

The Global Governance of Bioethics: Negotiating UNESCO's Universal Declaration on Bioethics and Human Rights (2005)

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UNESCO's Universal Declaration on Bioethics and Human Rights (2005) was drawn up by an independent panel of experts (the International Bioethics Committee) and negotiated by member states. UNESCO aimed for a participatory and transparent drafting process, holding national and regional consultations and seeking the views of various interest groups, including religious and spiritual ones. Furthermore, reflecting UNESCO's broad interpretation of bioethics, the IBC included medics, scientists, lawyers and philosophers among its membership. Nevertheless, several potential stakeholders—academic scientists and ethicists, government policy-makers and NGO representatives—felt they had not been sufficiently consulted or even represented during the Declaration's development. Better communications and understanding within and between national, regional and international layers of governance would help to avoid a recurrence of this problem in future negotiations.

INTRODUCTION

The completion of the Human Genome Project has opened up unprecedented possibilities in healthcare, but also new ethical and social dilemmas. Partly to address such issues, the United Nations Educational, Scientific and Cultural Organization (UNESCO) has adopted three international declarations on human genetics and bioethics. The last of these, the *Universal Declaration on Bioethics and Human Rights*, was adopted in October 2005.¹ The preamble states:

It is necessary and timely for the international community to state universal principles that will provide a foundation for humanity's response to the ever-increasing dilemmas and controversies that science and technology present for humankind and the environment.²

Among these dilemmas and controversies is the issue of how to harness the benefits of science and technology in a way that addresses rather than augments inequalities in health between North and South. As well as including common bioethical principles, the Declaration contains some articles that are considered innovative in the field. The most prominent of these is Article 14 on social responsibility and health, which calls on states to promote health and social development through advances in science and technology.

On adoption of the *Universal Declaration on Bioethics and Human Rights*, UNESCO pronounced that the drafting process had been participatory and transparent. Indeed, a wide range of actors from around the world had been involved, through oral and written consultations. Yet, as this paper shows, several potential stakeholders—scientists, ethicists, government policy-

makers and civil society members—felt they had not been given sufficient opportunity to take part, or even be represented in, the process. Drawing on empirical data from fieldwork conducted in Kenya, South Africa, France and the United Kingdom in 2005 and 2006, the paper charts how the Declaration came into being. It examines the negotiation process, from the first consultations and drafting meetings to the final adoption by member states. Using international relations theories on regimes and global governance, it looks first at the international level: the relative influence of (a) developed and developing countries and (b) state and non-state actors on the development of the Declaration. It then peels back a layer, to investigate how states arrived at the negotiating positions they wished to take to the table. It concludes with an assessment of the participatory process within the UNESCO Bioethics Programme, as well as some suggestions on how some of the limitations identified might be overcome.

THE UNESCO BIOETHICS PROGRAMME

According to its website, UNESCO actively pursues the Millennium Development Goals and “functions as a laboratory of ideas and a standard-setter to forge universal agreements on emerging ethical issues.”³ It aims to consolidate the universal values of justice, freedom and dignity, while acknowledging pluralism: “Scientific and technological progress must be placed in a context of ethical reflection rooted in the cultural, legal, philosophical and religious heritage of all our communities.”⁴ The UNESCO Bioethics Programme, part of the Division of the Ethics of Science and Technology, began in 1993 with the formation of the International Bioethics Committee (IBC). An Intergovernmental Bioethics Committee (IGBC) followed in 1999. Each committee has 36 members, the former made up of independent experts and the latter of representatives from selected states. Both committees aim for a geographical spread among members; the IBC must also display cultural and disciplinary diversity. IGBC members are appointed by their governments and can change during a country’s four-year period of office. IBC members are selected by the Director-General of UNESCO, after being nominated by their country, often in collaboration with the Bioethics Programme secretariat. They also serve in four-year stints. Beyond UNESCO Headquarters in Paris, many of UNESCO’s activities are administered through the National Commissions in each member state.

THE DECLARATION AND ITS ELABORATION

The Declaration is a normative, non-binding instrument containing 28 articles. It is concerned mainly with the ethical impact of medicine, science and technology on humans, but also touches on environmental and animal ethics. The primary purpose is to provide a universal framework for states to use in formulating bioethical legislation and policies. As well as outlining common ethical principles such as informed consent, a favourable risk-benefit ratio, autonomy and confidentiality, the Declaration encourages respect for cultural diversity, solidarity, social responsibility and benefit sharing. These principles should be promulgated through, *inter alia*, the establishment of ethics committees, public education in bioethics and international dialogue.

The Declaration was elaborated as follows. In 2001, the UNESCO General Conference invited the Director-General to look into the possibility of developing a universal instrument on bioethics. On the basis of the IBC's subsequent report on this topic, the 2003 General Conference declared the setting of universal standards in bioethics to be "imperative and desirable."⁵ A drafting group made up of IBC members was appointed and, in January 2004, an extensive written and oral consultation process began, involving member states and other stakeholders. Outline texts of the Declaration were discussed by the full IBC committee and by a joint meeting of the IBC and IGBC committees in January 2005. The UNESCO Executive Board and the United Nations Inter-Agency Committee on Bioethics were also involved. The Declaration was finalised by two meetings of government experts in April and June 2005 (open to representatives of all member states) and was adopted "by acclamation" by the General Conference, on 19 October 2005 at its thirty-third session.⁶ The full drafting process is outlined in the table below.

Table 1: The Elaboration Process

Date	Event/procedure
Jan 04	Written consultation launched on scope and structure of declaration (for member states)
Mar 04- Jan 05	National and regional consultations with experts (held in The Netherlands, Iran, Lithuania, Turkey, Argentina, South Korea, Mexico, Indonesia, Portugal, Russian Federation)
Apr 04	IBC extraordinary sessions on scope and structure (also attended by IGOs (7), NGOs (5), national bioethics committees (15))
Apr 04	1 st meeting of drafting group (composed of selected IBC members)
Jun 04	2 nd drafting group meeting – produced 1 st outline
Jun 04	Meeting of UN Inter-Agency Committee on Bioethics – discussed scope and content (FAO, UNESCO, UNU, WHO, WIPO, ALECSO, European Commission, Council of Europe, OECD, WTO)
Jul 04	3 rd drafting group meeting – produced 2 nd outline
Aug 04	IBC ordinary session – heard from religious/spiritual representatives and discussed 2 nd outline (250+ attendees)
Aug 04	4 th drafting group meeting – produced 3 rd outline
Oct 04	Written consultation on 3 rd outline launched (for states, IGOs, NGOs, national bioethics committees, individual experts)
Oct 04	5 th drafting group meeting
Dec 04	Meeting of UN Inter-Agency Committee on Bioethics – discussed 3 rd outline

