompted one of the IBC members to question why they considered a ban premature in 2010, but not in 2001 when the idea was first mooted at the UN (personal observations, IBC–IGBC meeting, October 2010).

Côte d’Ivoire disagreed that a convention would be premature, but was concerned about the possibility of a moratorium, as this would only postpone progress; a normative instrument giving shape to cloning and allowing it to develop would be welcome. Madagascar’s representative made a similar plea. They questioned the Working Group’s conclusion that there was international consensus that human reproductive cloning should not happen and insisted that the science should be allowed to develop. Scientific discovery is not about ‘playing God’, they said, but about understanding him better so that we can love him more. God knows this and knows when to put limits on human activity; scientists also know where to stop. Lebanon agreed that barriers cannot be put on scientific and human progress, as this is how mankind evolves, but considered this a reason for UNESCO to be vigilant, rather than employ a ‘wait and see approach’ to whether ethical values are respected in how research is applied (personal observations, IBC–IGBC meeting, October 2010).

Other states took a more pragmatic approach to the debate. Nigeria recognized that cloning already takes place with animals and plants and might have some use in medical applications, such as the replacement of diseased tissues and organs. The delegation described its position as in line with the Council of Europe and the WHO, in that the country does not subscribe to human reproductive cloning. It had decided that the issue was to be placed ‘on the front banner’, through a consultation involving all stakeholders, to encompass the totality of views of Nigerians. Kenya took the middle ground. It recognized that previous attempts at international governance have failed, but highlighted UNESCO’s role as a standard setter; as several developing countries still lack regulations on cloning, UNESCO should disseminate information that will help states to develop legislation where appropriate. Switzerland also made links to dissemination, the third strand of the Working Group’s mandate for 2010–11. It proposed an international conference as a good way of defining the kinds of actions that need to be taken. This would also afford the opportunity for a deeper international dialogue to rebuild the international governance framework. Switzerland itself would not find a convention problematic, subject to a discussion of what form it would take. The delegation also underlined the risks associated with conventions, in that they are only binding on those states that ratify them (personal observations, IBC–IGBC meeting, October 2010).

The Working Group was to finalize its report for the eighteenth IBC session in May 2012, but instead presented a draft ‘final statement’ repeating the recommendations of the 2010 preliminary report and adding that ‘technical manipulations of human embryo, either for research or therapeutic purposes’ [sic] (that is, what is commonly understood as therapeutic or research cloning) should continue to be regulated at national rather than international level, according to social, historical and religious contexts (UNESCO 2011d: 3). The IBC chose not to adopt the statement because of the ‘divergent positions’ of its members on both the ethics and governance of human cloning (UNESCO 2011f: 4). By this point several IBC members appeared to be tiring of the topic. They felt that, as political consensus on a ban remained elusive, the committee could not go any further in its deliberations. One said that if they left the debate open, they could still be debating the same points in ten years’ time (personal observations, IBC meeting, May–June 2011).

Some in the IBC would have liked to adopt the final statement as the culmination of its work in this area, including Maimets, the Chair of the Working Group. He was not overly optimistic that an international ban or moratorium could be achieved after the UN fiasco in 2005, but pointed out that it was for governments rather than the IBC to decide whether to take this forward. What the committee could say, as a body of independent experts, was that it does not support human reproductive cloning. Others opposed this. For the first time, ethics entered the debate (which the Working Group had been asked to steer clear of in its original mandate). Some members questioned the hitherto uncritical acceptance that reproductive cloning was undesirable and hence that the only barriers to a ban were political. Citing reproductive freedom, they felt that the philosophical arguments against cloning based on genetic determinism and the impact on the cloned child were not strong enough to justify a ban. These issues were not addressed in the draft statement, but one member argued that, as an ethical rather than political body, the IBC should be prepared to give at least a brief explanation of the ethical rationale for a ban (personal observations). This ethical turn was alluded to by Semplici, the incoming IBC Chair, in his progress report to the IGBC at its seventh session in September 2011. He commented that the IBC had been unable to endorse the draft final statement because this would require a strong ethical argument against the use of SCNT for the purposes of producing a child, which the IBC considered a very challenging undertaking, without any promise of agreement (personal observation).