Date	Event/procedure
Dec 04	6 th drafting group meeting – produced 4 th outline in light of written consultation
Jan 05	IBC/IGBC joint meetings – discussed 4 th outline and finalised preliminary draft (IBC)
Feb 05	Communication of preliminary draft (to member states, IGOs, NGOs)
Apr 05	1 st meeting of government experts – discussed draft
Apr 05	UNESCO Executive Board meeting – approved ongoing drafting process (58 member states)
June 05	2 nd meeting of government experts – finalised draft
Oct 05	UNESCO General Conference – adopted declaration

GOVERNANCE IN INTERNATIONAL INSTITUTIONS

The process outlined above is not unusual in the international arena. Regime theory seeks to explain why and how, in a world of sovereign states, collective action, such as the negotiation of the UNESCO Declaration on Bioethics, arises and is maintained. Regimes thus comprise understandings, formal or informal, between states and other actors, about how agreements on a given issue should be arrived at, what they should include and how they should be implemented. They often entail bargaining, concession and compromise in order to enable consensus. Together with regime theorists, global governance scholars have in recent years tried to find ways in which such arrangements might be strengthened or enhanced, in order to address global problems and issues more effectively. They generally advocate involving, to a greater or lesser extent, those with expertise or an interest in the matter at hand, alongside government representatives. To examine participation levels in the drafting of the bioethics Declaration, this paper draws on normative regime theory (Samhat and Ellis), as well as selected aspects of two specific approaches to global governance: governance through government networks (Slaughter) and cosmopolitan democracy (Held).

States are usually the principal members of international regimes, with other actors often becoming involved in both decision-making on norms and their subsequent implementation. Power differentials, between strong and weak states and between state and non-state actors, can affect the outcome of an institution's deliberations. Issues of representation, legitimacy and accountability are key here. On legitimacy Buchanan and Keohane write:

It is important not only that global governance institutions be legitimate, but that they are perceived to be legitimate. The perception of legitimacy matters, because, in a democratic era, multilateral

institutions will only thrive if they are viewed as legitimate by democratic publics.⁷

This perception of legitimacy is important in two aspects: both the procedures by which decisions are made and the substantive outcomes of those decisions (in this case, the Declaration) must be seen to be fair, by those they will affect.⁸ With regard to this first aspect, Held describes intergovernmental organisations (IGOs) as facing a “crisis of legitimacy” on two counts. Firstly, relations between strong and weak states are unequal and, secondly, “chains of delegation” from the international to the national are too long. On the first issue Held writes, “Increasingly, these institutions appear to speak for the powerful, or to be cast aside by these very same forces if they fail to fall into line with their will.” He points to the power imbalances between states during international negotiations by way of example. These can be both qualitative and quantitative; some countries can afford to make available large delegations of experts to back up their official representative, whilst others may only be able to send one person, who may not be a specialist in the field.⁹ Slaughter makes a similar observation with regard to less formalised relations between states, highlighting concerns with inequalities in power between rich and poor countries as government officials become increasingly involved in global governance: “Shifting authority to technocrats means privileging the views of those nations that *have* technocrats—inevitably the most developed nations.”¹⁰

Chasek and Rajamani outline specific difficulties faced by developing countries during international negotiations and ways in which these might be resolved. Further to the problems concerning the size and expertise of delegations highlighted by Held, Chasek and Rajamani describe how some delegates will arrive at meetings with “hollow mandates,” having not received clear instructions as to what their country’s negotiating position should be. Moreover, if they attend only later sessions, they will not only have missed out on agenda setting, but will also lack “institutional memory” and the corresponding leverage to influence proceedings. The two analysts make several practical suggestions on how developing countries could be better represented at international meetings and thus have stronger mandates and bargaining positions. Firstly, countries could hold national policy debates and strategic consultations. Greater coordination between relevant ministries might also “make for more effective delegations.” Secondly, regional preparatory meetings would aid networking among developing countries. Broad coalitions can be powerful, but given the diversity of national concerns and priorities, Chasek and Rajamani recommend that these should be complemented by smaller groups focusing on special issues. These measures might be realised through a ‘participation fund’.¹¹

The second crisis of legitimacy that Held identifies, the “chains of delegation” between IGOs and states, he attributes to weak and obscure mechanisms of accountability, particularly with regard to international negotiations.¹² Slaughter, by contrast, argues that when governance mechanisms are composed primarily of democratically appointed or elected government officials it is clear who is exercising power and on whose behalf. She believes that, unlike actors from the private sector or civil society, governmental officials can be held accountable through political mechanisms.

She acknowledges that these officials are often seen as unelected technocrats acting on behalf of vested interests, but suggests ways in which such perceptions could be mitigated; namely, government networks could host common websites, engage systematically with counterpart networks of corporations and civil society organisations and promote enhanced accountability at domestic levels. Slaughter further justifies why government officials should be the primary actors in international negotiations on the grounds that it is these officials who will be directly implementing, at national level, any agreements made. This requires the officials to be employees from a relevant department or ministry, rather than diplomatic *attachés*. Slaughter sees these types of government officials as prime repositories of expertise:

What better source on how to run a securities system, regulate commercial banks, protect the environment, pursue different types of criminals, safeguard human rights or foster business competition than networks of government officials from around the world charged with precisely those functions?¹³

Held advocates that individuals should be entitled to take part in policy formation at the global level as fully-fledged cosmopolitan citizens rather than through government representatives alone. He proposes that all those affected by an issue should have a say in its governance, either directly or through representatives selected from “overlapping communities of fate,” determined by similarity of circumstance rather than arbitrary national borders.¹⁴ As an interim measure, Samhat argues for international regimes to be considered as public spheres, characterised as frameworks within which interests and identities are constituted and actors engage in discussion and deliberation. Samhat believes the “democratic potential” of international regimes is growing as they involve a broadening range of actors, thus forming “transboundary political communities” around specific issues.¹⁵ For Ellis, who also frames regimes as public spheres, discourse within regimes enables “the articulation of international rules and norms grounded in consensus and therefore enjoying legitimacy.”¹⁶ Both writers see the inclusion of civil society as a key element. Ellis echoes Held in recommending that negotiations be made more open and thus “more permeable to influence from civil society.”¹⁷ Samhat contends that this is already happening, with documentation of international meetings becoming increasingly public and civil society actors now participating “across the gamut of regime and norm-building processes.”¹⁸ UNESCO seemingly bore this out in the elaboration of the Declaration on Bioethics, as the table of the previous section testifies. The remainder of the paper will explore in more depth the roles played these actors, as well as those of state representatives.

STATE INVOLVEMENT IN THE DRAFTING PROCESS

States first contributed to the drafting of the UNESCO Declaration on Bioethics through the written consultation launched in January 2004. 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.¹⁹ Of the sixty-seven questionnaires returned, 21 were from

Group I (Western European states and others, including the US), 10 from Group II (Eastern European states), 6 from Group III (Latin American and Caribbean states), 8 from Group IV (Asian and Pacific states, 21 from Group V (African and Arab states) and one from a permanent observer.²⁰ To the second written consultation, launched in October 2004, only 31 member states and permanent observers responded.²¹

In terms of participation at meetings concerning the draft Declaration, this was ostensibly fair and equal among member states. The chairpersons of IGBC and IBC meetings held in January 2005²² to discuss the draft 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.”²³ This practice was also stipulated for the intergovernmental meetings of experts (IGE meetings) held in April and June 2005, which an attendee confirmed 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.”²⁴ Nevertheless, some participants played a greater part in these various sessions than others. At the January 2005 IGBC and IBC meetings, representatives from Germany, the United States, the Russian Federation, Brazil and Egypt each made fifteen or more comments, whereas those of Malawi, Mozambique and Togo made none at all.²⁵

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.²⁶ This mirrors Held’s concerns about differences between countries in levels of expertise at international negotiations. In terms of numbers, also, an examination of the lists of delegates reveals that some countries were able to send bigger entourages than others to both the January IGBC and IBC 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 in the meetings.²⁷ 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 United States sent between five and nine.²⁸ 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 organised and had a panel of experts representing them).” She 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.” Her experiences further reflect Chasek and Rajamani’s findings in that, with the June 2005 meeting representing South Africa’s first real input into the negotiating process, it seemed to have come too late to bring anything new to the table, “when we hadn’t had a voice *a priori*.”²⁹

Of UNESCO’s 190 member states at the time, exactly half attended the April or June meetings. There were proportionately more countries from Group I than from the other four groups.³⁰ It is possible to speculate about why this should have been the case. Firstly, some developing countries may have considered bioethics to be a First World issue and therefore of little importance to them. One African delegate at the January 2005 IGBC and IBC meetings commented anecdotally that bioethics was not of general concern in

his country, as people had more immediate problems to deal with.³¹ Secondly, representatives from developed countries may have had the double bonus of greater funding for travel combined with a shorter distance to cover, compared to their developing country counterparts. A member of the Kenya National Commission for UNESCO, who had attended many international meetings, including those of the IGBC and IBC in January 2005, noted that “the participation from the developing countries is quite low.” This can be problematic, he said, because if countries do not participate in negotiations their interests cannot be addressed.³² His colleague, 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.) He thought it would be harder for these states to visualise how to implement the Declaration, because they had not been involved in its elaboration.³³ As only cosmetic changes were made to the Declaration’s final draft at the General Conference at which it was adopted in October 2005, it would seem that those states which did not attend the IGE meetings had little input into the Declaration.

Although developing countries were disproportionately few in number at negotiations, the Declaration represents a significant effort to address their needs and concerns. This had been the intention from the outset. The IBC, in its initial report on the possibility of a bioethics instrument, suggested that the priorities should be meeting vital needs and increasing access to drugs. Furthermore, the drafting group, at its first meeting, decided that the Declaration should “above all respond to the concerns of developing countries.”³⁴ By forming common regional fronts on some issues, these countries were able to voice their concerns relatively loudly, in line with 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 who had attended the IGBC and IBC January 2005 meetings 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’.”³⁵ The South African chief delegate to the June 2005 sessions also noted that people from the same region would speak with a common voice. She 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.”³⁶

The issue for which the regional groupings were most visible was that of social responsibility and health. This was initially introduced by the Latin American states and later also backed by the Asian and African groups.³⁷ It was during the second written consultation that the issue 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.” 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.³⁸

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.³⁹

The formulation of this article came in for much discussion at the January 2005 IGBC and IBC meetings, where it was described by Justice Kirby, chairperson of the IBC drafting group, as softer than the 'right to health', but innovative.⁴⁰ Several Latin American delegates emphasised the importance of the article and argued that it should go further. Other participants thought that developmental goals were beyond the scope of the Declaration. The dichotomous opinions did not represent a straightforward split between North and South, however; Chile expressed the view that issues such as poverty and illiteracy were not bioethical issues, whilst Finland supported the inclusion of access to nutrition and water, seeing these as important in preventing ill-health.⁴¹ 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." The meeting approved it by consensus, a somewhat unexpected outcome given the previous opposition of some member states, such as Germany and the United States.⁴² 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.

NON-STATE ACTORS WITHIN UNESCO

Although the various draft texts of the Declaration were drawn up by the IBC and its drafting group, decisions on the final version and whether it should be adopted lay ultimately with member states. This was not without its problems. Some countries sent civil servants (often from foreign affairs ministries rather than the type of technically appropriate department that Slaughter would recommend) or Paris-based embassy representatives to the IGE meetings, rather than bioethicists. A member of the Bioethics Programme secretariat said that this meant that what had been put together logically and rationally by a body of non-state experts, the IBC, was then overridden in a political process by inexperienced state representatives. He described the relationship between experts and states as "always a tension," giving the following example of how it can lead to weak compromises:

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.⁴³

Another illustration of this tension is provided by the debate at the January 2005 joint IGBC and IBC meetings over whether the Declaration should include reporting mechanisms, under which states would have to periodically inform UNESCO about measures they had taken to realise the Declaration's recommendations. In an informal conversation, a member of the IBC remarked that it 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.⁴⁴ 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 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 whilst 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 that it would be inappropriate to include any such mechanism in the Declaration.⁴⁵

INVOLVEMENT OF OTHER NON-STATE ACTORS

UNESCO regards the Declaration as unique among bioethics instruments because it is the only one to have been agreed by a global forum of governments. (The World Medical Association's *Declaration of Helsinki* is, by contrast, the work of a professional body, for example.) Nevertheless, it considered the involvement of actors other than member states to be crucial to the drafting of the Declaration. The website read, "Only the participation of all the actors concerned could ensure that all the different perceptions of ethical and legal issues are taken into account."⁴⁶ During the second written consultation launched in October 2004, the third outline of the text was sent for comment to IGOs, NGOs, relevant national bodies and around 40 independent experts, as well as states. Responses were duly received from 4 IGOs, 14 NGOs, 14 national bioethics committees and 12 individuals and were discussed by the IBC drafting group in December 2004.⁴⁷

Verbal consultations were also comprehensive. Just before the first meeting of the drafting group in April 2004, the IBC held an extraordinary session to gauge the opinions of "the actors concerned" on the scope and structure of the proposed Declaration (namely other IGOs, non-UN bodies such as the World Medical Association and the Human Genome Organisation and national bioethics committees).⁴⁸ At its eleventh session in August 2004 representatives of different "religious and spiritual perspectives" gave presentations. This meeting also hosted a public discussion, attended by more than 250 participants from 80 countries. In 2004-05, national and regional expert consultations were held in several states, including Argentina, Mexico and Indonesia, as part of UNESCO's "Ethics Around the World" project.⁴⁹ 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.⁵⁰