As the IBC always operates by consensus but could not agree on whether or not to adopt the draft statement, it was dropped by default. Evans, as outgoing Chair, explained to the IGBC in September 2011 that there had been some pressure at the IBC's meeting earlier in the year to go to a vote, but that he had resisted this. He also stated that he believed there would never be consensus on a ban, because the issue was a philosophical rather than scientific one, concerning the legal status of the early embryo. The IBC had not 'come up with the wisdom of Solomon' on this point (personal observation, IGBC meeting, September 2011). The IGBC largely agreed. The Danish representative thought it better to have a thorough report (from 2009) and leave it at that than to try in vain to reach a consensus. The US and Austrian delegates echoed these comments, saying that a tremendous amount of work had been done already and further headway might prove difficult. Lebanon felt that UNESCO should slow down rather than give up the issue completely as, despite its complexity, the academic community may be able to reach conclusions based on consensus in the longer term. Japan also felt that UNESCO should 'keep in touch' with cloning (personal observations, IGBC meeting, September 2011). The official conclusions of the meeting note the importance of the topic, but also the lack of consensus among both states and IBC members. Thus the IGBC merely 'encourages UNESCO, with the assistance of IBC as appropriate, to continue to follow the developments in this field in order to anticipate emerging ethical challenges' (UNESCO 2011c: 2–3). Consequently, the 2012–13 IBC Work Programme relegates cloning to monitoring by one or two IBC members, who are to report any significant developments in the field to the committee and thereby the Director-General (UNESCO 2012m).

Perspectives on cloning from sub-Saharan Africa

The Permanent Delegations (PDs) and National Commissions (NCs) which answered questionnaires in 2012 echoed several of the opinions on cloning voiced in the IBC and IGBC meetings. Most commissions supported the idea of a convention to ban human reproductive cloning. One West African NC wrote that, because African countries see science as key to development, without such conventions 'ethical ills would continue to be on the rise'. A Southern African NC believed a convention would help countries to adopt regulations on human cloning, even though it is not yet an issue in their region, due to lack of human cloning technology. Another Southern African NC thought that a convention would be useful as, in developing countries, it is only scientists who are interested in such issues, which makes it difficult to monitor and enact laws to prevent or regulate such practices. A third confirmed that conventions are useful in setting normative parameters that can be domesticated at national level, as did its PD, which favoured a convention over dialogue. Only one country, from West Africa, did not support a convention. Both its NC and its PD felt that international dialogue should come first, which should be 'based on full understanding of all issues involved, including the usefulness of such a convention to the developing countries'. Other respondents supported dialogue alongside a convention, as 'both are equally important as they are interdependent' and dialogue 'keeps states on their toes', enabling education and sensitization, sharing of perspectives and experiences, consensus building and (echoing the Lebanese delegate) eventual agreement on international standards. An East African PD added, 'In this interconnected world, no issue may be dealt with in isolation. Countries have to fully cooperate for tangible results.'

Opinions also differed on the ethics and usefulness of cloning. Like at the IGBC meetings, respondents were not unanimous in rejecting reproductive cloning. Illustrating the remoteness of the issue for some developing countries, as noted by Arsanjani, two NCs, from East Africa and Southern Africa, did not know the issue was being debated at UNESCO and did not feel qualified to give an informed opinion. A West African NC respondent gave their personal

view that cloning is not ethically right and so should not be promoted in the guise of development. A second Southern African NC, focusing on reproductive cloning, did not think cloning technologies would make an important contribution to development, because ‘for African countries we already have high birth rates which increases the probability of getting all the relevant skills which may be required’. A West African PD made a similar point, but with a more negative spin: ‘Not as it pertains to duplication of human beings in an already overpopulated world in a highly degraded environment.’ Its counterpart NC simply said, ‘Developing countries are yet to buy into cloning.’ Likewise, a third Southern African NC commented, ‘The positive results are not yet clear to developing countries.’ Its PD gave a different view, believing that cloning technologies could make an important contribution to development, if accessible and affordable. It warned, ‘In the contemporary world, many technologies exist that could address many development needs in many countries but their contribution is minimal due to high costs and restricted access.’ The fourth Southern African NC also saw promise in cloning technologies, if applied appropriately: ‘they must be regulated and used in a manner that respects human rights, peace and security’.

Within UNESCO’s Bioethics Programme, relations between North and South and between state and non-state actors are ostensibly equal – or at least balanced – at international level. The organization has put in place rules and procedures to ensure that all states, along with experts and stakeholders in bioethics and genetics, have the opportunity to be heard. Nevertheless, representation from developing countries has been disproportionately low at intergovernmental meetings and the ultimate power held by states has created something of a two tier system of decision-making between them and non-state experts. This was particularly apparent during the negotiations on the *Universal Declaration on Bioethics and Human Rights* in 2004–5, but has also been a feature of the discussions on human cloning. The need to heed all voices and yet achieve consensus has had a substantive impact on the content and nature of UNESCO’s bioethics instruments (existing and potential), as explored in the next chapter.

Tables

Table 4.1 Number of member states attending the April and June 2005 IGE meetings, by regional group

Group	Region	April	June
Group I	Western Europe and North America	20 (74%)	22 (81%)
Group II	Eastern Europe	8 (32%)	13 (52%)
Group III	Latin America and Caribbean	17 (52%)	20 (61%)
Group IV	Asia and Pacific	9 (20%)	12 (27%)
Group V	Africa/Arab states	21 (33%)	23 (36%)

Sources: UNESCO (2005e and 2005o).

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