In terms of formal negotiations, non-state actors took part to a limited degree. Only eleven NGOs attended the IGE meetings.⁵¹ The Provisional Rules of Procedure, published in February 2005, stated, "All plenary sessions shall be held in public, unless the Meeting decides otherwise."⁵² 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.⁵³ The low attendance of non-state actors at formal negotiations notwithstanding, at the first IGE meeting in April 2005 the Director-General highlighted the “transparent and participatory nature of the elaboration process.”⁵⁴ Similarly, at the 2005 UNESCO General Conference, member states expressed satisfaction that the drafting process had been open, involving a wide range of actors.⁵⁵ Bearing out Samhat’s observations, 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.”⁵⁶

These opinions were not necessarily shared outside UNESCO, begging the question of the degree to which an institution must open itself to civil society before the substantive legitimacy predicted by Ellis is conferred on its outputs. Several potential stakeholders in Kenya and South Africa, for example, had not thought to look at the UNESCO website in connection with bioethics.⁵⁷ Thus perhaps simply making the information available does not go far enough. In a September 2005 special issue of *Developing World Bioethics* devoted to the draft Declaration, John Williams (then Director of Ethics at the World Medical Association) 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.⁵⁸ One South African ethicist commented in an interview:

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?⁵⁹

Another 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.”⁶⁰ For some of those interviewed, these people would necessarily include those potentially vulnerable participants in biomedical research that the Declaration seeks to protect. One asked:

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?⁶¹

NATIONAL LEVEL DELEGATE SELECTION

The Director-General of UNESCO reported in 2002, “Despite the ever greater importance of bioethics worldwide, this discipline is still too often the preserve of a handful of specialists.”⁶² UNESCO considers people from various backgrounds to have expertise in bioethics (the IBC, for example, includes experts in law, human rights, philosophy, medicine and genetics). Reflecting

this, the Declaration was drafted as a “practical application” document rather than an academic one.⁶³ At the June 2005 IGE session charged with finalising the Declaration, the Director-General thanked member states for sending “strong, quality delegations.”⁶⁴ The chief Kenyan and South African delegates to this meeting were both scientists with experience of applying bioethical principles in their work. The Kenyan expert was selected as his country’s UNESCO Chair in Bioethics. He was accompanied to the June meeting by the Kenyan deputy permanent delegate to UNESCO (based in Paris) and to the previous session in April by a member of Kenya’s National Council for Science and Technology. His South African counterpart, a geneticist, was appointed by the Minister of Education. She attended only the June meeting, although the South African deputy permanent delegate was at both sessions. The Kenyan IGBC representatives at the January 2005 meetings were both from the National Commission for UNESCO.⁶⁵

Although the majority of people interviewed in Kenya and South Africa were unfamiliar with the UNESCO Declaration, several had strong opinions about who should be representing them at international negotiations in general, which perhaps belie Slaughter’s claims about the accountability of government appointed delegates. The views of two Kenyan participants are illustrative. The first, a civil society actor, could find no consistency from one meeting to the next: “The people who represent the government—today it’s this person, another month it’s somebody completely different from another ministry.”⁶⁶ The second also saw the appointment process as capricious, such that ill-informed government officials attend international meetings at short notice, with little time to absorb the relevant facts and statistics. She asked, “Who is representing my views as a geneticist?”⁶⁷

As in Kenya, South African participants were of the opinion that representatives at international negotiations need to have a certain level of expertise. They differed on where the requisite expertise with regard to bioethics lay, however. Some of those who conduct genetic research involving human subjects felt that experience ‘at the coalface’ was important. This would furnish an understanding of the intricacies of obtaining informed consent, for example. One commented, “I think it’s very dangerous to have a group of academics putting it [the Declaration] together when they don’t understand what the issues are on the ground, because they can dream up things that are wonderfully ethically sound, but are totally impractical.”⁶⁸ A long-standing member of a research ethics committee also thought that practical experience was important, but in terms of ethical review rather than research. Having seen some registers of those involved in UNESCO’s bioethics activities, he expressed concern that very few of the people listed had sat on an ethics committee, remarking, “I found one South African representative that I know has no bioethics research experience on any committee in this country, but is regarded as an expert. And that worries me.”⁶⁹ Others thought that those with a background in the philosophy of bioethics had a vital role to play, because they have been trained in the logical construction of arguments. One said of the completed Declaration, “I can’t see that there were bioethicists involved in the drafting of that thing... I think it’s unusable.”⁷⁰ The tensions between these different positions were articulated by a prominent actor in South African bioethics:

So what does it mean to be ‘a bioethicist’? Should everybody who calls him or herself a bioethicist be consulted? Bioethics is a contentious field populated by scholars, professionals and others from many disciplines, not all of whom have had an adequate training or experience. So whose voices should be heard?⁷¹

NATIONAL LEVEL CONSULTATION

Kenya’s role in the negotiation of the Declaration was coordinated by the National Commission for UNESCO. In formulating its position, the Commission garnered opinions from various people it considered experts, namely members of its own Natural Sciences and Human and Social Sciences Committees and officials from the Ministry of Justice and Constitutional Affairs, the Kenya Medical Research Institute and the National Council for Science and Technology. These expert views were sometimes overruled by the permanent delegates to UNESCO in Paris (who were members of the African negotiation group), in consultation with the Ministry of Foreign Affairs, as to what the official negotiating position should have been. Nevertheless, the chief Kenyan representative carried out a similar process to that of the National Commission, in order to be able to present a “Kenyan position” at the meetings.⁷² Thus the tension between experts and states identified at international level seems to have been mirrored at national level. There were no broader consultations with scientists, civil society groups or the general public in Kenya. On this point, the UNESCO Chair of Bioethics said:

No, there is not such a thing. Actually that’s an issue which myself and another colleague who also attended the April meeting raised when we came back, in our report: that before any of those meetings take place, there must be meetings to agree on our stand and formulate our agenda. And that one has not taken place.⁷³

There was less discussion of the draft Declaration in South Africa than in Kenya. The only input, albeit of a limited fashion, came from the South African Medical Association’s Human Rights Law and Ethics Committee. A quote from a senior member of a university bioethics department serves to demonstrate the paucity of consultation: “You know, UNESCO has never contacted me with anything, so it’s basically finding out from our bioethics circles as to what’s happening in UNESCO and then looking up things on our own. But I have never been contacted by UNESCO.”⁷⁴ The chief IGE delegate was thus left with what Chasek and Rajamani would term a ‘hollow mandate’ as to how she was to represent South Africa. She commented, “In hindsight, I attended the meeting poorly equipped to voice the opinions of the country.”⁷⁵

In both Kenya and South Africa, input into the negotiating positions for drafting of the Declaration on the part of government officials appears to have been curtailed by lack of communication within and between departments. At the time of fieldwork, both the Kenyan National Commission for UNESCO and the National Council for Science and Technology (NCST) fell under the Ministry for Education, Science and Technology. A member of the Commission described those at NCST as “very close partners” and, indeed, as mentioned in the previous section, an NCST representative attended the April

IGE meeting.⁷⁶ Nevertheless, two members of NCST, who deal with biotechnology and bioethics respectively, did not know of the Declaration. The former said that the connection with UNESCO had never been clear, the latter that he had never heard of UNESCO engaging in any kind of bioethics activities.⁷⁷ Despite the various connections, then, it seems that key information was not shared within and between the National Commission for UNESCO and NCST.

South Africa faced a similar problem, but between government units rather than within them, as it has separate departments for education and for science and technology. UNESCO headquarters deals directly with the Department of Education (where the South African National Commission for UNESCO is housed), which did not consult with the Department of Science and Technology with regard to the draft Declaration. Again echoing Samhat, the secretariat of the UNESCO Bioethics Programme, with a small staff, takes great pains to act transparently. To this end, a plethora of information on the Programme's activities is freely available on the UNESCO website. When it comes to actively distributing materials to member states, however, there can be problems. A member of the secretariat explained that it cannot be sure whether information is always getting to the most appropriate government departments, because UNESCO deals primarily with ministries of education, even though these might not perhaps be the most natural ports of call with regard to bioethics and genetics.⁷⁸ This would seem to substantiate Held's remarks on overlong 'chains of delegation' between international and national levels. A member of South Africa's Department of Science and Technology corroborated the difficulties described by the Bioethics Programme representative:

Basically we don't track the UNESCO processes directly from the department, which is something that made me think that we should do more, because the UNESCO relationship is owned by our Department of Education and they hadn't briefed us or asked us for assistance in this particular Declaration.⁷⁹

The lack of input into the Declaration among non-state actors in Kenya and South Africa may be partly attributable to a low level of engagement in genetics and bioethics policy-making generally, among both scientists and the general public. Although several geneticists were sceptical of the Declaration because they felt their views had not been adequately represented during negotiations, they were hesitant to involve themselves in policy-making. Their priorities are research and teaching, hence they have little time to spare for other endeavours, particularly given the relatively small size of the scientific community in each country.⁸⁰ With regard to public involvement in policy-making, the picture is somewhat mixed in both Kenya and South Africa. In the former, Ministry of Health guidelines for research into HIV/AIDS vaccines, published in 2005, were developed in consultation with NGOs, community representatives, faith-based organisations and professional societies (as well as government officials, researchers and healthcare workers). These guidelines notwithstanding, several interviewees were of the opinion that there is little public participation in bioethics and genetics matters in Kenya, with discussions tending to be confined to certain circles.⁸¹ In South Africa, the

mechanisms are in place for people to make comments on impending regulations or legislation. It was felt that it was mostly activist groups taking advantage of these, however, rather than the public at large, the problem being that public understanding of ethics and genetics is poor. At the time of fieldwork, a recent survey had shown that South Africans were “woefully ignorant” about biotechnology. One geneticist commented, “They wouldn’t know what to ask.”⁸²

It is important to take note of these low levels of input—into the Declaration directly and into genetics and bioethics policy generally—for two reasons. Firstly, the Declaration itself calls for broader education and engagement around bioethics. Secondly, if the Declaration is to be respected and implemented, it will need a wider support base than was evident during its negotiation. This was recognised by participants in the IGE meetings from both countries. The chief Kenyan delegate thought it necessary to share the Declaration beyond those few who had attended the international negotiations. “Otherwise,” he remarked, “we go to those meetings, we keep quiet, that’s the end of it.”⁸³ His South African counterpart likewise commented that the Declaration’s principles needed to be promoted among the general public:

We all have a responsibility to ensure—not just as scientists, but as members of the general public—that this sort of best practice is part and parcel of the very core of our moral values. It doesn’t matter that you only try to aspire to these when you’re doing genetic research, it should be core principles and perhaps we should have some education around it.⁸⁴

IMPLEMENTATION OF THE DECLARATION

As intimated by the Kenyan delegate in the quote above, perhaps the most significant test of a declaration’s success is not in its adoption but in its implementation. While a detailed examination of the progress of member states in this respect would require another paper, it is possible to make some general observations. Aside from the danger of false causality when assessing regime effectiveness, the decision taken by states to forego the self-reporting mechanism makes it difficult to analyse systematically the extent to which the Declaration has been adopted at national level. The Bioethics Programme hopes that UNESCO’s Global Ethics Observatory (GEObs) will 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. As of July 2011, 34 countries featured in the legislation and guidelines section of the database. GEObs is one of several capacity building initiatives within the Division of the Ethics of Science and Technology; given that the Declaration is normative and non-binding, the Bioethics Programme has adopted a policy of encouraging take-up by member states rather than coercion. Since 2005, it has helped several developing countries (including Kenya) establish national bioethics committees and has held ethics training courses across the regions, all of which are based on the Declaration’s principles. It also produced periodic reports on how different articles of the Declaration can be put into effect.⁸⁵

CONCLUSION

Pablo Sader, chairman of the intergovernmental meetings of experts, made the following statement at the final session in June 2005:

A bioethics-related event makes the international headlines nearly every week. It is a difficult topic. As we have all seen, there have been deep divisions in other meetings on specific bioethics issues. There are points of divergence within individual countries too. For this reason, it is doubly important for us to give a clear signal that we are capable of reaching agreement on important issues. If we do so, the Declaration will be proof that multilateralism works, and that will be a boon to our Organization.⁸⁶

Is the Declaration indeed proof that multilateralism works? During the official negotiation process, relations between developed and developing countries and state and non-state actors were ostensibly equal, or at least balanced, at the international level. UNESCO put in place rules and procedures to ensure that voices from all states, along with experts and stakeholders in bioethics, had the opportunity to be heard. Nevertheless, representation from developing countries was disproportionately low at intergovernmental meetings and the ultimate diplomatic power held by states created something of a two-tier system of decision-making between them and non-state experts. At national level, in both Kenya and South Africa, the legitimacy of the negotiation process was eroded by people's perceptions that it had been conducted in an unrepresentative and unaccountable manner.

In future endeavours, UNESCO might avoid several of these problems by implementing some pragmatic changes. In terms of the relative input of developed and developing countries, it could help low income countries meet the travel costs of their delegations. Indeed, at its sixth session in 2009 the IGBC decided to invite the Director-General of UNESCO to look into the possibility of financial provision to enable members from the least developed countries to participate in its meetings.⁸⁷ This would be a positive step, although if implemented it would remain to be seen whether the Bioethics Programme would be able to avoid some of the problems that daily subsistence allowances (DSAs) can engender. Chasek, in her recent studies of multilateral environmental agreements (MEAs), has shown that, while DSAs enable developing countries to send representatives to negotiations when they would not be otherwise able to do so, they have generated something of a "international MEA meeting 'industry'," which serves to exacerbate some of the problems she and Rajamani had earlier identified and which are already seen within the UNESCO Bioethics Programme. Government officials may vie for the opportunity to attend meetings, for example, in order to supplement meagre salaries, with the result that the representative chosen is not always the most appropriate: "such would be the case if a foreign affairs official attends a scientific working-group meeting." Alternatively, a state may opt to appoint a different representative to each meeting in the interests of fairness, with ensuing continuity problems.⁸⁸

The problem of unequal levels of expertise among states is actively being addressed by the UNESCO Bioethics Programme, through the capacity building activities outlined above. For Kenya and South Africa, however, the difficulty seems to have lain in their incapability to harness expertise, as much as a lack of expertise *per se*. Many of those who might be considered experts in bioethics (using UNESCO's broad criteria) were not asked to feed into their countries' negotiating positions, let alone to join a delegation. Chasek and Rajamani's suggestions of national policy debates, strategic consultations and greater networking between relevant government ministries would seem relevant here (although the reluctance on the part of Kenyan and South African scientists to get involved in policy-making sounds a note of caution). Such networking would enable states to garner input from all relevant departments when deciding on negotiating positions. Slaughter believes this coordination should be straightforward, commenting only briefly on this aspect of her model, "Regulators of all kinds, from health to education to the environment, would conduct their own foreign relations, subject to some kind of domestic interagency process that accepted this phenomenon but nevertheless attempted to aggregate interests."⁸⁹ As the Kenyan and South African cases demonstrate, however, the existence or efficacy of such a "domestic interagency process" should not be presumed.

Slaughter's suggestion that government networks should engage systematically with their counterparts in the corporate and civil society sectors would help to avoid some of the problems UNESCO has encountered in terms of visibility.⁹⁰ In essence, however, the hierarchy between state and non-state actors would not be diminished and thus could be a source of tension, as it was during the drafting of the Declaration at both international and national levels. By contrast, regimes as public spheres and cosmopolitan democracy have been put forward as possible means to encourage not just a greater but a more equal involvement of non-state actors than is seen in traditional governance mechanisms. This more revolutionary approach, in its turn, carries probable complications. How can everyone affected be included in the decision-making process without it becoming unwieldy? If relevant groups or 'communities of fate' are to be represented, how and by whom is that relevancy to be adjudicated? Is there a danger that, without the controls offered by electoral democracy, only those groups that have the backing and power to 'shout the loudest' will be heard? Bioethics is an issue that can concern a wide range of people, including scientists, ethicists, medical professionals, policy-makers, pharmaceutical companies, funding bodies, research participants and recipients of healthcare. Making participation both fair and manageable within and beyond state-based networks is therefore a daunting task, particularly given the limited resources of UNESCO's Bioethics Programme secretariat. Pragmatic solutions to this dilemma, beyond the dissemination and awareness-raising work that UNESCO is already doing, are hard to identify. Thus while the need for better coordination and communication among and between different layers of governance and potential stakeholders may be evident, the means to effect these improvements are far less obvious.

INTERVIEWS

Code	Location and date	Description or affiliation
K_01	Nairobi, 4.10.05	Kenyan representative at the UNESCO IGE meetings, April and June 2005
K_02	Nairobi, 5.10.05	Social and Human Sciences Committee of the Kenya National Commission for UNESCO
K_03	Nairobi, 5.10.05	As above
K_05	Kilifi, 11.10.05	KEMRI-Wellcome Trust Collaborative Programme
K_13	Nairobi, 24.10.05	Natural Sciences Committee of the Kenya National Commission for UNESCO
K_14	Nairobi, 26.10.05	Biosafety News
K_16	Nairobi, 1.11.05	Kenya National Commission for UNESCO
K_18	Nairobi, 3.11.05	Advisor on national biosafety policy
K_19	Nairobi, 3.11.05	Member of a research ethics committee
K_20	Nairobi, 7.11.05	Kenya National Biosafety Committee
K_21	Nairobi, 5.10.05	Ministry of Education, Science and Technology
K_26	Nairobi, 25.10.05	Geneticist at a university
K_30	Nairobi, 8.11.05	Ministry of Foreign Affairs
SA_03	Cape Town, 28.3.06	Geneticist at a university
SA_04	Cape Town, 29.3.06	Division of Human Genetics, University of Cape Town
SA_07	Cape Town, 30.3.06	South African National Bioinformatics Institute
SA_08	Stellenbosch, 31.3.06	Centre for Applied Ethics, University of Stellenbosch
SA_09	Cape Town, 3.4.06	International Research Ethics Network for Southern Africa (IRENSA)
SA_10	Cape Town, 10.4.06	Member of a research ethics committee
SA_12	Durban, 5.4.06	Centre for HIV/AIDS Networking

Code	Location and date	Description or affiliation
SA_15	Pietermaritzburg, 6.4.06	South African Research Ethics Training Initiative (SARETI)
SA_16	Johannesburg, 10.4.06	Bioethics Division, University of the Witwatersrand
SA_17	Unspecified	An academic in a senior position in bioethics at a health sciences faculty
SA_19	Johannesburg, 12.4.06	Human Research Ethics Committee (Medical), University of the Witwatersrand
SA_20	Johannesburg, 12.4.06	Geneticist at a university
SA_21	Johannesburg, 13.4.06	As above
SA_23	Johannesburg, 13.4.06	South African representative at the UNESCO IGE meeting, June 2005
SA_24	Pretoria, 24.4.06	Geneticist, research ethics committee member and ethics lecturer
SA_25	Pretoria, 19.4.06	Senior member of an independent ethics institute
SA_26	Pretoria, 20.4.06	Department of Science and Technology
SA_27	Pretoria, 20.4.06	Geneticist at a research institute
SA_29	Pretoria, 21.4.06	Public Understanding of Biotechnology programme
SA_30	Pretoria, 25.4.06	Geneticist at a university
SA_33	Pretoria, 26.4.06	Council for Scientific and Industrial Research
SA_35	Pretoria, 2.5.06	Faculty of Health Sciences Research Ethics Committee, University of Pretoria
UK_01	By telephone, 5.9.05	Attendee at the UNESCO IGE meetings, April and June 2005
UK_02	London, 30.11.05	As above
F_01	Paris, 29.8.05	UNESCO Bioethics Programme secretariat
F_02	Paris, 30.8.05	Attendee at the UNESCO IGE meetings, April and June 2005

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¹ The 2005 declaration was preceded by the 1997 *Universal Declaration on the Human Genome and Human Rights* and the 2003 *International Declaration on Human Genetic Data*.

² UNESCO, *Universal Declaration on Bioethics and Human Rights* (2005), available at www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/ (15 March 2011).

³ UNESCO, "What is it? What does it do? About UNESCO," available at http://portal.unesco.org/en/ev.php-URL_ID=3328&URL_DO=DO_TOPIC&URL_SECTION=201.html (22 June 2007).

⁴ UNESCO, "Social and Human Sciences," available at http://portal.unesco.org/shs/en/ev.php-URL_ID=1830&URL_DO=DO_TOPIC&URL_SECTION=201.html (22 June 2007).

⁵ Giovanni Berlinguer, "Bioethics, Health, and Inequality," *The Lancet* 364, no. 9439 (2004): 1086-1091.

⁶ UNESCO, "Different Stages in the Elaboration of the Declaration on Universal Norms on Bioethics," available at http://portal.unesco.org/shs/en/ev.php-URL_ID=3850&URL_DO=DO_TOPIC&URL_SECTION=201.html (9 July 2007).

⁷ Allan Buchanan and Robert Keohane, "The Legitimacy of Global Governance Institutions," *Ethics & International Affairs* 20, no. 4 (2006): 405-437.

⁸ For detailed expositions of the concept of legitimacy in an international context see Daniel Bodansky, "The Legitimacy of International Governance: A Coming Challenge for International Environmental Law?" *Scholarly Works Paper* 443 (1999); Colin Scott, "Governing Without Law or Governing Without Government? New-ish Governance and the Legitimacy of the EU," *European Law Journal* 15, no. 2 (2009): 160-173; and Steven Bernstein, "Globalization and the Requirements of 'Good' Environmental Governance," *Perspectives on Global Development and Technology* 4, no. 3-4: 645-679.

⁹ David Held, *Global Covenant: The Social Democratic Alternative to the Washington Consensus* (Cambridge: Polity Press, 2004).

¹⁰ Anne-Marie Slaughter, *A New World Order* (Princeton, New Jersey: Princeton University Press, 2004).

¹¹ Pamela Chasek and Lavanya Rajamani, "Steps Toward Enhanced Parity: Negotiating Capacity and Strategies of Developing Countries," in *Providing Global Public Goods: Managing Globalization*, eds. Inge Kaul, Pedro Conceicao, Katell Le Goulven and Ronald Mendoza (Oxford: Oxford University Press, 2003).

¹² Held, *Global Covenant*.

¹³ Slaughter, *A New World Order*.

¹⁴ Held, *Global Covenant*.

¹⁵ Nayef Samhat, "International Regimes and the prospects for Democracy," *The Whitehead Journal of Diplomacy and International Relations* (Winter/Spring 2005): 179-191.

¹⁶ Jaye Ellis, "International Regimes and the Legitimacy of Rules: A Discourse-Ethical Approach," *Alternatives: Global, Local, Political* 27, no. 3 (2002): 273-300.

¹⁷ Ibid.

¹⁸ Nayef Samhat, "International Regimes as a Pragmatic Institutional Form" (draft), paper presented to the International Studies Association, Montreal, Canada (March 16 2004).

¹⁹ UNESCO, "Report by the Director-General on the Drawing Up of a Declaration on Universal Norms on Bioethics," 171 EX/13 (Paris: 9 March 2005).

²⁰ These are the regional groupings which UNESCO uses to categorise its member states, in accordance with 155 EX/Decision 9.2 of the Executive Board. The 36 seats on the IGBC, for example, are divided proportionally among the five groups. In 2004 the total numbers of states in each group were as follows: Group I, 27; Group II, 24; Group III, 33; Group IV, 42; and Group V, 64.

²¹ UNESCO, "Towards a Declaration on Universal Norms on Bioethics: Progress Report January 2005," PowerPoint presentation, available at [http://portal.unesco.org/shs/en/file_download.php/50523d754289e00aad6d16990d576e22Bioethics+Declaration\(jan.2005\).ppt](http://portal.unesco.org/shs/en/file_download.php/50523d754289e00aad6d16990d576e22Bioethics+Declaration(jan.2005).ppt) (9 July 2007).

²² 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 author was an observer at each meeting.

²³ IGBC and IBC meetings, Paris, 24 to 28 January 2005 (personal observations); UNESCO, "Intergovernmental Bioethics Committee: Rules of Procedure" (adopted 14 May 2001).

²⁴ Interview with K_01 (see table for details of participants); UNESCO, "First Intergovernmental Meeting of Experts Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics: Provisional Rules of Procedure," SHS/EST/05/CONF.203/2 (Prov.) (Paris: 4 February 2005).

²⁵ IGBC and IBC meetings, Paris, 24 to 28 January 2005 (personal observations).

²⁶ Interview with K_01.

²⁷ Interview with F_02; IGBC and IBC meetings, Paris, 24 to 28 January 2005 (personal observations). See also UNESCO, "Fourth Session, Intergovernmental Bioethics Committee (IGBC): Provisional List of Participants," SHS/EST/CIGB-4/INF.2 (Paris: 25 January 2005).

²⁸ UNESCO, "First Intergovernmental Meeting of Experts Aimed at Finalizing a Draft of a Declaration on Universal Norms on Bioethics: List of Participants," SHS/EST/05/CONF.203./INF.1 (Paris: 6 April 2005) and "Second Session of the Intergovernmental Meeting of Experts Aimed at Finalizing a Draft of a Declaration on Universal Norms on Bioethics: List of Participants," SHS/EST/05/CONF.204./INF.1 (Paris: 25 June 2005). Canada, France and the United States sent six, seven and eight delegates respectively to the April meeting and five, eight and nine to the June meeting.

²⁹ Interview with the SA_23.

³⁰ At the April IGE meeting there were 20 states from Group I, 8 from Group II, 17 from Group III, 9 from Group IV and 21 from Group V; at the June meeting there were 22 from Group I, 13 from Group II, 20 from Group III, 12 from Group IV and 23 from Group V.

³¹ Informal conversation, IGBC and IBC meetings, Paris, 24 to 28 January 2005.

³² Interview with K_16.

³³ Interview with K_01.

³⁴ UNESCO, "Report of the IBC on the Possibility of Elaborating a Universal Instrument on Bioethics," SHS/EST/02/CIB-9/5 (Rev. 3), (Paris: 13 June 2003); UNESCO, "First Meeting of the IBC Drafting Group for the Elaboration of a Declaration on Universal Norms on Bioethics," SHS/EST/04/CIB-Gred-1/1 (Paris: 24 May 2004).

³⁵ Interview with K_16.

³⁶ Interview with SA_23.

³⁷ Interview with F_01.

³⁸ UNESCO, "Results of the Written Consultation on the Third Outline of the Text of a Declaration on Universal Norms on Bioethics (27 August 2004)," SHS-2005/WS/15 (Paris: 10 January 2005).

³⁹ UNESCO, "Sixth Meeting of the IBC Drafting Group for the Elaboration of a Declaration on Universal Norms on Bioethics," SHS/EST/04/CIB-Gred-6/3 (Paris: 14 January 2005).

⁴⁰ IGBC meeting, Paris, 24 January 2005 (personal observation).

⁴¹ IGBC and IBC meetings, Paris, 24 to 28 January 2005 (personal observations).

⁴² Interviews with F_01 and F_02; UNESCO, "Second Session of the Intergovernmental Meeting of Experts Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics: Compilation of Proposed Amendments Submitted by Member States," SHS/EST/05/CONG.204/5 (Paris: 6 June 2005).

⁴³ Interview with F_01.

⁴⁴ Informal conversation, IGBC and IBC meetings, Paris, 26 January 2005.

⁴⁵ UNESCO, "Second Intergovernmental Meeting of Experts: Final Report."

⁴⁶ UNESCO, "Towards a Declaration on Universal Norms on Bioethics," http://portal.unesco.org/shs/en/ev.php-URL_ID=1883&URL_DO=DO_TOPIC&URL_SECTION=201.html (7 October 2004).

⁴⁷ UNESCO, "Towards a Declaration on Universal Norms on Bioethics" (PowerPoint presentation); UNESCO, "Report by the Director-General on the Drawing up of a Declaration on Universal Norms for Bioethics."

⁴⁸ UNESCO, "Extraordinary Session of the International Bioethics Committee of UNESCO (IBC): 'Towards a Declaration on Universal Norms on Bioethics'," SHS/EST/04/CIB-EXTR/1 (Paris: 12 July 2004).

⁴⁹ UNESCO, “Towards a Declaration on Universal Norms on Bioethics” (PowerPoint presentation); UNESCO, “Eleventh Session: International Bioethics Committee of UNESCO (IBC),” SHS/EST/04/CIB-11/CONF.504/2 (Paris: 6 January 2005); UNESCO, “Report by the Director-General on the Drawing Up of a Declaration on Universal Norms on Bioethics.”

⁵⁰ Interview with F_01.

⁵¹ UNESCO, “First Intergovernmental Meeting of Experts: List of Participants,” and “Second Intergovernmental Meeting of Experts: List of Participants.”

⁵² UNESCO, “First Intergovernmental Meeting of Experts: Provisional Rules of Procedure.”

⁵³ Personal e-mail, 16 March 2005.

⁵⁴ UNESCO, “First Intergovernmental Meeting of Experts Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics: Final Report,” SHS/EST/05/CONF.203/5 (Paris: 6 April 2005).

⁵⁵ UNESCO, “Address by Mr Koïchiro Matsuura, Director General of UNESCO,” twelfth session of the IBC, Tokyo, Japan, 15-17 December 2005, DG/2005/201.

⁵⁶ UNESCO, “Report by the Director-General on the Drawing Up of a Declaration on Universal Norms for Bioethics.”

⁵⁷ Interviews with SA_03 and SA_27 and informal conversations with staff at the KEMRI-Wellcome Trust Collaborative Programme in Kilifi, Kenya (11 and 12 October 2005).

⁵⁸ John Williams, “UNESCO’s Proposed Declaration on Bioethics and Human Rights – A Bland Compromise,” *Developing World Bioethics* 5, no. 3 (2005): 211-224.

⁵⁹ Interview with SA_25.

⁶⁰ Interview with SA_19.

⁶¹ Interview with SA_17.

⁶² UNESCO, “Report by the Director-General on Action to be Taken in the Light of the Round Table of Ministers of Science on Bioethics (22-23 October 2001),” 164 EX/15 (Paris: 10 April 2002).

⁶³ UNESCO, “First Intergovernmental Meeting of Experts: Final Report.”

⁶⁴ UNESCO, “Second Intergovernmental Meeting of Experts: Final Report.”

⁶⁵ Interviews with K_01 and SA_23.

⁶⁶ Interview with K_14.

⁶⁷ Interview with a K_26.

⁶⁸ Interviews with SA_12, SA_20 and SA_21 (quoted).

⁶⁹ Interview with SA_19.

⁷⁰ Interviews with SA_08 and SA_16 (quoted).

⁷¹ Interview with SA_09.

⁷² Interviews with K_02, K_13 and K_16 (quoted) K_30.

⁷³ Interview with K_01.

⁷⁴ Interviews with SA_16, SA_17 (quoted) and SA_23.

⁷⁵ Interview with SA_23.

⁷⁶ Interview with K_16.

⁷⁷ Interviews with K_20 and K_21.

⁷⁸ Interview with F_01.

⁷⁹ Interview with K_21.

⁸⁰ Interviews with K_03, K_05, SA_03, SA_04, SA_07, SA_21, SA_30 and SA_35.

⁸¹ Ministry of Health, Republic of Kenya, *Kenya National Guidelines for Research and Development of HIV/AIDS Vaccines* (Nairobi: 2005); interviews with K_01, K_02, K_14, K_18, K_19, K_21 and K_26.

⁸² Interviews with SA_04, SA_10, SA_15, SA_16, SA_21, SA_24, SA_26 (quoted), SA_27 (quoted), SA_29, SA_30 and SA_33.

⁸³ Interview with K_01.

⁸⁴ Interview with SA_23.

⁸⁵ UNESCO, “Promoting Bioethics: Steps Ahead”, PowerPoint presentation, available at www.unesco.org/new/fileadmin/MULTIMEDIA/HQ/SHS/pdf/ibc_igbc_presentations_2010.pdf (18 March 2011).

⁸⁶ UNESCO, “Second Session of the Intergovernmental Meeting of Experts: Final Report.”

⁸⁷ UNESCO, “Report of the Sixth Session of the Intergovernmental Committee on Bioethics (IGBC),” SHS/EST/IGBC-6/09/CONF.202/5 (Paris: 21 September 2009).

⁸⁸ Pamela Chasek, “Confronting Environmental Treaty Implementation Challenges in the Pacific Islands”, *Pacific Islands Policy* 6 (2010).

⁸⁹ Ibid.

⁹⁰ Slaughter, *A New World Order*.